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**University of Southampton**

**FACULTY OF SOCIAL AND HUMAN SCIENCES:  
SCHOOL OF EDUCATION**

**Exploring parents' experiences of support  
when they have a young child  
with a learning disability**

**by**

**Georgina Sherwood**

**Thesis for the degree of Doctor of Philosophy**

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## **ABSTRACT**

Government policy states that early intervention and working in partnership with parents is essential as part of a preventative system. However the recent review of SEN and Disability (DfE, 2011a) highlights how support often works against the wishes of the family. By exploring with parents how support is delivered in practice, this thesis identifies strengths and improvements that could be made to address these problems.

An ethnographic case study approach was adopted to capture a close, detailed and in-depth view of the world of the parent-participants (Yin, 1984). Data was collected from six parents via semi-structured interviews that were audio-recorded. Twelve months later four parents agreed to be observed and compile their own evaluation of an experience of support. Supplementary and contextual detail was recorded in fieldnotes and via a non-participant observation. Findings are encapsulated in six narratives inviting the reader into the world of the parent.

The research represents a journey of how interpretation unfolded with the parent-participants alongside the researcher who also reflected her learning and changing perspectives. Each narrative portrays the unique experiences of the parents and indicates that the way in which each individual defines themselves and the professional providing support has an impact on the quality of the encounter. For this reason applying the transactional model (Sameroff, 1991) which is consciously aware of the factors that influence definitions is recommended as a way forward. When practised by the professional a positive partnership relationship could emerge. This would mean that support options could be tailored to individual needs that respect and involve the parent. This research therefore identifies effective ways to engage in providing the high quality arrangements the government recommends.

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## CHAPTER 1: INTRODUCTION

### 1.1 The problem

In my teaching role I have contact with parents and child care professionals, which would enable me to use this research to shape my practice and to share my findings with those who provide support. I was influenced by a comment from parents reported by Stainton and Besser (1998:67) that, "for a while we put our trust in those professionals ... our hope ... and then we realised ... they hadn't a clue what we were living". I decided to investigate what parents' lives and experiences are like and what they find useful in the support they receive when they have a young child with a learning disability. The research problem, therefore, became to share parents' stories of support. I hoped that this research would be interesting to professionals because they would find out more about parents experiences of effective support and, like me, use their stories as a guide to improve services in the future. I also intended to present my learning to an academic audience sharing a critique of the methods I had selected. In addition to this thesis being in the public domain, it was important to me that the parents who participated in this research benefited in the ways expressed by Hanley *et al.* (2003) who suggest that involvement in research can become

a route to effecting change and improvement in issues which concern people most. It can also help raise self-esteem ...Involvement in itself can sometimes be 'therapeutic' (p4).

I intended to give parents participating in the research a voice - to share their opinion about experiences of support - and at the same time to educate me and others.

I was interested to uncover what happens to individual parents when they become sucked into, or left out of, services that offer 'support', hearing this from their own perspective. This would offer me, and other professionals, the opportunity to consider how to shape services to meet the parents' values. I wanted to conduct research that could make a difference in the way Dewey (1938) sums up: 'Having been motivated by some interest,

concern, or value inquiry, if we are sincere and consistent, terminates in action'. In this case the action was to be taken by me and communicated to professionals who provide support and academics who study the research process.

In investigating the problem of the relationship between parents and the support offered, I relished the opportunity to share, watch, manage and reflect, to make sense of what Thorne (2004:254) refers to as a 'jangling chorus of selves'. Through probing the subject more deeply, being creative and rigorous, the problem could become illuminated. As a result of this exploration with parents I anticipated that my voice would become entangled with the individuals who contributed to this study.

In gathering parents' stories of support I aimed to compare these with the intentions set out in government policy and reports from researchers, looking for patterns, similarities and differences to set alongside current knowledge. I wanted this study to enable parents to join in the debate about how support is presented and the impact that professionals have on families when they deliver it. I recognised how feelings of caring, excitement, fear, hope, belief, despair, reasoning and empowerment would become interwoven as I joined with the parents to explore their experiences of support. In the process of listening and observing aspirations, expectations, benefits and disappointments arising from all encounters with support I would gain a greater understanding of perspectives from each individual's perspective. Each encounter with a parent would offer a mixture of breaking new, and finding common, ground. From this, unique perspectives would meet with universal understandings, an idea that is central in Simons (1980) rationale for case study research.

To explore the problem I chose an ethnographic case study approach with six parents, interviewing them in their homes, so that I had the chance to probe deeply, sensitively and rigorously, in order to tell their individual stories. I anticipated that the stories would provide rich examples that supported a greater understanding from a personal perspective where the complexity of experiencing support retained 'greater importance than overarching trends or generalizations' (Pole and Morrison, 2003:3). The

'thick description' (Geertz, 1973) that emerged from each parent-participant would need to be verified by them before being scrutinised. I hoped that the personal narratives would come 'close to experience because they directly represent human experience' and 'close to theory because they give accounts that are educationally meaningful for participants and readers' (Connelly and Clandinin, 1997:81). The intention was that each ensuing story would contain the 'individual's personal field of experience, a construct of the individual's particular biographical store of episodic memories' (Campbell, 1988:61).

## **1.2 The Context**

Political and social perspectives stand side-by-side in influencing parents' experiences. The historical interpretation of learning disability shows how current policy has developed. I summarise the response to learning disability in England through the ages to show how, over time, policy has been shaped in response to changes in thinking. It reflects the dichotomies that Connors and Stalker (2003:13) identify: 'extreme cruelty alternating with protection, neglect alternating with enlightened provision, exploitation alternating with respect.' The impact of this is discussed in the literature review and later when linked to the findings of the research.

Looking back through history attitudes to learning disability in England have often been linked with negative connotations. One possible influence came through messages in the bible, which although set in another culture and time, suggested that mental retardation was linked to demons. This attitude was reflected in many quarters in England. As McConkey (2003) observes, folklore explained it as being possessed by evil spirits that needed to be exorcised. Perhaps as a result of this, one route taken by people over the centuries was to search for healing through rituals which often find their origin in religious rights.

Another reaction has been incarceration and from the Middle ages onwards asylums were built with solely custodial functions to accommodate so-called 'homeless, psychotic or demented individuals' (Shorter, 1997:4). These methods were ratified by the government and became the expected response to mental disability. This continued through the ages with people

placed either in prison, asylums or hospitals (Bannerman and Lindsay, 1993; Shorter, 1997).

The stimulus to regulate institutions began in 1773 apparently provoked by social pressure on humanitarian grounds. The outcomes were that patients were assessed to decide on whether long-term care was appropriate, rather than improving conditions (Bannerman and Lindsay, 1993). The 1845 act of parliament making it compulsory for counties to provide institutions for the mentally ill, implied that accommodating people away from their families was the preferred option (Burt, 2003).

Although advances in medicine in the twentieth century meant that learning disability became better understood attitudes remained largely negative. In the early part of the century people were described as 'mentally handicapped' and the medical model which focused on finding a cure was still a preoccupation (Bannerman and Lindsay, 1993). The language of 'body, patient, help, need, cure, rehabilitation' (Fulcher, 1989:27) further reinforced this idea. The impact was that many individuals were defined by their disability and what they could not do (Allan, 1999). A collectivist approach emerged as a result of amplifying an individual's limitations that focused on welfare needs, where everyone was treated in the same way (Hessler and Kay, 1993). The impact for parents was that they were often considered unfortunate to 'possess' a child with learning disability and as Nind *et al.* (2003) and Sheehy and Kellett (2003) reflect, in some cases felt they were to blame for their child's condition. Brigham *et al.* (2005:114) maintain that because the outside world did not know how to react, the subject was met with 'silence and isolation'.

Since the eighteenth century alongside reactions of fear and protection there has been evidence of a more philanthropic caring concern towards people. St Luke's Hospital in London was opened in 1751 by William Battie with the intention of providing a therapeutic asylum (Shorter, 1997:8). Later, in 1796 The York Retreat was founded by William Tuke, a Quaker, and was managed and financed by The Society of Friends who focused on spiritual as well as practical imperatives (Bing, 1909). The impact of changes for the 'mentally ill' was that they were no longer perceived as a

threat which in many cases represented a release from chains. Conditions improved as residents were given opportunities to carry out domestic tasks, gardening, listening to music and consuming good wholesome food. These records imply that in certain quarters there was a caring and therapeutic response from some members of society in relation to mental impairment.

During the nineteenth century, social conscience grew with voluntary organisations defending the rights of the mentally handicapped. Pioneer workers such as Dr Barnado and Lord Shaftsbury began to influence a political response as they laid the foundations for the health, education and social services that developed rapidly during the twentieth century (Ross, 1983). Evidence of this continuing into the twentieth and twenty-first centuries is shown in the work of the third sector. Perhaps the best known, although not always endorsed by disabled people themselves, is Mencap set up in the 1950s and mainly organised by parents who had a child with a mental handicap (sic). With branches across England and Scotland their aim, described by Welshman *et al.* (2005:23), was for 'more and better education in the form of occupation centres and industrial centres, often paid for and run by themselves'. Over the following decades other charities have emerged, set up by parents and linked to particular conditions such as the Down Syndrome Association (2009) and the National Autistic Society (2008). In 1971 the British Institute for Mental Handicap, now British Institute of Learning Disabilities (BILD) (2009), brought together educationalists, sociologists and other professionals to assess the needs of those with a learning disability (Roy, 1991). Together this has led to information being shared through training and work with government and public bodies to raise awareness of the impact that discrimination towards those with a learning disability and the need to combat this.

More recently, Care Co-ordination Network UK (2008) and Parents for Inclusion (2004) work has been to raise broad issues of support for families across a variety of cultures and campaign and to change attitudes through publications and training. KIDS (2008) aim to support families through providing short breaks, counselling and guidance, providing childcare and education for the children. The National Portage association (2008) was set up to work with parents in their homes and with child care practitioners in

pre-school settings providing both support and guidance for children with learning disabilities.

As charities continued to spring up so groups such as Disabled People's International began, set up to challenge where voluntary organisations were taking control away from disabled people. The British Council of Disabled People, a social movement and disability pressure group, was seen by some as forcing 'society to consider the disabling barriers and negative attitudes that disabled people faced as a denial of their human rights' (Campbell and Oliver, 1996:103). Although in the minority, those with a learning disability have been represented by, for example Simone Aspis, working as a Parliamentary Campaigns and Media officer for the more recently re-named UK Disabled People's Council (Wallace, 2009).

These examples show that throughout history groups were prompted to campaign for the rights of those with a learning disability whether through experience of disability, through having close contact with it, or because they cared about people. They suggest that 'community attitudes change over time and political realities cannot be counted on to stay the same' (Twain, 1975:46). Campaigning has led to changes in support provision and a continued focus towards developing positive attitudes to learning disability. The ideas they express are examined in more detail in the literature review.

In politics the majority of the changes which impact on parents' experiences today occurred half way through the twentieth century. A catalyst was the publication of the findings of the Royal Commission in 1957 (HMSO) that advised that it was not in the child's best interests to place them in an institution. This led to more children staying at home and meant that parents required support, although Welshman *et al.* (2005) record that the necessary funding from local authorities was often absent. When in 1970 Social Services took over provision from the Health authority there was a gradual increase in the variety of support services made available to parents. The government paper 'Better Services for the Mentally Handicapped' (Department of Health and Social Security, 1971) recommended that those with a learning disability would be better served in

the community rather than an institution stimulating resources to support this.

Mittler (2000) contends that people influence change, arguing that 'policies change not because politicians are waiting for researchers to say the word but because society demands change' (p.vii). However elsewhere there is evidence of the impact of research, for example in the Warnock Report (DES, 1978), which included input from parents and recommended a continuum of provision in education for children with special needs. It directed professionals to listen to parents regarding 'their contribution as intrinsically important' (DES, 1978:115). This message continued and became contained in the Children's Act in 1989. The role of consultation is a consistent theme reflected in legislation and research (DfES, 2006; DCSF, 2007; Mitchell, 2008). In pursuit of articulating this, the role of parent/professional partnership has been interrogated and currently finds a place in the first stages of education, in the Principles into Practice within the 'Positive Relationships' identified in the Early Years Foundation Stage (DCSF, 2008). The significance and effectiveness of partnership models are explored as part of this study.

Policy initiatives identified within the Every Child Matters framework (DfES, 2003a) and the Every Disabled Child Matters campaign (National Children's Bureau, 2009) highlight an agenda for both prevention and protection for children, specified in the document 'Contact a Family' (2008). As a result early intervention is recommended when a young child is diagnosed with a learning disability. This led to the development of the Early Support Programme, for children 0-5, described by Temple *et al.* (2008) and defined as containing 'parent friendly' information' (DfE, 2011b:42). As a result records are shared with parents and each child's development and support needs are clearly identified. In the background the influences of the UNESCO Salamanca Agreement in 1994 and the Disability Discrimination Act 2005 remind parents of their rights because discrimination by association is outlawed (Directgov, 2009).

High quality, family-centred provision has been recommended within policy since the National Service Framework for Children, Young People and

Maternity Services (DoH, 2004), and is included in the report Aiming High for Disabled Children (DfES, 2007b). These are commitments that are further endorsed through the Children's Plan (DCSF, 2007a) and in the more recent Green Paper 'Support and Aspiration: A new approach to special educational needs and disability' (DfE, 2011b).

The social and political landscape shows movement from the view that a child with a learning disability should be hidden away and regarded as something tragic for the parent. The historical context represents a shift in thinking, with the government moving from legislation that protects society from people with learning disability, to a position that is focused on improving support for families. This is in pursuit of safeguarding the welfare of children and preventing the perpetuation of social problems that bring with them costs for society (Smith, 1999). Through this brief summary of changing perspectives it is clear that

Issues are not simple and clean, but intricately wired to political, social and historical and especially personal contexts. All these meanings are important in studying cases. Issues draw us toward observing, even teasing out, the problems of the case, the conflictual outpourings, the complex backgrounds of human concern (Stake, 1995:16-17).

Understanding the messy context prepared me to find the subject of support complicated and uncertain, which although uncomfortable would bring about new insights. It would involve delving deeper into the literature in order to examine how attitude and delivery of support have been influenced. Inevitably the emerging learning would bring to light personal perspectives which needed to be challenged. Confronting these would add weight to my decisions on how to approach my empirical research that aimed to listen and find out more. I hoped that this exploration would lead to a new way to understand and implement support when working with parents who have a young child with a learning disability.

### **1.3 The Personal Context**

A number of experiences led me to want to find out more about the relationship between parents and support when they have a young child with a learning disability. To introduce them I have chosen to write vignettes that describe snapshots of particularly vivid memories. They have been selected to communicate specific areas of my work and experience and to provide information about the context in which I have encountered disability and parents. They aim to show how I became interested in developing my knowledge of this subject. As these portray an individual, personal reflection I have recorded them in italics. The use of rich description matches the style of the parents' narratives shown in the findings.

#### **1.3.1 My life as a childcare professional**

*One ordinary morning [some years ago] I drop my three boys at their school and I begin to drive to work. When I reach the first road junction I look to my left and on the pavement see two mums that I recognise. One is obviously sobbing and in distress, the other has her arms around her. I feel a surge of emotion as I empathise with the feelings of fear, anguish, helplessness and desperation and the compassion of the comforter.*

The distressed mother had just discovered that the child she was carrying had Down syndrome. This was one extraordinary moment in an ordinary day and I drove on to work in the further education college to teach students preparing to work in childcare. Years later, I was to witness and share these strong emotions with the parents I regularly met in a Children's Centre, and the significance of this memory remained as vivid and instructive as when I first experienced it.

*It is lunchtime and we are discussing the plans for the afternoon. David will be arriving in half an hour so we have time to tidy up and get ready. The children know that although David is now four he does not play in exactly the same way that they do, due in part, to the fact that he has Down syndrome. Benedict, my son and Jodie talk about what David likes doing. Jodie suggests gloop (cornflour and water), a favourite activity for her. I remind the children that we need to think of four things to do because*

*David likes variety. We decide on a story, duplo building, gloop and a trip to see the horses.*

*At 2.00p.m. the door bell rings and David's Mum is smiling with David at her side. As soon as the door opens he pushes passed me and goes to the shoe rack. He sits down and carefully removes his shoes and places them in 'his place'. I comment on the fact that he has remembered and thank him for putting his shoes there in such a tidy way. His Mum calls out to say goodbye and David disappears into the play room. Benedict arrives at my side and presses a key into my hand communicating a 'meaningful look' by raising his eyebrows. He wants to show me that he remembers the time that David locked himself the other side of the door and I had to walk around the house to get in and rescue him while Benedict stood and reassured him. I am struck by his demeanour suggesting that he is proud of himself and ready to be responsible for keeping David safe.*

*After a short story we are in the kitchen making the gloop, David is restless and I can see that he wants to get down from the stool at the breakfast bar and leave the room. David loves roaming the house and the others enjoy following him and talking about what he is doing; they are very aware of the things he can and can't do and I decide to let them explore together before returning to the gloop activity. In the living room I watch David pause in front of the television. A memory triggers a pang of anxiety and concern, a time when he stood begging me in words that I did not understand, telling me, I later discovered that he wanted me to put on a 'Thomas the Tank Engine' video which we do not have. I was grateful that I could practise the advice his Mum had given me and so soothed him by whispering nursery rhymes in his ear and diverting his attention away from the television. I am keen that he experiences something different from television and videos when he is in my home which is consistent with the other children I care for. In David's case I find the decision to follow this line more difficult as I am torn between wanting him to be happy and to feel a sense of belonging here.*

*Whenever I work with children I find myself drawn to connecting deeply with their worlds in order to meet their needs. In David's case I find myself*

*measuring this intention through the absence of negative emotions rather than the ability to detect positive ones with any certainty. [These feelings are summed up by Isarin*

*Relating to my son, I feel like Alice walking around in a looking-glass world that is very different from our daily reality, a world that knows its own rules and logic. It is a world that makes no sense and yet is sensible on its own terms; a world that is incomprehensible and at the same time more comprehensive than our own. It is a world one wants to be part of without wanting to belong to it, a world one wants to belong to without being part of it (2005:260).]*

*The children return from their tour around the house and together we decide it is a good time to go and feed the horses. I use Makaton signing to prepare David for the trip out and the other two, using a high-pitched enthusiastic tone say, "Yes David, you like to see the horses." David looks from them to me, his expression does not change and then he walks off to the stairs and slowly climbs them. After another journey around the bedrooms and bathroom he returns and we get shoes and coats on. As we walk slowly down the road with David holding my hand on one side and Benedict's on the other, Jodie walks slightly ahead of us. David tries to pull away and I ask Jodie to help him to walk safely with me, by holding my other hand. She steps back to do this and David relaxes. As we walk along I see someone approaching and as she comes closer I recognise her as one of the pre-school staff who knows Benedict. She stops for a moment and says to me "You've got your hands full." She turns to look at David and then to me, "He isn't yours is he?" she asks. I explain that I am childminding him and an expression of relief mingled with pity seems to cross her face. She moves on.*

*On David's next visit, I am looking after him on my own with Benedict and with some concern I decide to take them both shopping. David's mum has said that he is not very keen on shopping with her, so I realise that we may have to cut the trip short if he becomes distressed. We prepare in the usual way with Benedict 'writing' his own shopping list and me encouraging David to use some thick crayons to draw on some paper. Armed with these we*

*head off the supermarket. I decide to transport David in the trolley, he is still quite small for his age and light to lift, however he looks slightly out of character compared to some of the toddlers who travel around the store in this way. He does not protest and begins to point and make noises as we move up and down the aisles. Benedict spots things we need to buy and we give them to David to 'put' into the trolley. Each time he turns around and throws the item in with gusto and a look of satisfaction seems to flicker across his face. As we walk around I notice people look at David and turn away and when I catch their eye they give me a weak smile. I wonder if my perception of them shrinking from me is more a reflection of my own behaviour when I meet an adult with a child who has a learning disability, than reality. We reach the till and the lady begins to scan our shopping, meanwhile, David sits passively staring ahead of him. She says "Bless him; I knew one like that once". I decide not to explain that he is not my son as I often do when I'm out with the children that I childmind and wonder whether it is because I don't want her to think that I am grateful that he is not.*

*As we leave the shop I praise both the boys for their help and very good behaviour. Benedict looks proud; David's expression does not change. It is as if he is 'concealing some secret hinterland behind these appearances, one that is tantalizingly inaccessible' (Eagleton, 1996: viii) leaving me to struggle to reach him.*

### **1.3.2 My life as a family learning tutor**

Six years ago I moved from working in a further education college to become a freelance tutor. Much of my employment takes place in the local Children's Centre and encounters such as the ones described below show my interactions with parents.

*Entering the kitchen to make drinks for the group I am tutoring, I meet Beth bustling about. I notice how speaking and moving are entangled in her communication style. She speaks quickly in a jerky fashion, avoiding eye contact, intent on sorting out the kitchen, tidying, cleaning, producing order where she seems to perceive chaos. This scene is juxtaposed with her description of her daughter waking her at 3.30.a.m. disturbing her from a light sleep because she was expecting to be woken. She tells me about how*

*she must get up with her daughter, it is not safe to leave her to roam the house on her own; besides she would wake up her son and disturb her husband. So they go downstairs together. It was fine today because she was okay to watch a video, sometimes it's more tricky, when she won't sit still, then "I have to entertain her". As I listen the image of a coiled spring comes to mind and I try to picture what it must be like day in and day out, silently imagining the exhaustion that must creep up on you and make its home within.*

*Beth breaks into my thoughts. She is telling me about the very good school she and her husband have selected for their daughter, it specialises in supporting children who have autism, the best in the country. As she begins to explain her battle with the authorities her tone changes; the pace of her speech slows. It is costing them money but she doesn't care - it will be worth it and she must be hard and determined. After all, her daughter needs this opportunity. She and her husband will make it happen somehow. "We are not going to give up."*

*I ask her about the holiday she told me she was planning the last time we met, and she relaxes a little, smiling for the first time this morning. "Yes it was good" she says and returns to her original excited pace. She checks to find out if I know that they took a carer for her daughter and explains that it made all the difference. There was more time to enjoy things together, time to spend with her son. I realise how little I know about him and how much I feel I know about her daughter, although I have only seen photographs of her. She continues, explaining that the accommodation was just right for them all and they were lucky with the weather.*

*The conversation shifts again, this time to the support group. Beth tells me they are still meeting up regularly, it is going well. I think about all the outings, special evenings, the chocoholics visit and cosmetic demonstrations, and I wonder how and in what ways these experiences benefit the parents who attend.*

*As I leave the kitchen I look at my watch and realise that we have only spent five minutes together. Thinking about how much Beth has*

*communicated in this short time reminds me of another encounter I had recently with a Mum whose child has Down syndrome and how she described her life history in a period of ten minutes, seemingly putting her experiences into context so that she could finally begin to take control of her life. In both these exchanges the personal intensity of their experiences feels almost tangible, their drive to keep moving, holding things together, keeping emotions in check, the need to keep doing as if stopping would obliterate their notion of composure.*

### **1.3.3 A Dad's point of view**

*John has arrived early for the 'Confident Dads Confident Kids' course and is telling me about his day. He speaks proudly of how the chef is asking him to do more in the kitchen, recognising the importance of his role as a kitchen porter. He reminds me, as he has done before, that it's pretty tough, working shifts, cycling to work and coming home feeling tired. As he continues, he punctuates each sentence with the words "you know what I mean?" As I listen I think about how little I do know of what he means, because my life is so different and I try to imagine him returning home to the flat he shares with his partner, his seven-year-old son and 'the baby'.*

*Each week he talks about his relationship with the older boy, the things he has bought him, how much they cost, things he says to him. With every example there is the tinge of fear in his voice; a fear that he could go off the rails as he did as a kid growing up in Glasgow.*

*When I ask about 'the baby' he dismisses his role quickly. I describe him as a toddler because he is two-and-a-half and he reminds me that he has learning problems, "you know he's not right in the head... behind." Anyway the 'missis' looks after him, "he's a bit of a handful at times," but she knows what to do. He passively explains that she has to because when he started 'play school' they said he would have to stop coming because of his problems. I ask if they are getting any advice or support from other areas. He ignores the question as if he has not heard me and although I try to pursue the subject by asking about whether he is in touch with a family support worker, he makes it clear he has decided that it is not his business and 'she' (his partner) will have to get on with it, 'they' will manage on their own. I wonder whether he has written 'the baby' off – dealing with 'that*

*problem' is a step too far, something outside of his knowledge, his confidence, his sphere? When I reflect on what he shares, it is all about focusing his energy to make things good with the older boy and maybe worry about 'the baby' later.*

#### **1.3.4 Reflections**

My response to what I saw from the window of my car all those years ago led me to consider how the extraordinary can break through the ordinary, as I witnessed a poignant moment where emotions were shared. They influenced my decision to make this an ethnographic study with the intention of portraying 'an insider's perspective, in which the meaning of the social action for the actors themselves is paramount' (Pole and Morrison, 2003:4). By sharing my encounters with parents through narratives I would be able to focus on the relationship between what is familiar and what is strange, attempting to approach each aspect of behaviour with a naïveté to enable me to examine it as if it is new, unfamiliar and potentially significant (Clough and Nutbrown, 2007). This reveals 'the remarkable in the mundane' and '*...mundane* elements of *remarkable* events and contexts' (Silverman, 2007:16-18).

Through reflecting on my experiences of caring for a child with a learning disability, I saw how to celebrate individuality and what David could do rather than see him through the lens of the condition. Noticing how other children respond by making sensitive adjustments to the environment, without the need to attach a negative label to the child has challenged, and continues to challenge, me. Through receiving reactions from other adults who, like me, think and really want to understand a situation that is beyond comprehension, yet judge it with pity, impressed upon me a need to convey the experiences of parents as authentically as I could.

As I re-lived my encounter with Beth I was struck by the energy she invested in controlling areas of her life that 'belong' to her and the importance that she seemed to attach to this, in order to manage the demands of caring for a child who has autism. This encouraged me to question whether these are typical responses. This encounter showed me that I would never gather a complete picture of the parent's world but, as in this case, I could focus on capturing significant snapshots. I knew that

my methodology would have to include ways to check out ideas I had gathered over a short intense periods of being immersed in each parent's world. However as Denscombe (2007) maintains, I would never be able to claim certainty from my findings, a point that was in one sense liberating and in another of concern: Liberating because it implied there is more than one answer and of concern as it may render this study useless.

Each encounter reminded me of the significance of the radical listening recommended by Clough and Nutbrown (2007) and helped me to consider the many sources that would lead to thick descriptions (Geertz, 1973). I decided that the reason why listening was important was not only to broaden my understanding of the subject but also to convey the richness and complexity of individual experiences that are unique. I wanted to inform the reader of reactions that over time may be claimed as more universal. Listening would enable me to communicate the multi-layered characteristics of each parent's experiences. The ethnographic case study approach meant that although limited to a few parents I could focus on portraying experiences individually, authentically, making use of my 'intuition, empathy, and general ability to learn another culture' (Taft, 1997:74). By sharing personal accounts I hoped to reveal the 'subjective reality of the experiences of those people who constitute and construct the social world' (Pole and Morrison, 2003:5) where a young child has a learning disability.

The reflective vignettes served as a starting point and communicated the importance of hearing the opinions of the 'insiders' and the 'outsiders', from my position of an 'insider' and 'outsider'. This left me vulnerable because, as LeCompte and Preissle (1993:97) warn, 'I risk losing the outsider's perspective by over-identifying with participants, and risk losing the insider's perspective by under-identifying with them'. I therefore aimed to ameliorate the affects of this by making my position transparent, declaring personal influences and assumptions (Silverman, 2004).

Writing the vignettes alerted me to any inclination to deny or gloss over experiences that are difficult and emotional to acknowledge. I realised the pitfalls of recording and interpreting for someone else and decided to make

the work participatory where I could so that the audience had the chance to see the 'differing views on how the world is constructed and how it operates' (Clough and Nutbrown, 2007:29). I therefore decided to apply a variety of methods to elicit responses to support, to invite interpretation of the situation and present findings in a holistic way, encouraging the reader to draw conclusions. This commitment set the tone for the study, applying ordinary rather than technical language and narratives that embraced the parent-participants reflecting their voice. I planned to portray their story by matching the communication style of each individual. Through sharing the narrative of each parent, I encountered a mixture of representation and interpretations which meant that, like Stake (1995:134), each 'descriptive report is laced with and followed by interpretation', inviting 'readers to make their own interpretations'.

The vignettes offered an opportunity to empathise with Beth's emotions regarding the rights of her child, to see the love that seemed to drive her, almost relentlessly. I noticed the maternal connection I shared as a mother, realising that others would identify with this in another way. As she shared the impact of her holiday, giving her a break from the everyday routine and enjoying being with her family, the role of having a carer to support her took on new meaning. I recognised that at a time when her own life was so demanding and full of tension, her role in providing support and distraction for other parents in her situation seemed to have a personal significance.

As a listener, I heard the perspective of a father that suggested separateness, fear and a need to hand-over. I noticed my reaction of concern, wanting to draw him in and help him to see that he had an important role to play. Yet at the same time I found myself concerned that his response might mirror that of other parents more closely than they dare to acknowledge.

These experiences, along with the review of literature, were a guide to the research question, giving a clear shape to the methodology enabling me to situate myself in relation to the project. The decision to explore experiences of real lives in order to expose the relationship between parents and professionals became an imperative to examining support from a fresh

perspective. I recognised the limitations of being on one side of the fence looking across and applying my own interpretations to their situation and I therefore decided to explore *with* the families rather than do research *on* them and draw conclusions from my short encounters. Reflecting on these decisions led me to realise that this research could make a difference and influence my role as a family learning tutor, at the same time providing me with information to share with other professionals about what parents find useful when accessing support. By reflecting on my experiences as a researcher I intended to share my insights on the methods I had chosen and the process of enabling a theory to emerge from the stories of the parent-participants. I realised that my lack of confidence in addressing the research community was a potential barrier which would become my teacher as I considered the connection between this and how parents may feel when addressing professionals.

Before planning details of how and when to meet the parents I considered my priorities in gathering data and developed my own set of guidelines.

#### **1.4 Starting Principles**

In preparing to undertake the research, my first principle was to give the parents a central role which meant that I began by considering how to support their well-being so that I could portray their voice faithfully. This involved building a relationship of trust guided by a carefully constructed ethical protocol (see Appendix 1). As part of this I identified steps that would be taken to protect each parent-participant's identity and considered how to involve them in choosing a pseudonym for themselves and other family members. As each parent made a personal contribution it was important that the reader could make connections between the parent and child. I therefore planned methods so that this information was accessible. My intention in these aims was to value and respect the voice of the parent so that their experiences of support could be clearly recognised.

I planned ways to communicate with parents using written and verbal channels so that parents realised the purpose of the research, their role and rights (see Appendix 1). I approached the Children's Centre manager as a gatekeeper to provide additional support for each parent. Further guidance was provided by my supervisor. To gather parent-participants' experiences

in a way that was comfortable to them I chose face-to-face contact so that I could assess communication at two levels, hearing their voice and listening to the impact of what they were sharing through their body language. Shuy (2003) recommends that when the subject is sensitive and complex, requiring probing and deep reflection, a natural context 'might yield greater accuracy' (p.179). This was a key objective in this study.

In considering techniques for analysis I rejected the idea of selecting one theory in advance and applying it deductively to the fieldwork. Instead I planned to gather data and allow the theories and patterns to emerge inductively. This was important because I wanted to listen attentively to what I was hearing, rather than selectively focus on one aspect of the experiences that the parents were sharing with me.

Through reading research on the subject of learning disability and parents' experiences of receiving support I aimed to reflect the views of a broad range of writers, both in relation to approaches used and outcomes shared. This was so that I could consider a variety of aspects to the problem of finding out how to make parents' experiences of support effective. The following chapter contains the results of this quest.



## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 Introduction**

Reviewing the literature became part of my learning journey, leading to the choice of questions that focus the research and represent the parents' contribution in stories to 'develop the most 'grounded' set of hypotheses about their experience and response' (Wengraf, 2001:325). The audit trail enabled me to construct the convincing argument that Bassey (1999) recommends, as I wanted to explore support in depth and identify improvements in the future.

In this section of the thesis I share how my views altered and this prepared me to enter the world of the parent-participants. The vignettes present snapshots of encounters with parents representing my position at the beginning of this journey, conscious of the negative impact of having a child with a learning disability. During my literature search I found examples that reinforced this view and helped me to understand how my attitude to disability had been influenced. I call this section 'living in the shadows' as it represented when I saw parents as situated in a dark place. My research also revealed examples of a response to parents which I call, 'trying to help'. This improved my knowledge of how and why support is provided. In offering help I noticed that the examples often reinforced a negative position for the family as they communicated their need for rescue. As a result of further research I became challenged to see the importance of 'celebrating difference'. This journey led me to identify actions that could improve current support, celebrating and affirming difference and I call this a 'possible way forward'. At the end of the chapter I add research which was undertaken following the analysis of the parent-participants' stories. This showed how a transactional model offers a way forward in enriching support in the future.

### **2.2 Living in the shadows**

The historical overview shows that the dominant opinion of learning disability has been negative. The common view of disability per se was medical. Hevey (1993) describes the medical orientation as linked to tragedy, prompting pity. Oliver (1996) argues that this perspective was

universally applied to all disabilities, claiming that people viewed impairment as a personal tragedy that should be corrected. Goodley and Roets (2008:239) maintain that applying the term 'impairment' 'symbolises social death, inertia, lack, limitation and tragedy.' Penn (2000) observes that the dominant opinion is that the disabled person stands out, either physically or by their behaviour, failing to fit in with society because of their difference. This explains what Mittler (2000:3) defines as a 'defect model', 'based on the assumption that the origins of learning difficulties lie largely within the child'. These perspectives had an impact on parents because up to the 1970s many children with a learning disability were placed in residential care away from their family. As Murray (2000:686) says, 'custodial care offered parents the relief of day-to-day care and removed the stigma of having a disabled family member'.

The impact of these attitudes is explained by Abberley (1987:14) who contends that, 'whilst his/her 'primary identity' resides in disability, the legitimacy and value of this identity is simultaneously denied'. While parents may choose to challenge this perspective, adults such as Aspis (2010) describe how her early experiences led to feelings of isolation and being confined by a 'mental impairment', labelled and stigmatised by society. This implies that the contentions of Goodley (2001) and Chappell (1992) that politics, culture and society have their part to play in restricting the role of people with learning disability are accurate.

Ryan and Runswick-Cole (2007) describe how the negative perspective of disability impacts on parents because the child is categorised as a burden and the cause of stress for the mother. Pinney (2007:17) reflects this as inevitable in the statement: 'Parents with disabled children face higher levels of stress'. Murphy *et al.* (2006) show a higher incidence of parent health problems, which they see as due to increased stress, burden and worry residing in the child's disability. This research builds a narrative that to have a child with a learning disability would have a negative impact on the parent.

It has long been contested that children with disabilities should be entitled to the same rights as everyone else. Although the normalisation agenda

aimed to promote this, Chappell (1992) argued that the material constraints experienced by those with learning disabilities continued. Writers such as Beresford *et al.* (2007) identify a list of constraints that having a child with a learning disability brings to parents such as physical barriers through financial and practical constraints as well as a loss of personal identity. This brought into focus Yates *et al.*'s (2008) challenge that in the aims of normalisation the disability itself does not hold value in its own right and that while this continues it will be understood as inevitably leading to restrictions and problems.

The literature exposes how parents' experience is influenced by the reactions of others, for instance, when their child is judged on features which others define as 'normal' behaviour (Morris, 1991). Culham and Nind (2003) explain that where 'normal' continues to be thought of as good, children with a learning disability receive the message that they should either conform or become invisible. Dale (1996:67) contends that this upholds a 'discriminatory and devaluing attitude towards disabled people in society, which in turn contributes to the injustice of segregation and long-term disadvantage for the child and whole family'.

Definitions of 'normal' versus 'abnormal' are present in research which describes the response to providing a label for a child's condition. Barnes (1999:578) proposes that labelling children as different leads to 'an implicit if not explicit denial of the disabling effects of a profoundly unjust social system, and a positive disabled identity'. Goodley (2001:221) concludes that labels applied to those with learning difficulties mean they are 'considered a homogeneous, infected group'. He argues that this negative definition leads to people with learning difficulties being viewed as lesser than another. When combined with the view of 'tragedy' Swain and French (2000:574) say this 'denies disabled people's experiences of a disabling society, their enjoyment of life, and their identity and self-awareness as disabled people.' This is reinforced when charities apply emotive language and refer to disabled people as 'suffering' (Hevey, 1993). Morris (1991) and Oliver (1996) add that the greater the fear attached to the label the more the condition will be seen as negative with a tendency to exaggerate

difficulty and in the case of children mean that their skills are underestimated (Mittler, 2000). It is Murray's contention (2000) that:

In the main, our children, under the dominant medical model of disability which views disability as being less than perfect as a result of their impairment, are seen as intrinsically defective.' (p.684)

These examples suggest that parents may begin their journey towards support with a negative view of their child's condition. By examining research on the impact on parents of their child's diagnosis of disability I hoped to understand how these arise when parents meet professionals.

### **2.2.1 Diagnosis**

In order for a label to be securely applied a process of diagnosis is required. This experience is described by Case (2000), Gray (1994) and Williams (2007) who report parents finding this emotional, awful and devastating and envying other parents with typically developing children. Woolfson (2004:9) maintains that 'not only do parents perceive this to be a tragedy for them, they also view disability as a tragedy for the child'. She argues that this can mean they feel sorry for the child and try to make up for the loss they think the child will experience. Like Crnic, Friedrich and Greenberg (1983), she asserts that this can lead to the parent becoming over-protective.

Yates *et al.* (2008) and Rix and Paige Smith (2008) propose that following diagnosis parents need to undergo a process of adaptation. McCubbin *et al.* (1982) and Allan and Owen (1993:11) describe the loss 'not of our child but of our expectations of our child'. Parents speaking to King *et al.* (2006:58) described a loss of dreams that completely turned their world upside down feeling "devastated and I couldn't fix it." Cowan (1998) and Penn (2000) describe mothers experiencing internal turmoil, unable to return to 'normal' life. Sameroff and Fiese (1990) explain that even when parents have experience of common caregiving practices they dismiss them believing that a child with a disability requires specialist help. These findings match the model of psychic crisis described by Cunningham (1979) which describes the shock phase of paralysis, confusion and disorganisation; reaction phase of sorrow, grief, disappointment, anxiety, aggression,

denial, guilt, failure, defence mechanisms; adaption phase where the parent asks "what can be done?" using a realistic appraisal; the orientation phase during which parents organise, seek help, information and plan for the future and crisis over when appropriate services are provided.

Some research suggests that the professional's response to a diagnosis could influence the parent's reaction. Evans (1996:22) describes how the junior doctor 'was virtually in tears' when he told her that her daughter had Down syndrome. Parents speaking to researchers described 'silence, delay and obfuscation' (Brigham *et al.*, 2005:113), anger and anxiety due to the process and delay in diagnosis to Welshman, (2005), which Brynelsen (1983) defines as emotionally difficult. Stainton and Besser (1998:57) found that in the 1950s and 60s research assumed that the reaction to a diagnosis of learning disability would be 'chronic sorrow'. As Trute *et al.* (2007) continue to record professionals expecting and looking for examples of family disintegration because the child had a learning disability, it would appear that these attitudes have left a deep impression.

Some reports show that professionals continue to hold a negative position, assuming that parents will focus on problems and negativity. In an extreme case Stainton and Besser (1998:67) recorded a professional saying "are you gonna keep it?", a response consistent with the findings of Rolph *et al.* (2005) when listening to accounts of parenting in the 1960s. The implications of these views are a form of 'disabilism', which arises when professionals focus on families' shock and grief. Darling (1979) suggested that parents are often caught in a 'no win' situation because they are either judged as unable to cope, or delusional if they appear to be coping well. Much research portrays parents in a helpless position left relying on the guidance of professionals, which implies that having a child with a learning disability is necessarily a bad thing.

Dale (1996) stresses the point that descriptions are limited because records fail to fully encompass and explain the intensity of reactions. She divides the models of adjustment using two categories: *personal*, focused on the individual and *interpersonal*, based on a social dimension of adjustment. Shock represents a personal response and becomes interpersonal when

outsiders recognise and respond to different behaviours that follow diagnosis. When the personal construct model is applied the attitudes of those surrounding a person, are shown to shape the individual's experience and adjustment through symbolic interaction. Dale (1996) contends that it is the individual's beliefs, values and knowledge arising from social encounters which become the greatest influence. Stainton and Besser (1998:67) claim that parents' responses are based on both personal and interpersonal influences because families are 'not only victimised by their own fears, they're victimised by what society tells them'. Dowling and Dolan (2001) propose that negative reactions are socially constructed as shown in the findings of Wolf *et al.* (1989) and Milgram and Atzil (1988) where autism is portrayed as inevitably leading to stress and a negative impact on psychological wellbeing. These opinions reflected in the literature helped me to see that where parents are exposed to these views it is likely to leave a negative residue.

Woodgate *et al.* (2008) record parents who were disappointed at the lack of understanding of autism, experiences that led to feelings of being stigmatised which left them in isolation and 'having to "go it alone"' (p.1078). Gray (1994:295) argues that most parents of children with autism experience a 'shrinking social world as it becomes easier to keep to themselves rather than to risk embarrassing incidents'. The parents who spoke to Brett (2002:832) extended an understanding of this experience, describing it as 'disablement by proxy' – the child's impairment being 'transplanted' to themselves as a parent'.

A further influence on the parents' reaction to a diagnosis of learning disability is that of tentative responses of friends questioning whether it is appropriate to send congratulations if a child is born with Down syndrome (Rix and Paige Smith, 2008). Both Murray (2000) and Morgan (2006) portray frustration in being labelled as a saint for coping, which they claim leads to parents putting unrealistic expectations on themselves and the child. Language used to describe the child as offering 'special competence' also set them apart, placing an expectation that parents see their situation as something to be treasured (Ryan and Runswick-Cole, 2007).

The majority of the research focuses on the impact that diagnosis has on the mother and as I also hoped to meet a father in this study, I was keen to explore research that showed their reaction to diagnosis. Carpenter and Towers (2008) record fathers describing a variety of responses ranging from it transforming their lives, to stress affecting work patterns, disorientation and destruction of life plans. All 21 fathers in their study shared narratives of diagnosis being difficult to face, but that they had quickly settled down to get on with it. Roach (1998) reports a likelihood of fathers having higher rates of depression and anxiety, somatic illnesses, sleep disorders and indigestion problems. When Nunkoosing and Phillips (1999) compared the reactions of mothers and fathers they found that mothers were more likely to be emotional whilst fathers were more inclined towards denial. Challenging this, Mays (2005), a mother, described feeling 'numb and icy' in contrast to her husband who expressed his confusion and fear through tears. Rix (Rix and Paige Smith, 2008) described his response to the diagnosis of his son with Down syndrome as feeling guilt that the learning disability may be his fault. A father who spoke to Espe-Sherwindt (2008) described the need to explain why his son had autism. These imply a range of responses that while mainly negative also reflect that adapting to a diagnosis is dependent on individual characteristics.

Finch (2008) and Gray (1993) explain that due to the uncertainty of the implications of a diagnosed condition parents were left both isolated and pitied; a subject taken up by Roach (1998) in her study of fathers' experiences where a stigma attached to Down syndrome was noted. Parents in Dowling and Dolan's (2001) research describe people either staring at, or ignoring them. Philp and Duckworth (1982) discussed the problem of neighbours being unaware of the additional stress that the family experience. These writers challenged me, as I realised that their observations matched those shared in the vignettes where I had presumed life was difficult for the parent and left them stigmatised by the community. This made this study pertinent and highlighted my need to listen to each story without presupposing reactions.

I found that the research about diagnosis led to support from professionals and I now turn to examples of how this can leave the parent in the shadows.

### **2.2.2 Support and relationships with professionals**

Many studies shared parents' experiences of meeting professionals in pursuit of support. Those who talked to Woodgate *et al.* (2008) told them that they had met unsupportive professionals, who lacked training and knowledge about autism. Tomlinson (2008), who was looking for partnership and continuity of support, was disappointed to find Social Services Home Care regularly sent a different person to visit her son. She described the resulting experience as 'dehumanizing', causing 'emotional torment ... like a knife being turned in your heart' (p.102). Although reassuring, Rix and Paige Smith (2008) argue that the appointments organised after the child has been diagnosed fed a relationship of power for the professional.

Atkinson *et al.* (2002) and Connors and Stalker (2003) identify the challenges of meeting with a variety of professionals, made more difficult when parents are expected to retell the history of the child. They contend that there is pressure on parents to adopt the values of professionals and that 'within this conceptual framework the parent has become an ad hoc professional, whether they like it or not' (p.219). Goodey (1991:106) illustrates this saying that because she did not know anything, she put her trust in the professionals and 'just followed whatever they said', implying an unequal partnership.

In reviewing negative experiences of support the role of the 'expert model' of partnership depicted an expert-novice relationship, where advice given to parents was 'normally someone else's opinion or solution to another person's problem' (Allan and Owen, 1993:14). Historically this represented parents' experiences when they handed their children over to experts in an institution (Murray, 2000). Mittler and Mittler (1983) explain that even when more children began to stay at home, control continued to be firmly placed in the hands of the experts. Case (2000) argues that the model places the expert in a more powerful position than the parent, especially when they are in control of the budget and resources. Case (2000) and

Dunst *et al.* (2002) describe the impact of this, arguing that professionals make the decisions, removing responsibility from the parent, leaving them powerless as shown in the comments made to Brett (2002) where the four parents identified this as leading to unequal power.

When professionals are in a more powerful position Atkinson *et al.* (2005:195) maintain that the expert model could mean 'the territory of the "experts" was vigorously defended'. Walmsley (2005) describe parents facing professionals who dismissed their input because they were not trained professional people. Espe-Sherwindt (2008) reports parents feeling excluded because professionals portrayed themselves as being more clever than them and attempted to take responsibility for the progress of the child. The situation is made worse when, as Todd (2003) contends, professionals begin to view parents as a problem.

Although this research suggests that professionals stimulate the expert model, Rix and Paige Smith (2008) explain that when parents seek the opinion and reassurance of the professional this places that professional in a superior position of knowledge and skill. Stainton and Besser (1998) propose that some parents are looking for a cure for their child rather than partnership with the professional. This can lead to them handing over control to the professional and expecting immediate results (Russell, 1983). This exposes some parents' motivation for the expert or intervention to make improvements to the child's condition or circumstance. Yet as Baker and Feinfeld (2003) say, in spite of some encouraging evidence that intervention is effective, there is no one approach that can be said to definitely make a difference.

A further influence in maintaining the 'expert model' is the fear that their child will miss out (Rix and Paige Smith, 2008). Prezant and Marshak (2007) agree that parents want to avoid 'biting the hand that feeds them' (p.32). Temple *et al.* (2008) found that parents were reluctant to challenge or question poor information and explanations, impacting on the families' ability to make informed decisions leading to them being acquiescent to professionals' suggestions. Nunkoosing and Phillips (1999) identified this within Portage (which is discussed in more detail in the next section)

describing the professional in charge within a 'highly structured curriculum' (p.208). This led me to question whether, due to the demand outweighing the available support (Russell, 2007), parents were more likely to overlook the domination of the professional to protect the support and the positive impact it would have on their child's progress (Clare and Pistrang, 1995; Russell, 2007).

Dale (1996) articulates the mismatch between 'a number of new rights for parental participation in special educational decision-making' and practice failing to meet parents' expectations of one-to-one advice and support. Hughes and MacNaughton (2001) examine the role of parent involvement in early years settings (not specifically focused on children with a learning disability) characterising it as hard, complex and problematic, but essential to effective work with young children. They discuss the challenge of equitable communication between parents and professionals, asking whether it is realistic to expect shared understandings to evolve and what professionals should do if they cannot be reached. As I expected to interview parents who were using early years' settings I was keen to find out whether these experiences matched or refuted these findings.

Mittler and Mittler (1983) explain that in the early 1970s Jeffree proposed the 'transplant phase' or model to challenge the 'expert model' by involving parents. The intention was for professionals to share their skills and empower the parent by advising them on how to support their child. This led to parents being expected to take on the role of 'co-therapist' or 'co-teacher' in their own home, a role that Drew *et al.* (2002) acknowledge as challenging for some families. This should have given parents a role in decision-making, yet Russell's (1983) research showed that they regarded it as unreasonable for professionals to tell them what to do. Cameron (1996) and Russell (1996) report that this form of partnership was less successful because when professionals were dominant, it compounded the idea of deficit in both the family and the child.

Research shows that in some cases parents meet a negative response when they disclose their concerns. Goodey (1991), for example found her issues dismissed, eroding her trust in the professional, and leaving her thinking

she had been labelled 'a trouble maker' (p.108). Rosa a mother with a learning disability told Roets (2008:106) that professionals "deprived me of every spark of hope, all they did was dishearten me and make me question whether I could be a good mamma". Although these examples refer to specific parents in particular circumstances the impact was troubling and therefore had a place in my investigations.

There are a number of possible reasons why parents avoid working in partnership with professionals; Blok *et al.* (2007) suggest that it may be linked to parents' feelings of hopelessness. Atkinson *et al.* (2002) report that in some cases parents choose to avoid professionals as they attach stigma to asking for help. Temple *et al.* (2008) go further, suggesting that when professionals label families 'as hard to reach' (p.228) in reality it is the professionals that are inaccessible to some parents not the other way around. Although frustrating to professionals, Mittler and McConachie (1983) maintain that parents have a right to opt out of partnership. Where funds are limited Atkinson *et al.* (2002) question the wisdom of parents being placed on a waiting list for a service they do not want. This implies that partnership involves motivation from both parties.

When children enter pre-school, parents need to work in partnership with the professionals there. Clough and Nutbrown (2004) found that a minority of staff in a pre-school avoided communicating with parents for two reasons; firstly to protect them from hearing negative things about their child and secondly to protect themselves because they thought that parents may make the situation worse and blame the setting for their child's behaviour. They also showed a paradox between a willingness to embrace inclusion alongside a negative attitude to learning disability due to a lack of specialist resources, staffing and a perceived negative impact on the non-disabled children. These different propositions led me to consider that partnership models are likely to be different according to the service being used and the position and motivation of the parent, something I became interested to explore.

Broach and Williams (2006) research showed that relationships with professionals become a problem when a doctor tries to explain a child's

learning disability as the reason for a physical condition. Morgan (2006) describes how this led to her own child's medical needs being overlooked. Oliver (1996) observes that some health professionals become so entrenched in making the child 'normal' they impose inappropriate, even oppressive interventions. However, Woolfson (2004) maintains that parents are also capable of over-generalising the effect of a child's impairment anticipating problem behaviour as being inevitable and unchangeable.

The examples above show that relationships with professionals are complex and ambiguous and that for some parents they lead to a focus on the negative aspects of a child's learning disability. This raised my awareness of how attitudes had crept in and made a home in my practice, something I had overlooked until now. I hoped that my research would expose both the extent to which this is experienced and direct ways to build an alternative perspective.

### **2.3 Trying to help**

The historical context at the beginning of this study shows that there were concerns about the quality of life of those with a learning disability stretching back to the eighteenth century. This led to providing help which is the focus of this section.

In the late 1960s and early 1970s Campbell and Oliver (1996) argued with organisations on behalf of all disabled people for changes in the attitudes portrayed through the medical model. The organisation, 'The Union of the Physically Impaired Against Segregation' (UPIAS), campaigned to develop a different understanding of disability. As a result a distinction between the biological and social aspects of impairment emerged. Through this an alternative view of disability was created and communicated through the social model. From the perspective of Oliver (1983) and Finkelstein (1980) this model explained that it is society and the conditions that people live in that make them disabled not the individual themselves. Barnes (2003a:9) sums it up as representing 'nothing more complicated than a focus on the economic, environmental and cultural barriers encountered by people viewed by others as having some form of impairment'. This placed responsibility in the hands of society for helping to address those barriers

and implied that parents could expect adjustments to be made which would enable their child to enjoy the same opportunities as others.

Barnes *et al.* (1999) propose that the social model could be summed up from three perspectives of help, one focused on the experiences of disabled people, another on the rights agenda arising from it, and finally examining opportunities to enhance the lives of individuals and challenge out of date attitudes. The position of rights was taken up by the 'British Council of Organisations of Disabled People' (BCODP) who began 'to consider the disabling barriers and negative attitudes that disabled people faced as a denial of their human rights' (Campbell and Oliver, 1996:103). At the UNESCO conference in Salamanca in 1994 rights to inclusion and participation were agreed as essential to human dignity, stressing that human differences are normal and that education should be adapted to the needs of the child. Its challenge is encapsulated in the statement that 'for far too long, the problems of people with disabilities have been compounded by a disabling society that has focused upon their impairments rather than their potential' (UNESCO, 1994:7). This observation invites parents and others to see things from the child's perspective, helping to ensure that they enjoy equal opportunities and to correct stereotypical attitudes about what the child is unable to do.

### **2.3.1 Policy which aims to help parents**

Government strategy and policy aimed to embed children's rights through inclusion and the involvement of parents to reflect the shift in perspective described above. Help in education was identified in The Warnock Report (DES, 1978) which recommended investment and parents' involvement in assessment. Mittler (2000:9) maintains that this 'helped to change the emphasis from defects and deficits to an identification of the unique needs of individuals, regardless of categorical labels'. The 1981 Education Act that followed contained a commitment to early identification of special needs and a statement that where possible children should be educated in their local mainstream school. Later, the impact of the 'initial assessment of need' (in the 1989 Children Act) was to provide a 'care package' linked to individual need offering parents access to relevant agencies. Combining care and education aimed to break the cycle of social exclusion and support

parents. Specific improvements in assessment, health services, social care, family support and early years education were outlined in the Framework for Action (DoH, 1998) and the white paper that followed in 2001. Short, medium and long term performance indicators were set out (Glass, 1999). Targets were given shape in a prevention model described by Smith (1999), designed to help families, it identifies the importance of general well-being for all under-fives and targeted services for families considered at risk.

In 2000 the government began to invest in the Sure Start programme, aimed at children under five living in the poorest and most disadvantaged localities, focused on improving children's life chances and preventing social exclusion (Glass, 1999). In the Sure Start Children's Centres parents had the opportunity to meet with professionals and become competent in their parenting via a delicate balance of advice and independence. The support focused on health and well-being often linked to attachment, to influence the child's internal working model (Aldgate, 2007) in which the relationship between 'the self' and 'the other' form a critical role in the development of the personality. As the internal working model is understood to originate through early relationships the potential impact is regarded as profound, shaping the child's expectations and plans for the rest of their life (Bowlby, 1973). Bagley and Ackerley (2006) describe how collaborative working between local parents under the supervision of a health visitor is helping to achieve the outcomes above and improve parents' self-confidence, self-worth, self-esteem and self-efficacy. These outcomes are embraced in the action plan set out in Every Child Matters (DCSF, 2009) and include the importance of 'parenting courses and family learning opportunities, if and when needed' (Hampshire County Council, 2009:4). While this policy placed my work in context it raised the question of what and how it was helping parents who were looking for support.

Other policies that are a catalyst for help include: the National Family and Parenting Institute, reform of tax credits, the implementation of the Working Time Directive and the National Childcare Strategy. Early Excellence Centres, made distinctive through a multi-agency approach with specific advice and support for families with a child who has a special need, began to be built. To address the commitment to early intervention,

Together from the Start (DfES and DOH, 2002) aimed to help by providing resources and information for parents, carers (seen as 'active partners') and practitioners where a child is

experiencing significant developmental impairment or delays, in one or more of the areas of cognitive development, sensory or physical development, communication development, social, behavioural or emotional development; or has a condition which has a high probability of resulting in developmental delay (p.7).

To counter the criticism that these aims reflected the medical model Removing Barriers to Achievement: The Government's Strategy for SEN (DfES, 2004b) was published, advising an inclusive model where partnerships between parents and providers in education, health and social services are central. This communicated a corporate response to support applying the social model, rather than focusing on the individual as a problem.

When the Green Paper Every Child Matters (DfES, 2003b) was published it became the spearhead for restructuring, integrating and co-ordinating services shown in the Children's Act in 2004. The aims, stated in the Ten Year Strategy for Childcare (DfES, 2004a) are to provide families with "integrated" services, or "integrated" working, encompassed in the notions of "multi-agency" working and "interagency" co-operation' (Jones and Pound, 2010:64). Within this strategy there is a target to locate all services under one roof by 2010, aiming to avoid disjointed services and to improve both arrangements for identification and early intervention.

Where families need additional help the Common Assessment Framework (DfES, 2006) was introduced to provide a clear structure setting out early intervention, signposting additional services and developing a common understanding by appointing a lead professional and team around the child. This system was made more accessible with the launch of National eCAF in 2009, enabling practitioners to gather and record information electronically to support families who either move or use multiple services in different areas.

The report 'Improving Life Chances of Disabled People' (DfES, 2005) recommend providing individualised budgets because they acknowledge that parents' needs in relation to well-being and development change in the early years. The targets set out in this policy were added to when 'Aiming High for Disabled Children: Better support for families' (DfES, 2007b:3) was published communicating the intention to 'transform the life chances of disabled children', and continuing the theme of consultation with parents and children, professionals and charities. This identifies strategies to empower parents, supporting them in making choices and responding to a variety of needs particularly at times of transition. This is specifically addressed in 'The Transition Support Programme' (DfES, 2007b:7) to facilitate an 'intensive, coordinated support and person centred planning'; improving quality and capacity including short breaks and quality childcare so that parents can go to work. Russell (2008:110) argued that 'this policy will recognise that families themselves have changed and must include lone parents and step families, and acknowledge the growing engagement of grandparents in bringing up children supporting equality and inclusion. However, following a consultation with parents the government recognise that many families continue to find the system 'impenetrable, bureaucratic and inefficient, and [that it] does not sufficiently reflect their family life' (DfE, 2011b:41).

Reviewing the grey/policy literature sheds light on the connection between responding to the social model and addressing children's rights which shape policy and advise practice. They reflect a variety of methods of helping parents, applying practical support and encouraging parents' engagement in their child's development. This study offered me the opportunity to review this with the parent-participants exploring how government commitments were translated into practice for them, helping me to delve deeper to find out how to make support effective in the future.

### **2.3.2 Sources of help**

Reviewing the literature showed that the aim of support is often to provide children with the same opportunities as their peers. Diagnosis becomes a gateway to both resources and services to support them, for example

medicine, education and social opportunities (Ryan and Runswick-Cole, 2007).

As parents begin to interact with professionals they often experience the expert model described above. Parents in Gray's (1994) research sought expert help in times of crisis seeking reassurance. Dunst *et al.* (1991) describes how the expert model can be developed by using the family-allied model, where although the decisions are still made by the professional, who is seen as an expert, there is scope for inter-relationship because the professional is recognised as on the parents' side and acknowledges their skills. This links to the transplant model (Mittler and Mittler, 1983) described above which was introduced to counter the dominance of the professional and became reinvented with the introduction of Portage in 1976 when professionals entered the home to teach parents skills they could use with their child (Cameron, 1996; Russell, 2007). The results have led to positive help suggesting that it is the individual supplying the support, rather than the model which has the greatest influence and acknowledging that the softer qualities of care and empathy identified by Leyin and Wakerly (2007) have particular significance in building positive relationships. As Paige Smith and Rix (2006) suggest, it takes time for a supportive partnership to emerge and is based on common aims and language.

Reports on Portage identify how it adopts a family-centred approach. This includes setting targets that are of interest to the child, which are presented in small achievable steps. In reviewing progress the parent can alter their perception that their primary role in the development of the young child is helpless and instead see how they can make a positive difference (White, 1998). Russell (1996) explains that 'the achievement of each step, however small, is celebrated with the child and family' (p.679). He contends that by placing the parent at the centre of the child's life it empowers them to support their learning and development, offering the opportunity for 'individual autonomy with team accountability' (1996:286). Mittler (1996) maintains that when the parent sees the child acquire skills practised over time it improves the family's understanding of what they can

do. He argues that because the child responds positively to this support, parents demonstrate the effectiveness of their role as a teacher.

Russell (2007) explains how a family focus, that includes emotional support to empower the parent through active listening, helps to promote inclusion. When Nunkoosing and Phillips (1999) evaluated the Portage service they found that because of the intensity of the programme, Portage workers were in 'situations that call for advanced human relationship skills' (p.204). They describe the role of the 'listening ear' in becoming an advocate in helping the family secure services for the future. Due to sustained contact, sometimes over a period of years Portage workers may become regarded as a friend of the family. Whilst these features suggest a positive help to a family, it is equally important to support the parent to be independent.

Clare (1995) and Russell (2007) report parents describing regular contact with a caring person as the most valuable aspect of the Portage, along with the consistency and quality of the practitioner in a home-based environment. The encouragement, advice and information along with noticing the significant progress the child makes, was recognised as helpful. In some cases the Portage worker facilitated contact with other families. This information sparked my interest in gathering more individual stories of the impact of Portage on the parents I hoped to meet.

Schmalzer Blacklin (1998) described home-based services as helpful because the child is in his or her natural environment and more likely to learn and generalise the skills to other situations. The context provides the potential for advice that can empower the parent to solve problems and manage behaviour in a way that suits the family. Professionals who home visit include health visitors and family support workers, nursery nurses, behaviour and speech and language therapists. The relationship can be managed in a number of ways, for example the 'consumer model' devised by Cunningham and Davies (1985) aimed to show how professionals respect individual families. In practice this meant using the parents' natural style of interaction, taking account of the particular needs and resources, so that families were offered a range of options which they could choose from to suit their needs. Mittler and Mittler (1983:10-11) maintained that its

success was dependent on parents being seen as 'the only true experts and best resources we have'. In reality Appleton and Minchom (1991) argued that its success relied on the capability of the parent to represent themselves and the availability of resources.

The Special Educational Need Code of Practice (DfES, 2001:16) identifies that 'partnerships can be challenging, requiring positive attitudes by all, and in some circumstances additional support and encouragement for parents'. Clough and Nutbrown (2004) agree because, as the child's main carers, parents need information about processes, systems and intervention strategies so that they can work with professionals effectively.

Bishop and Swain (2000) describe how the transplant model is applied in a nurture group set up in the nursery unit of a primary school. Here parents were 'trained' to apply techniques to manage their child's behaviour positively, which once introduced in the school are continued at home. The parents' priority was that it would lead to their child becoming integrated into mainstream education. Practitioners hoped that they could train parents to provide appropriate discipline at home so that the children would behave better in class. Although the method is open to question because it required the child to change to fit in and exposed challenges to partnership that should represent 'a two-way flow of information, knowledge and expertise' (QCA/DFEE, 2000:9), parents became committed to the process because they thought it would be helpful in the longer term.

Rather than being expected to conform, the research of Espe-Sherwindt and Broach and Williams (2006) showed that a participatory approach where parents' input was encouraged by professionals was helpful. The outcome was changes in decision-making that meant existing knowledge was used to shape action. Beresford *et al.* (2007) also included parents in measuring the outcomes of support. When parents were offered multi-agency support professionals told Atkinson *et al.* (2002:233) they felt 'a lot more comfortable about the way they are managing individual problem behaviour'. Desforges and Abouchaar (2003) propose that during parents' and professionals' negotiations relational factors are identified so that there is continuity of experience for the child. Sylva *et al.* (1999:5) sum up this

idea maintaining that, 'what parents do with their children is more important than who the parents are.'

Voluntary organisations or charities have a history of supporting families that stretches back to the 1940s. In this part of the literature review I examine how they have helped parents. The first example is KIDS, set up in London forty years ago to provide a named support worker service for children with a physical or learning disability. Parents told Dale (1996:235-236) that they valued the support worker as someone who was both 'impartial' and independent providing 'emotional support, care and concern' which meant that 'parents felt supported and valued; they appeared to become more confident and competent'. They found that because of the availability of staff, quality of listening and positive attitudes, it helped to them to feel equal.

A second example is the National Association of Parents of Backward Children (NAPBC) founded by a parent Judy Fryd in 1946 who identified a lack of support for families. Renamed, Mencap (2010) it has grown to include more than 450 affiliated groups with parents at the centre of its campaign. Ross (1983:64) describes their primary objective as increasing awareness of the needs of disabled people and their families to 'create a sympathetic climate of public opinion as a necessary pre-requisite of their acceptance into the community'. Rolph *et al.* (2005) provide many specific examples of the help that families have both received and contributed to, as Hardy (2005:44) says, 'we [parents] could use other skills – not just parenting'. Parents who access support from Mencap today identify the benefits as: providing information; reliable respite care and practical and emotional support.

A third example is Home-Start (2009) which, since 1973, has grown to become the largest family support organisation in England providing parent-to-parent help with an open referral system. Volunteer parents are carefully matched to each family and provided with training and resources. Asscher *et al.* (2008) explain, that a volunteer is referred to a family who has a pre-school child and is finding it difficult to cope and regularly visits for half a day a week. They contend that Home-Start has an important role

to play because the well-being of the parents is intrinsically linked to outcomes for the child in infancy and early years. McGuffin (2002:253) maintains that each family has 'layers of need reflecting complex situations particular to the individual family' and that this service helps to prevent family crisis and breakdown.

Asscher *et al.* (2008) show that parents who received Home-Start were more consistent and sensitive in their care-giving than the comparison group. They propose that the likely reasons are a combination of practical assistance, emotional support and advice from the volunteer. Chapman (2005a:214) records a mother's perspective: "I've found the best support that I can get is from volunteers. They're there because they want to be there". Frost *et al.* (2000) report that twenty parents who had a child with a disability described the positive impact of sharing feelings, gaining advice and information and working together. They identified the value of Home-Start filling a gap in a society where the pace of life often leads to superficial relationships leaving people feeling isolated and 'excluded' (p.339) because of their individual problems. Although Home-Start is not specifically directed to families with a child who is disabled, this shows their value when it is and I was interested to find out if any of the parents in my study had access to this support.

Barnes (2003b) names Home-Start as a means of promoting the transactional model (Sameroff, 1987), where maternal relationships are enhanced because parent-infant and infant-parent reciprocal transactions are improved. Although she recognises that volunteers help to improve the maternal emotional state through emphasising strengths within the family, she also argues that 'to achieve lasting impact with high-risk infants and parents, multidisciplinary strategies are needed' (p.389). Akister *et al.* (2003) also acknowledge that although parents named Home-Start as a listening ear, selected professionals such as the health visitor were required for advice. This provides an example of how voluntary organisations and professionals work in tandem as recommended in the policy review above.

The research undertaken by the Allan Roeher Institute (1989) showed that being part of a support group was helpful to parents. They described people

from different backgrounds blending together like 'soup and biscuits' (p.11), sharing the common experience of having a child with a learning disability. They had a combined commitment to change and developed goals for action. This was important to a parent who spoke to Ross (1983:65) and said that, "I seem to find new energy from the realisation that at least I can talk and relax with other parents who know what it is like." Participants in research by Murphy *et al.* (2006) said that as a result of being in a support group negative emotions had reduced and resolve improved. Parents interviewed suggested that the mutual support meant that they helped each other out which led to them feeling better. Both Finch (2008) and Case (2000) report parents saying that they got the most useful advice and help from other parents.

Flewitt and Nind (2007) add that making contact with other parents through a support group leads to an improved social network for themselves and the child as well as sharing information. Kausar *et al.* (2003) go further claiming their findings indicate that through sharing experiences with parents they became more hopeful because they could see what others had done and achieved. As part of my work involves parents supporting each other I was inspired by these reports and wanted to find out more about whether these connections helped the parents I met.

Although the research above promotes the role of organisations and individuals who set out to help parents, Gray (1994:299) put these into perspective saying that 'service agencies, the family, religion, individualism and withdrawal' are all useful but one method cannot be guaranteed to help everyone. This reinforced my commitment to listen to individual stories because they would become a lens through which to view the components of support enabling personal experiences to shed light on what was helpful and why.

In this section I have described the research which showed how support has led to parents being helped. The prompt for this was my opinion that parents need help. In the next section I explain an alternative understanding of learning disability which led to my view being broadened.

## 2.4 Celebrating difference

Although the influence of the social model of disability has led to parents receiving many opportunities of helpful support, another argument is that this falls short of challenging negative attitudes that still exist in society today. Swain and French (2000:569) propose an alternative model which they describe as '*affirmative*'. They aim to discard the tragic view and replace it with positive social identity that validates the individual and their experiences. As Whittemore *et al.* (1986:5) contend, people with learning disabilities 'are not helpless, involuntary victims of genetic adversity, or the degenerated shells of individuals who 'might have been.' Murray (2000) endorses this, describing her feelings that her son had equal value to any other child, comparing this to past ideology that to be disabled with learning difficulties is to be 'lesser than' (p.696). Mays (2005) is clear that her aspirations for her daughter who had a learning disability were the same as those of her typically developing son. She wanted her to fulfil her full potential, 'to contribute to her community, to feel needed, wanted and useful' (p.253), while parents in research by Beresford *et al.* (2007) said that they wanted their child to become part of the wider community by being accepted without their differences being highlighted.

In reading this I became challenged to notice that when people try to help it can be communicated as a response of pity, or with the intent to alter the individual. I began to reframe my view seeing that individuals are 'pleased and proud to be the person he or she is' (Swain and French, 2000:570). Where parents highlight the positive experiences of having a child with a learning disability they repudiate 'the dominant value of normality' (Swain and French, 2000:578), which allows the child to be themselves rather than insisting that they conform. Parents in King *et al.*'s (2006:361) study responded by changing their values and priorities, finding that their children taught them 'what is really important and some of the things which often we miss in everyday life.'

As discussed above, normalisation can lead to support, but Wolfensberger (1983), responding to the criticism that it implied people with disabilities should alter their behaviour and be 'normal', took this a step further in adopting the term 'social role valorisation' (SRV). This aimed to create a

space for those with disabilities to have their new found competencies valued. Case (2000) provides an example of how to value competency through seeing the child as an 'experiencing agent' (p284). Elsewhere Allan (1999), Kay (1993), Stewart (1993) and Welshman (2005) suggest that challenging stereotypical views of learning disability have the potential to both improve support and attitudes to disability. Culham and Nind (2003) note that in practice the influences of normalisation and SRV have been far from straightforward stating that it is important to recognise how the aims have been distorted leading to mistakes that all should learn from. This helped me to realise the complexity of this field and how self-reflection is necessary to challenge my response to learning disability. I therefore planned to include this as part of my role in the research.

#### **2.4.1 Positive outcomes from celebrating difference**

Although less prolific, the literature includes reports of parents' positive responses to their child's disability, for example Harty *et al.* (2007) found reactions that reflected generally high maternal efficacy for mothers whose child had a communication disability. Mullins' (1987) critique of how disability was portrayed in sixty books recorded that parents' experiences showed 'most parents concluded that their lives have been enriched and made more meaningful by virtue of parenting an exceptional child' (p.33). King *et al.* (2006:363) describe how parents of children with autism and Down syndrome recognised the 'positive contributions made by their child to themselves, their family and society as a whole'. Woodgate *et al.* (2008:1081) report that parents 'fought to ensure that friends, professionals and society in general knew about the unique characteristics made to the world by children with autism'. The research of Welterlin and LaRue (2007) also provides examples of positive responses to children with autism born to immigrant families. Burke (2004:12) sums up these reactions by explaining that difference is seen in some families as welcome, 'confirming individuality and a sense of being special'.

Although diagnosis has been discussed from a negative perspective in some quarters and leading to help in others, it is also identified as an opportunity to open channels in learning and socialising (Connors and Stalker, 2003; Howie-Davies and McKenzie, 2007; Stainton and Besser, 1998). Stainton and Besser (1998) and Finch (2008) report that where families have access

to a variety of opportunities to mix with others, personal and social networks grow. Parents describe losing and gaining friends, finding out who their 'real friends' are along the way. This suggests changes occur over time, a point reinforced by Ryan and Runswick-Cole (2007) and Woodgate *et al.* (2008) who conclude that the way we operate in the social world shifts and flexes over time. Krauss and Selzer (1999) identified that support leads to parents and children finding new paths of communication and warmth which creates a stronger bond between them. Scorgie and Sobsey (2000) similarly described how time becomes part of a transformational process where parents altered in their personal growth, improved relations with others and changed their philosophical or spiritual values. Woolfson (2004) uses redefinition to explain this, claiming that with support parents can redefine their expectations and realise that behaviour can be linked to stage of development rather than the child's condition.

Within families redefinition is not always necessary, as Connors and Stalker (2003) found when listening to siblings who showed a positive attitude to their brother or sister, seeing them as an individual rather than the label of their learning disability. Stainton and Besser (1998) also record that siblings benefit from being part of a family where a child has a learning disability because it makes them more tolerant and understanding. This research implies that there is a potential for members of the family to play a role in helping society to celebrate difference.

#### **2.4.2 The role of partnership in celebrating difference**

When the expert partnership model was challenged, new components were identified: for Beveridge (1983) these were exchanging information in collaboration with the parent; for Cross (1989) using the information for a common purpose and joint decision making; for Pugh (1989) a willingness to negotiate; and for Wolfendale (1985) a process of identifying parents' strengths and expertise so that they become involved and mutually accountable. Within these alterations I could see how parents would be offered more opportunities to provide input so that the child could be accepted, valued and celebrated as an individual.

Dunst *et al.* (2002) describe how a family-focused model applies the consumer model in a positive way because professionals present parents

with options which are linked to what the family needs. This means that parents are viewed as competent to select the one that suits them best. The family-centred model emphasises strengths not deficits, promotes family choice and control over resources within a collaborative relationship between professionals and parents (Davis and Meltzer, 2007). Espe-Sherwindt (2008) concludes that this model leads to services that are on an equal footing because they are flexible and responsive to the individual's personal values and beliefs. She claims that by working with the family in this way parents' confidence is improved and their strengths become building blocks for the future. I therefore see that this way of interacting with parents has the potential for them to celebrate the different skills the child has and use these to plan a way forward.

Appleton and Minchom (1991) recommend the implementation of an empowerment model, in which the family becomes represented as a social system by which disability may be better understood and celebrated. It acknowledges the parent's right to choose at which level to engage personally. Although this model implies greater control to families, in practice it is very often the professional who identifies the unique strengths and needs of the family and then incorporates them in the assessment and intervention procedures. Emerging from the features of the consumer and empowerment models Dale (1996) proposed a negotiating model to stimulate joint decisions. This enables the parent and professional to acknowledge constraints and concerns through a shared perspective. When tensions arise from cognitive and emotional viewpoints they are resolved by a process of sharing issues that lead to solutions, sometimes producing consent and at others dissent, which Case (2000) proposes makes it fit for partnership in present day society. Although the outcome is not always exactly what parents want, the opportunity to identify concerns and priorities as well as having a role in the plan of action can be viewed as empowering and positive (Bagley and Ackerley, 2006).

This review enabled me to see the potential of partnership as a catalyst for identifying the unique qualities embedded in a particular condition. In order to share how partnership was experienced by the parents in my study and

learn more about its impact I began to explore the value of applying an ethnographic case study approach.

While professionals are not responsible for how parents feel about themselves, where they can contribute to building confidence they can help them and their child. Woolfson (2004) maintains that professional support can help a parent to reappraise any beliefs that are barriers to seeing the child in a positive light. Harty *et al.* (2007) report that when the parent has positive expectations of their child's progress it leads to improvements in their own self-efficacy. In exploring the outcome of self-esteem Kelly and Barnard (2000) found that there was a complementary relationship between a child's outcomes and maternal efficacy. The conclusion was that the more efficacious the parent, the more actively they engage in the process of supporting their child's development. This married two intentions, one related to my work supporting parents in building confidence and self-esteem, and one to apply it to my research procedure so that I could review opportunities to celebrate difference and encourage parents' efficacy from listening.

Celebrating difference has the potential to have an influence beyond the boundaries of the family. This is highlighted in the work of Bagley and Ackerley (2006) who reported the results of Sure Start, showing extended partnership relationships that encompass horizontal and vertical ties with other parents, voluntary organisation representatives and leaders, health, education and social service professionals. Similarly, Wolfendale (2000) describes how the concept of parents as 'informed experts' has led to their representation within local early-years partnerships. Parent Partnership Services are now recognised as an effective vehicle to provide parent-focused services, some within the Sure Start Centres which at best epitomise partnership and at the least offer information, support and sympathy (Wolfendale, 2001). Where parents engage in this way I saw an opportunity to re-present disability in a positive way.

#### **2.4.3 Celebrating difference through education**

Listening and learning from parents are key components set out in education, early years and social policy. 'Valuing People: A strategy for learning disability for the 21st Century' (DoH, 2001:8) acknowledges that

negative attitudes to learning disability have a 'very damaging impact'. The commitments in this Green Paper are attached to funding and recognising the importance of applying a person-centred approach. For this to be successful there is a role for the affirmation model in valuing the individual child's achievements set out in the EYFS (DCSF, 2008), a point endorsed as crucial in Tickell's (2011) recent review of this curriculum.

As professionals and parents meet in an education setting, Carr (2004:61) recommends an 'alternative credit model' which focuses on 'the learner-in-action or in-relationships.' This proposal challenges the idea that children should fit in and rid themselves of what are perceived as inappropriate behaviours. Instead the professional and parents observe the child interacting and playing and review the learning environment from the child's point of view. This allows for Murray's (2000) point that her son should be respected and accepted and not expected to change in order to fit into the educational system. Where these recommendations are implemented parents' self-esteem may grow which, as Trute *et al.* (2007:7) suggest, is 'a salient issue for both mothers and fathers as they enter childhood disability services' and beyond.

Looking back I could see how this review had led me to a different attitude and way of thinking, altering my values and beliefs through learning and reflecting on past experiences. This shift in my understanding meant that I entered the field from a different perspective. It had an influence on the way I planned my research, how I decided to interact with the parents and my method of analysis, because I could see how an iterative approach would mean that I could explore parents' experiences of support and attitudes to their child's learning disability in a more honest and open way.

## **2.5 A possible way forward**

In this section of the literature review I turn to the recommendations made within the research which show how support could be improved in the future. This was so that I could identify how these linked to the experiences of the parents I met.

A position some researchers take is to improve society's understanding and attitude to disability. Goodley and Roets (2008:243) task the reader to

challenge 'stereotypical associations of forms of personhood with particular 'impairments''. Dowling and Dolan (2001) argue for family involvement in social care initiatives, working more closely with the government, professionals and voluntary organisations so that disability can be better understood. Mittler (2000:3) recommends 'interventions at a variety of levels: teaching, parenting, peer support and friendships, positive attitudes from neighbours, removal of barriers of all kinds', because as Allan and Owen (1993:17) point out (albeit in language that jars) 'the greatest barrier in handicap lies not with the sufferer but with the observer'.

Although examples of good practice are set out earlier in the chapter in the sections 'trying to help' and 'celebrating difference', writers suggest that positive key features need to be applied more consistently. For example Espe-Sherwindt (2008) identifies the importance of consistently applying relational qualities that are shown in interpersonal behaviour such as warmth, active listening, empathy and viewing the family in a positive light. For this to happen Beresford *et al.* (2007) contend that families need to feel that their input is being taken seriously and valued as part of the partnership relationship. Chapman *et al.* (2005) say that parents want professionals to show an interest and a personal commitment towards their child. Dale (1996) proposes, that when families' aspirations are met and their input valued, the experience leads to a combination of independence and inter-dependence, enabling professionals to withdraw. Pinney (2007:7) acknowledges the difficulty in maintaining the balance between empowering parents and engendering dependence saying 'there is a need to maintain a clear focus on *'moving families on'* enabling parents to cope themselves'. This means that solutions and values need to be rooted in the parents' agenda.

The work of Mir *et al.* (2001) and Welterlin and LaRue (2007) describe how professionals build significant relationships with families from differing cultural backgrounds which I propose is valid generally. This is because, Beresford *et al.* (2007) report that parents want their culture to be respected and to be listened to. In pursuit of this Moes and Frea (2002) state that contextual information needs to be included in the training of professionals. Welterlin and LaRue (2007) advise professionals to take an

interest in the culture from the standpoint of 'curious ignorance' (p.756). They identify the important role of questions like 'can you tell me more about...?' so that the family feels respected. They maintain that the parent becomes empowered when professionals focus on their strengths and resources. This means they can build resilience from within the home network rather than relying on professionals. For this to be successful they recommend that the professional identifies their personal beliefs, values and culture as these provide a bias that may conflict with those of the parent. Once acknowledged, they contend that differences can be respected more easily. Dale (1996) makes a similar point reminding the professional that 'their different positioning within society leads to varying and multiple perspectives of the same situation' (p.15). Mir *et al.* (2001:62) identify the benefit of cultural sensitivity to enable 'a level of continuity between home and other environments.' When this happens it is possible to select goals with the parent which reflect their world rather than that of the professionals (Schmalzer Blacklin, 1998).

Goodley and Tregaskis (2006:644) argue that 'professionals need to be sensitive not only to how they talk about impairment but also how they understand and react to impairment in their practices.' This would have an impact on the parents' experiences of support and involve Crnic and Greenberg's (1987) advice to undertake a thorough appraisal of the parental attitudes and perceptions of the child. Such actions could lead to what parents told Case (2000) they were looking for: caring attitudes from professionals, information that is co-ordinated and emotional support including access to counselling following the diagnosis. Connors and Stalker (2003) provide a specific example of a parent who wanted to make a connection with her GP so that, through a positive relationship her child would be understood as an individual with illnesses that are distinct from the learning disability. Woodgate *et al.* (2008:1083) also listened to parents' experiences of support recommending that their expertise 'could become invaluable assets in helping professionals understand human relationships and responses.'

This advice was relevant to me at two levels; firstly as a researcher raising my awareness of differences in my values and culture compared to the

parents taking part in the study. Secondly, in exploring parents' experiences to find out whether their encounters with professionals resonated with the recommendations made by the researchers above or suggested that there was more work to be done.

Case (2000) and Mittler (2000) address the subject of how relationships with parents can be improved by professionals supplying information and offering a high quality of relationship represented through working in partnership. King *et al.* (2006:365) argue that

a family-centred model of service delivery recognizes that families are different and unique, and emphasizes the importance of identifying needs, individualizing services to meet needs, accepting diversity, and respecting and supporting families

Dale (1996) contends that the qualities of parents can be supported when professionals offer advocacy, enabling them to find a voice. Through this, the parent can become 'confident, assertive and effectual' (p.270). In this situation the professional acknowledges the potential power and capability of the parent and helps them to utilise their own resources, promoting independence. Advocacy also allows the parent's viewpoint to be heard through the professional acting as a representative with a focus on interdependence.

Schmalzer Blanklin (1998) states that professionals working with parents on early intervention programmes need to be flexible in their role 'sometimes serving as a teacher or therapist, sometimes serving as a counsellor or advocate' (p.306). This makes it possible to respond to each individual child and family by identifying their strengths, needs, priorities and concerns. As Parsons *et al.* (2011) maintain, children with autism are not a homogeneous group which means that the views of parents, practitioners and service providers need to be included.

Woolfson (2004) recommends an appraisal of the psychosocial factors realising that behaviour problems are experienced differently in different families. Barnes' (2003b) work provides advice about how to do this in

practice by listening at two levels, addressing the overt parenting behaviour whilst tuning in to 'associated underlying attitudes and beliefs' (p.389). This research guided my actions in the field so that I planned to listen to parents at two levels, hearing the experiences of support that were overt and searching for the underlying influences that were guiding the evaluation. This would enable me to gather a depth of understanding about the experience of support.

Prezant and Marshak (2007:41) provide details about how improvements could become 'helpful actions seen through the eyes of parents', beginning with professionals listening with respect, then being competent to provide information and thirdly to offer collaborative communication. This could be delivered through the person-centred approach that Routledge and Sanderson (2002:12) say shows,

a process for continual listening and learning, focussing on what is important to someone now and in the future, and acting upon this in alliance with their family and friends.

Roberts and Lawton (2000) endorse this by recommending that any assessment of a child who is disabled should seek to develop a clear picture of the child's additional care needs within the family setting, with due consideration given to the time involved in providing extra care. Bradshaw (2008) states that more consistent support is required through increased spending on health, education and childcare, ensuring that these are available. Dowling and Dolan (2001) add that there needs to be greater availability of professionals, maintaining that it is a problem for parents to travel long distances to appointments. They recommend that this should be addressed by visiting their home, a care setting or a Children's Centre that offers appointments, treatments and short breaks. I planned to find out more about the practical implications to gaining support from professionals in order to compare this with the improvements identified above and the commitments outlined in the section on policy.

Although in 1990 the government (DOH) set out a declaration to 'ensure that service providers make practical support for carers a high priority' it is

clear from research in 2001 (Dowling and Dolan) that the provision of short breaks could be improved. This subject was raised almost three decades ago by Cunningham (1983), then called 'respite'. The support was defined as two-fold, partly to give the parents a break but also to give the child an experience of independence from the family. The government acknowledge this, claiming short breaks are to give the family a break from care duties 'allowing children to experience new relationships, environments and positive activities' (DfES, 2007b:45). However, in the same document, it is argued that when there is too much attention on this service it may 'divert focus from other essential support services ... such as equipment and inclusion in universal provision' (p.34). More recently the requirement for this has been re-instated with a government commitment to invest £800 million 'over the period of 2011-2012 to 2014-2015 as part of the Early Intervention Grant for local authorities' (DfE, 2011b:53). This shows how priorities alter, suggesting parents will not always experience consistency in the support they receive.

A debate about the role of direct payments within support has exposed different positions, challenging their part in moving forward. Riddell (2008) reports that, because of a fear that they will lead to poor care, or relatives exploiting their child's disability as a means to gain additional income for themselves, managers are reluctant to endorse them. In contrast, Blyth and Gardener (2007) and Arksey and Baxter (2011) identified their positive impact because they enabled families to select sources of support rather than depend on professionals. Beresford *et al.* (2007) also propose that direct payments would constitute an improvement for parents and is a 'legitimate' way of helping children to achieve positive outcomes' (p.54) because there is a link between the well-being of the parent and the outcomes for the child. The issues that they could address include: providing parents with more time to explore an identity outside of being a 'carer'; improving their health; having the opportunity to focus on their relationship and providing for siblings so that they did not feel left out. These concerns continue to be acknowledged and have led to a government commitment to give parents the option of personalised funding by 2014 (DfE, 2011b).

In this study I was interested to find out whether both short breaks and direct payments were part of the support package offered to parents. I also wanted to test out my personal concern that access may be related to the confidence and tenacity of the individual applying for them, something I had not been able to gather evidence of through my literature search.

The subject of multi-agency working has been examined earlier in this chapter and I therefore highlight the way in which parents would like to see this improved. In 2001 (DoH) parents claimed they wanted more co-ordinated services and early identification and intervention. Atkinson *et al.* (2002) report that it is particularly important to parents who have a child with a disability where assessment involves health, social services and education. Parsons *et al.* (2011:57) record that experts believe that providing a 'seamless service' would 'avoid the confusion, anxiety and overload that can result from multiple separate agencies attempting to support one family'. Professionals said that parents wanted the assessment to take place in a 'one stop shop' (p.36). The argument is that when services are delivered through a multi-agency approach parents become more knowledgeable about what each service has to offer and are able to make informed decisions with better outcomes for the child and support for the family.

The literature reviewed throughout this chapter suggests that families are searching for different things to support their child's education. Lindsay *et al.* (2005) propose that parents need up-to-date and detailed information so that they can make informed choices. Parsons *et al.* (2011:52) reviewed literature from the evidence of experts and found a consensus that early assessment and intervention not only recognise difficulties but also lead to improvements in 'emotional, educational, social and cognitive development and their health'. For these benefits to be realised Flewitt and Nind (2007) identify that parents need a pre-school that is local, inclusive, resourced 'with skilled staff who had a positive attitude towards the abilities of children with special needs' (p.436). This research was of interest because it resonated with the intention to celebrate difference, giving the learning disability value that had the potential to build on a positive attitude throughout society. I realised that this could be dismissed as ideological

and even naïve within my limited first-hand experience of learning disability, which added weight to my plan to explore in depth.

The examples above reiterate how parents' needs are reflected in the policy and embedded in the Early Years Foundation Stage (DCSF, 2008) where advice on diversity and inclusion is set out. However, there are also areas of concern, expressed by practitioners talking to Brooker *et al.* (2010:42) who said that the current age bands in the EYFS 'demean children with developmental delays'. As a result the Tickell Report (2011) evaluating this curriculum document recommends that the age bands need to be 'broken down into much smaller steps to help them to recognise the progress of children with developmental delays' (p.33).

Earlier in the chapter it became apparent that fathers' involvement is beneficial and Green (2003) focused on improvements that would encourage this. The suggestions include encouraging fathers to participate in early years' settings, joining advisory groups and supporting a centre in practical ways. Carpenter and Towers (2008) say that it is important to respond to fathers who have encountered poor experiences in education, personal difficulties and have ethnic differences. They also recommend improvements in communicating with fathers who adopt or are stepfathers. Fathers told them that professionals often disregard their ideas and input, so it is important for professionals to regularly seek their opinion in future. Roach (1998) highlights the need to treat fathers as individuals, providing them with specific information about their child's development, assessment, future prospects and needs.

It has long been recognised that if fathers are to become involved in assessment and support there is a need for flexibility. Nearly three decades ago McConachie (1983) recommended that case conferences and meetings with professionals should be held in the evenings in the family home. Carpenter and Towers (2008) include this as a recommendation, adding practical improvements, such as providing advanced notice of meetings and extending the use of IT so that fathers can choose to communicate either virtually or face-to-face. Children's Centre workers told Brooker *et al.* (2010) that it is sometimes difficult to engage with fathers and so they stop

them in the street to speak to them and give them leaflets inviting them to attend. Although this review largely focused on the problems of access and involvement, it also highlights the more general point made in this section that improvements are linked to relationship, which involves treating the father as an individual. I hoped to learn more about how this is put into practice through exploring the subject of support with one or more fathers.

The literature in this section highlighted a need to make further improvements and I was inspired by Stainton and Besser's (1998:68) recommendation that 'further research, particularly narrative research on the positive impacts of disability on the family and the broader community would enhance and broaden our understanding of the effects of disability'. This resonated with Goodson's (1995) argument that the narrative researcher, takes the opportunity to listen to the participants rather than reporting a political agenda, saying

Only if we deal with stories as the starting point for collaboration, as the beginning of a process of coming to know, will we come to understand their meaning: to see them as social constructions which allow us to locate and interrogate the social world in which they are embedded. (p.98)

The stories that parent-participants shared when I took this approach helped me to see how interactions with sources of support had led to shaping how they defined themselves and professionals. For this reason I turned to review some of the literature that described the transactional model because I saw how this had the potential to enrich practice of support in the future.

## **2.6 The transactional model**

I decided to investigate the literature on the transactional model after I had completed my analysis of the data because this approach provided a context for interpreting the experiences of the parent-participants and a way forward. Sameroff (1991) first suggested the transactional model as a way of understanding the complex two-way influences in which infants and parents influence their environments, which in turn become influenced by them. Sameroff (1991) proposes that 'within this 'transactional model', the

development of the child is seen as a product of the continuous dynamic interactions of the child and the experience provided by his or her family and social context' (p.173). In my study the professional and parent entered a relationship characterised by dynamic interactions that were influenced by their social context. Sameroff and Fiese (2000) propose several actions to support the relationship between the parent and the child including remediation, redefinition and re-education. Because parents told me that professionals used assumptions to define them, I decided that redefinition would be a useful focus. As King *et al.* (2006:355) propose, interactions can give parents 'characteristics such as hardiness, sense of control, and powerlessness.' The positive outcome of using the transactional model is identified by Llewellyn and Hogan (2000) who propose that transaction produces a fluid relationship, helping to shape the self-concept of each individual. This could be applied to this study, as offering the opportunity for the parents and professionals to be redefined positively could lead to more effective interaction.

The transactional model presents individuals being influenced through interaction with the environment and becoming active synthesisers of information. Sameroff and Fiese (2000) argue that the context of development is 'as important as the characteristics of the child in determining successful development' (p.135). Combs-Ronto *et al.* (2009) explored the impact of bidirectional relationships between a parent and child and found that the behaviour between the two parties set up patterns of behaviour. Spano *et al.* (2009) also examine how feedback systems influence and shape patterns of behaviour. I was keen to relate this finding to interactions between parents and professionals because it situates each party as contingent in making support effective by considering the 'particular problem for a particular child in a particular family in a particular culture' (Sameroff and Fiese, 2000:135).

Research that explores the impact of interactions using a transactional model reflects the significance of the cultural code within each family. Sameroff and Fiese (2000:141) identify a 'constellation of environmental influences', including the family, the neighbourhood, education, money and the culture at large. Based on my earlier literature review, I could see this

would be relevant in the relationship between professionals and parents because each hold particular beliefs, influenced in part by the values and the personality of the individual, shaped by interaction patterns and socialisation beliefs which support their cultural understanding. When examined, a regulatory pattern emerges which helps the professional to see both their position and that of the parent. Sameroff (1991), again referring to parents and children, recommends applying 'attunement' (Stern, 1984), which involves recognising the mental state of another in order to connect with their experience. Within a professional relationship Makau and Arnett (1997) explain that the transactional model of communication has an ethical framework, so that each party is listened to with mutual respect which invites 'reciprocity and inclusiveness, and to live openly and responsibly with the dialectical tensions inherent in commonality and difference' (p.x). This was a commitment I had set out with in preparing to meet with parent-participants and was also relevant to future practice in my interactions within my work.

Sameroff and Fiese (2000) describe how personal values shape parents' expectations of the child. They found that parents looked for features they thought were missing in order to confirm the definition they had placed on the child. Combs-Ronto *et al.* (2009) identified the connection between the definition and the response made by the child so that when the parent expected non-compliance this set up a pattern of child non-compliance. Llewellyn and Hogan (2000:161) claim that when this is exposed and challenged things alter because 'behaviour change in one person, influences the behaviour and is then fed back transformed to the other'. However, there is complexity embedded in 'multiple realities arising from natural differences in the development of human perception' (Isaac and Michael, 1997:218). This showed me that applying the transactional model was complex and required commitment to the process which may be considered a challenge for professionals, and yet through realising its potential and how it works provided a secure base on which to build.

Llewellyn and Hogan (2000) found that when an authority figure labelled a person as difficult (in their case a child), this had a negative impact on the individual's self-belief. They found that the behaviour of the child with a

learning disability altered according to the person they were interacting with and the way that they were viewed by them. This suggested that both the professionals and the parent could be influenced by the expectations and assumptions based on first impressions and that this was likely to have an impact on the quality of support.

Major *et al.* (2003:87) explored definitions through examining how people respond to prejudice and established links between its impact and the individual's 'dispositional optimism, locus of control and self-esteem'. They showed that those with a stronger personal identity were less influenced by any negative social identity which arose from the group they were affiliated with. When Cudré-Mauroux (2010) examined the role of caring for those who have a learning disability he found that self-efficacy was complex and fluctuating showing that strength became a transactional factor. He emphasised the importance of well-being, goals to achieve, resources and accessibility. These findings enabled me to see how interactions between parents and professionals could be altered through considering the transactional factors identified, whose root may be due to material or emotional factors. For redefinition to take place, the professional would need to be prepared to meet the parent afresh, using a knowledge of their personal beliefs, expectations and experiences, so that these did not hinder the connection, leading to more effective support.

Bruner (1986) describes the key components of transaction as mutual sharing of assumptions and beliefs about how the world is, how the mind works, what we are up to and how communication should proceed. He claims that the social realities that are constructed by people have to be situated, negotiated and distributed. This respects the individuality of the parent who may not be ready to embark on the partnership relationship that the professional has in mind as an ideal. Instead it recommends that the professional negotiates by sharing assumptions and beliefs which enables the parent to feel heard and respected.

The negotiation identified above would involve a feedback process which exposes social realities and, according to Woodward (2000), invites feedback which leads to reciprocity so that 'collective action based on

mutual adjustment and relations of trust' (p.257) can occur. He proposes that this helps to ameliorate doubt and uncertainty which impact on relationships. This offers a way forward for the relationships between parents and professionals providing advice about how to achieve the family centred partnership model which empowers the individual and is recommended throughout the policy and research above. At the same time if the professional is to commit to this process they need to allow the parent to take the lead and accept that the journey to partnership may take time and energy and may not result in the outcome they had in mind.

This literature above presents the transactional model as demanding, however, Sameroff and Fiese (2000) explain that the most cost effective way to approach support is to target 'relevant nodal points for a specific child in a specific family in a specific social context' (p149). Goodley and Roets (2008:250) argue that both 'impairment' and 'development disability' are 'uncertain, productive and moveable' which means that we cannot hope to apply a single intervention and imagine that this will suit every parent for all time. Crnic and Greenberg (1987:345) describe the transactional phenomena as dynamic 'with different developmental factors asserting their importance at different times'. They note the interruptions that can arise when parents fail to tune in to the cultural code of the child or are tired, stressed or overwhelmed by work, factors which can equally be linked to the professional's situation or be factors affecting the parent when they receive support.

Nind and Powell (2000:100) explain the transactional model requires that both parties (the child and parent) become active participants 'to develop and extend the existing sense of reciprocity'. This would involve professionals inviting parents to enter an arena of 'multiple feedback loops between the behavioral patterns, beliefs and emotional reactions' proposed by Bricout *et al.* (2004:52). In practice this will be dependent on the individual parent as some are likely to be more willing and able to embrace this than others.

As the literature shows, using a transactional model enables both parties to alter their definition of the other and use this to change responses. This is a

complex process involving self-awareness, identifying with the culture of the parent, developing a relationship of trust and accepting unexpected outcomes.

## **Conclusion**

The literature reviewed in this chapter exposed a mixture of responses to disability. These are organised in sections which reflect how my understanding of the subject grew alongside my research. I began with the influences that are historically embedded in society and lead to a view that anything different from 'normal' is tragic. This position was challenged and led to action which meant that the individual was no longer blamed for their disability and that instead we hold a corporate responsibility to make adjustments to support inclusion. The outcome was that support was provided. However when I considered this I noticed that the actions embedded in the support ran the risk of implying that the person with the disability was inadequate and in need of help. In realising the possible impact of 'trying to help' I found that the literature which, instead, celebrated difference offered a positive dimension to the subject of support. As the research drew attention to improvements that could be made I used these as a guide for the future. This journey containing these different perspectives helped to shape my approach to exploring the experiences of parents receiving support.

Later the analysis of the parents' stories led me back to the literature and to a connection with the transactional model to which I dedicated a final section. Although explored after the field work, and influenced by it, I was able to detect threads of the ideas of transaction that had been woven into other research discussed. These were apparent when parents talked about how they would like to be treated by professionals when they were accessing support.

As a result of reviewing the literature I noticed that to uncover information that would help me to approach the problem of making support effective I needed to include elements that were on-going and dialectic. The literature taught me that impairment is 'complex, messy and ambiguous' (Goodley and Roets, 2008:240). As I prepared to enter the world of parents who had

close-up experience of this I planned to listen to stories within a context of access, attitude, responses, policy, partnership and change. These areas shaped the research question and sub-questions which begin my chapter on methodology and are presented next.

## **CHAPTER 3: DATA COLLECTION**

### **3.1 What I wanted to find out and why**

The aim of the research was to explore in depth the issues concerning the support that parents experience when they have a young child with a learning disability. Through listening to personal accounts I planned to capture stories as they were recounted to me. I wanted to involve the parents in the process of analysis and interpretation, at the same time including my own voice in their narratives. This became increasingly significant as I realised that I was learning from the parents both about support and about my own response to it. The reciprocal meaning-making involved became essential in my quest for integrity and authenticity of their story and mine.

The literature chapter showed that the subject of parental support and experience has been explored from a variety of perspectives by researchers from different backgrounds. The original contribution that this research offered was a re-presentation of individual and unique narratives, with the potential for personal and professional impact due to greater understanding of parent experiences of support. This involved challenging my thoughts and assumptions about parents' position both at the time and in the future. To achieve this I aimed to examine parents' experiences in a holistic way, rather than examining one service, or aspect which would have led to the atomised approach already applied by some researchers.

As a relative stranger to learning disability and the services offered, I planned to approach the subject from the position of a stranger learning, inviting the parents as 'experts' to open my eyes to the issues they encountered. From this position I entered the research field as a novice, rather than as a parent or professional regularly encountering support services. This, along with the unique contribution that each individual would make from their personal experience, meant that findings would be different to those already published. The purpose was to enable each parent to share their experiences, allowing their perspectives to contribute to a theory that illuminated their relationship with professionals explaining why some encounters had been more helpful than others. I hoped that the

knowledge arising would improve parents' experience of support leading to a change in practice for me, and that through communicating this to professionals, services would become more effective.

My previous experience of research was restricted to two dissertations which placed me in a position of learning, during the process of collecting and analysing data. As I planned to describe my strengths and weaknesses during the journey I hoped to contribute new knowledge to the academic community. This would arise from my evaluation of using the ethnographic case study and the participatory approach along with the methods I chose for analysis.

My primary question was:

**How do parents experience support when they have a young child with a learning disability?**

Using the literature and my experiences of working with parents as a guide I identified a number of sub-questions to enable me to focus on a variety of aspects of each parent's experience. The aim of the sub-questions was to provide an opportunity to review the parent's contribution holistically and in depth, so that I could compare each narrative with the issues that have been highlighted in previous literature. Although my analytical lens was steered by the literature, I rejected the idea of having sub-questions about the role of education and the voluntary sector etc as I wanted to leave the foci to emerge from the parent rather than guide them down a path that was influenced by my prior assumptions. This would mean applying an inductive approach to the analysis in place of trying to prove a position taken up by another researcher. I therefore set out to find out more about:

**What sources of support do parents identify and how are these experienced?**

The literature review highlighted a broad range of sources of support ranging from health and education professionals to voluntary organisations and support groups. I expected to find that the parents taking part in this study would be able to access these and I wanted to find out more about

how they were experienced. Through parents recording these in a way that was personal to them, I aimed to uncover the characteristics of support, how they emerged and whether some were more significant than others. I was interested to explore whether parents identified certain support as more influential and the factors that contributed to this, including their personal opinions of what had been, and continued to be, useful. I planned to search for evidence of impact from the parents' perspective so that I could compare my findings with other research and show it in a way that would invite reflection on how the information could influence practice. I also intended to express the individual nature of experience, capturing this as both unique and where appropriate similar to that of others.

**How effective is current legislation in ensuring the delivery of support to parents?**

Evidence to answer this question would come from comparing the aims of current policies with the experiences that parents described. Examining how parents received the support would mean that I could identify the areas that reflected the principles of current legislation and where discrepancies existed. Through listening to each person's story, I could hear how they interpreted support and identify options that could be shared with professionals to enhance services in the future. I hoped that lessons could be applied to training professionals so that they could respond to parents in a way that respected their individuality.

**Are all parents able to access the support they need?**

I aimed to find out how parents access support and whether the information and services received were broadly similar. I was interested in the factors that affected the individual when they sought support, where and why barriers exist and ideas about how they may be overcome. I hoped to unravel how arrangements work for parents and what makes support accessible.

**How do people's attitudes impact on the support that parents receive?**

As there was evidence of a negative attitude towards learning disability in the literature I was interested to find whether this was pertinent for the parents who participated in the study. This would involve listening carefully to their own interpretation of both learning disability and support and the extent to which they felt that people's attitudes had influenced their experiences. I was concerned with evidence of the origins of particular interpretations and to reflect on the extent to which negative attitudes prevail or positive attitudes have replaced them. Through this I wanted to raise the awareness of professionals regarding the range of attitudes among parents and society generally and their impact.

**How does the partnership between professionals and parents impact on their experience of support?**

As the literature review had offered the chance to review partnership models I wanted to explore what they might mean in reality. They appeared sterile and I hoped that the parents' stories would bring them to life. Through using the lens of partnership, I wanted to learn how professionals could make their interactions more effective in empowering the parent and selecting support that would make a difference. I hoped that my analysis would lead to a theory that would help me and others to understand and enrich partnership relationships.

**In what ways do the support needs of the participating parents change over time?**

I planned to explore the dynamic of support over time, finding out the ways in which support changed for parents from when it was first experienced and how it altered as the research progressed. Through capturing a breadth of sources of support, each parent would provide information showing what made a difference at particular times in their lives. By re-visiting some of my parent-participants twelve months after my initial interviews I could review changes that had occurred in the intervening period.

I wanted to use the sub-questions to dig down into areas that at first sight may seem trivial, yet over time may take on a life of their own, determining positive or negative experiences of support. They were selected to

challenge my assumptions of what issues are most important to parents, 'opening my eyes to 'real life' situations which are as far as possible undistorted ... in a way which conveys the subjective reality of the interior world of the participant' (Pole and Morrison, 2003:6). The information that emerged was set to inform practice in the future. How the methodology was shaped through these questions is explored next.

### **3.2 My approach to gathering information from the parent-participants**

All research aims to address problems and concerns of everyday existence and Dewey (1938), among others, points out that there is a connection between quantitative and qualitative approaches to research. I selected the qualitative paradigm because it fitted my intention to explore experiences with parents. While the quantitative approach focuses 'primarily with the external realities of any given social situation... [the qualitative gives] meaning to and experience by social actors' (Pole and Morrison, 2003:7). To develop a deeper understanding of parents' inner experience I selected a small sample and used an idiographic approach in place of the scientific, nomothetic methods aimed at generalisable outcomes.

In place of the control and explanation found in quantitative research, the qualitative paradigm offered an opportunity to reveal 'the complex interrelationships among all that exists' (Stake, 1995:37) in relation to support. I planned to reflect 'a direct concern with experience as it is 'lived' or 'felt' or 'undergone... as nearly as possible as its participants feel it or live it' (Sherman and Webb, 1988:7).

The qualitative paradigm would enable me to illuminate the situation that a parent encounters when receiving support, recording individual accounts that become experiences which are visible for 'contemplation'. The shared behaviours and attitudes of parents would act as a starting point for the parent, myself and the reader to enter into a reflective frame. Their examples would reveal the 'dynamics of behaviours in comparable situations in order that those behaviours can be understood and attended to in a more appropriate way' (Hart, 1998:46). By inviting parents to participate in the process of interpretation, I hoped that the descriptions would be substantive and closely linked to everyday realities. This process

would mean that I could focus on what was relevant to them and identify a credible way forward for those working in the field (Corrie and Zaklukiewicz, 1985).

To avoid allowing the data to act as a filter that framed and shaped my perceptions of the parents' world (Barr, 2010), I used an inductive approach. This would mean that the interpretation process could contribute to a theory that would explain how parents experience support when they have a child with a learning disability. To facilitate this I would take an iterative approach to the research, listening and re-listening to the unique to find patterns that could inform theory.

The qualitative route highlighted pitfalls and limitations. Silverman (2004), warns that without thorough scrutiny results can be limited to 'anecdotal', personal accounts. To limit the possibility of this I chose a participatory approach so that parent-participants were involved, aiming to ensure that the narrative was authentic. This meant that each parent's story could be used to make their 'world visible' (Denzin and Lincoln, 2004:4)

I chose an ethnographic lens over phenomenology because, although I was interested in examining the phenomenon of support, without analysis I would fail to address the problem of making practice more effective (Denscombe, 2007). The ethnographic approach meant I could gather a wealth of rich data and use it to make connections between categories, concepts and constructs (LeCompte and Preissle, 1993) to develop a theory. It would mean the parents' experiences could be seen to have a holistic quality selecting 'from several stances but also moving toward the beginnings of our [my] own position' (Smith, 1980:190). In order to give each parent a voice I chose the case study approach so that I could treat 'the uniqueness of individual cases and contexts as important to understanding ... coming to know the particularity of the case' (Stake, 1995:39). Through connecting with each parent as an individual case I would have the opportunity to gain what Pole and Morrison (2003:8) describe as an 'insider's view', revealing the impact of support. By applying ethnography parent-participants had a rare opportunity to invite me into

their world and 'become representers of their own experiences' (Nespor and Barber, 1995:51).

One challenge within the ethnographic approach is that when becoming entangled in the lives of the parent-participants my personal perspectives would influence interpretations. I would carry bias from my 'cultural background, academic training, life experiences, and individual personality traits' (LeCompte and Preissle, 1993:121) which interferes with the process. I planned to set up a participatory dialogue to help me to recognise and challenge these personal influences making them more transparent and adding rigour to this research (Hart, 1998).

In summary, the research questions and selection of the qualitative paradigm and approach led me to an ethnographic case study with six parent-participants where results were expressed using narrative analysis, as explained below.

### **3.3 Choosing ethnographic case study and narrative**

My rationale for selecting case study was Cohen *et al.*'s (2007:253) assertion that,

it provides a unique example of real people in real situations, enabling readers to understand ideas more clearly than simply presenting them with abstract theories or principles.

The literature review showed few opportunities to see parents' individual lived experiences of support. To portray these I aimed to: include rich and vivid description; provide a chronological narrative of events from the time that the parent noticed that the child had a learning disability; blend descriptions and analysis; focus on individuals in order to understand their perception of events and attempt to portray the richness of the case in writing their story (Hitchcock and Hughes, 1995). As explained above to keep the uniqueness of each case intact I decided that each parent should represent a different case. The narratives arising would come from listening to parents and would 'optimize the opportunity of the reader to gain an experiential understanding of the case' (Stake, 1995:40). In practice I would need to focus on the in-depth experiences of a limited number of

parents showing them respect and care and inviting them to engage with the data in their own way as advocated by Sturman (1997).

To bound the case and release what Adelman *et al.* (1980:59) describe as the 'subtlety and complexity of the case in its own right' I decided to select six parent-participants. Their individual contributions were intended to make 'the world more answerable to understanding' (Walker, 1980:231), stimulating changes in my practice and enabling others to review their own. The emerging theory could add to guiding principles in the future. I expected to be limited to what Bassey (1999) calls 'fuzzy generalization', if predicting what might happen but being able to do so without measurable certainty.

I took up an ethnographic position in the home of each parent to ensure their comfort and gather a clearer picture of their culture and way of life (Hammersley and Atkinson, 2007). I invited them to describe their home and compared it to my own view finding ways to recognise 'it in new and foreign contexts' (Stake, 1980:69) aiming to make 'the familiar strange' (Clough and Nutbrown, 2007:49). Walker (1980:224) presents this as a journey during which ideas are dismantled, reassembling 'conventional or common-sense meanings, altering the balance between what seems strange and what is familiar, striving to find new ways of looking at the world.' As the vignettes show in the introduction, short encounters can lead to one becoming immersed in the other person's culture. However, in my fieldwork I fell short of completely entering into the parent's world and was therefore unable to capture all 'the wordy nature of the meanings within that culture' (Goodley and Clough, 2004:341).

Throughout the research process I found my position shifting, realising that I was gradually moving from making the familiar strange to making the strange familiar. This was because when I first met each parent-participant I identified a situation that appeared familiar, yet as time went on I recognised that the world I had entered was also foreign and strange, outside of my experience. I therefore altered my intention, this time making the strange familiar so that the reader could identify more closely with the parent-participant's experience. This change in perspective began

to shed light on the role of transaction, as changes in my behaviour and interpretation occurred (Sameroff and Fiese, 2000) altering my definitions. I was no longer the knowledgeable expert who had to tell the parent what to do. Instead I was a listener using my knowledge to identify what was strange and make it familiar. By working alongside capable parents, finding the solutions with them that matched their circumstances, I had the chance to face and discard my assumptions altering interactions, enabling parents to redefine themselves in a more positive light.

I became interested in presenting parents' experiences as a personal story because I found, like (Riessman, 2008:26) that, 'working ethnographically with participants in their settings over time offers the best conditions for storytelling'. In this environment I entered 'the subjective reality of the lived experience of those who inhabit that location' (Pole and Morrison, 2003:16). Within each parent's story I anticipated a blend of life story, personal document that included 'snippets of experience and opinionated narrative' as described by Goodley and Clough (2004:340). To be invited into the private world of each parent was a privilege of and demanded respect and responsibility. I was therefore consistently aware of the care and support I could give each parent as they shared their personal experiences with me. By inviting their comments on what I had recorded, I hoped that the final corroborated result would enable me to convey their 'voice' and compare their interpretations in pursuit of more general understandings linked to theory (Corrie and Zaklukiewicz, 1985; Guba and Lincoln, 1989).

During our meetings I aimed to capture what Cohen *et al.* (2007:254) describe as 'the close up reality ... of participants' lived experiences of, thoughts about and feelings for a situation'. This was to show that human interactions have 'a characteristic wholeness or integrity and are not simply a loose collection of traits' (Sturman, 1997:61). However, this is limited because, as Geertz (1973:373) argues: 'We cannot live other people's lives, and it is a piece of bad faith to try. We can but listen to what, in words, in images, in actions, they say about their lives .... It's all a matter of scratching surfaces'.

The stories of the case study parent-participants ultimately shaped a theory, or a re-working of an existing theory. By getting to know each person I was able to be responsive to the needs and perspectives when differing experiences of a variety of professionals were shared. This meant that I could illuminate the complexities of the issues around support in an effort to make it relevant to 'public and professional decisions that may arise from the research' (Simons, 1980:5).

Based on my work with parents, I anticipated that the researcher-participant relationship, though tentative in the beginning, would move to more sure ground. Although I found that our interactions enriched 'concrete data by [providing] deeper knowledge of why people act as they do in the context of their own life situations' (Weiss, 1975:362), it was also important to give the parents space to explore their experiences in a positive way for themselves. As Macdonald (1980:18) argues 'case study... is about identifiable individuals and events, and is always likely to have consequences for those it portrays'. The parent-participants showed this in their writing on transcripts, through verbal feedback and when they evaluated the experience of taking part in the study. This enabled me to report examples of what Cohen *et al.* (2007:181) identify as 'the complex dynamic and unfolding interactions of ... human relationships and other factors in a unique instance'. The partnership of exploration that grew reflected the 'mutually influencing contributions of each partner' (Dale, 1996:43), an outcome that through its reciprocity is linked to the transactional model (Sameroff and Fiese, 2000).

Meeting parent-participants meant I could see what Adelman *et al.* (1980:50) call 'tacit knowledge' reaching out through the 'shock of recognition'. I aimed to extend this to the reader sharing 'existing experience and humanistic understanding' (Stake, 1980:72), because I understood from Goodley and Clough (2004:336) I would find out about each parent's identity 'in varying conditions of alienation and empowerment.' Through telling their story I hoped that the reader would feel a connection with them so that, like me, they would be stirred to greater understanding and practical change.

Case study enabled me to see the unique and individual rather than common descriptions, drawing out what Barr (2010:101) calls the 'complex, contradictory nature of human subjectivity' which was to become the foundations of a theory to illuminate understanding. I added the ethnographic approach to this which involved entering the lives of each case study parent and immediately challenged my knowledge and understanding of what I thought I knew. Later, by applying a combination of careful and rigorous analysis using an inductive approach to data that included the participation of each parent, my conclusions helped me to construct a theory through which to inform support in the future.

I found conducting case study research inspired me due to the opportunity to gather 'accuracy and detail, both of which depend upon trust operating effectively both ways' (Graef, 1980:173). The participatory approach and my fieldnotes which lay bare my thoughts and reactions enhanced this intention. However, inevitably, there were uncharted waters that could not be entered and I had to content myself that my final chapter would inevitably advise the reader that more research is necessary (Walker, 1980).

In exploring parents' experiences I was conscious of Kemmis' (1980:100) observation that 'those who expect to follow the progress of science in brilliant light will be ill at ease following the case study worker stumbling from lamplight to lamplight in the fog.' The stumbling spoke of my experiences, those of the parent-participants taking part, and of my findings in other research which portrayed support as a complex, ambiguous and complicated domain.

While case study had advantages, limitations to the approach are acknowledged. Nisbet and Watt (1984) explain that because findings are difficult to cross-check they can be criticised for being selective, biased, personal and subjective. They therefore run the risk of giving a distorted picture of the world (Walker, 1980). These charges could not be refuted, which meant that involving parents in commenting on and revising data was important to help counter inaccurate internal subjectivities. A further criticism is that the researcher shows bias towards striking features that

might lead to only reporting evidence which supports a single theory (Barr, 2010). As a theory began to emerge, I looked for examples which challenged or contradicted the pattern. By collecting the data in two parts I could explore with parents how experiences had altered or remained unchanged.

The parent-participants' commitment to this research was central and I turn to them next.

### **3.4. Introducing the parent-participants**

To access parents who would be willing to participate in the case studies I used the Children's Centre I work in as a gatekeeper, firstly gaining permission from the Centre manager. As I work as part of a team of professionals, including family support workers who support parents in a variety of ways, I was able to seek their help. They not only recommended parents on their case list but also agreed to provide a point of reference for each parent-participant. This was important to me as I wanted the parent to be able to approach someone they knew for any additional support they needed as a consequence of taking part. Although in practice it did not become necessary, it was an important part of my ethical responsibility to them. Four of the parent-participants who chose the pseudonyms, Andrea and Alfred, Ruby and Tasmin were introduced in this way. A fifth, Catherine had been referred to one of the courses I deliver by a family support worker and approached me to ask if she could participate. Lastly, Barbara came forward because she heard about my study through a third party. As Barbara had not had previous contact with the Children's Centre a family support worker offered to meet with her to assume a support role during the research.

All parents had white British ethnicity and Table 3.4 below shows their age and family structure. They are presented in the order in which they were interviewed as shown on the time-line in Figure 3.4. The children's and parent's ages are recorded as those at the beginning of the study. Parents in bold typeface met with me twelve months after the first phase of data collection.

**Table 3.4 Details of parent-participants and their families**

<b>Parent participant</b>	<b>Partner</b>	<b>Target child</b>	<b>Sibling</b>	<b>Sibling</b>
<b>Barbara</b> (33)	Brian (35)	Bernard (2)		
Ruby (33)	Richard (36)	Reece (3)	Robbie (2 months)	
<b>Alfred</b> (32)	Andrea (26)	Amber (3)	Amanda (6)	Andrew (2)
<b>Andrea</b> (26)	Alfred (32)	Amber (3)	Amanda (6)	Andrew (2)
Catherine (22)	Clive (23)	Courtney (4)	Christopher (18 months)	
<b>Tasmin</b> (40)	Ted (42)	Tony (2)	Tammy (2)	

Gathering information from Parent Participants

ID	Task Name	Start	Finish	Qtr 2, 2009			Qtr 3, 2009			Qtr 4, 2009			Qtr 1, 2010			Qtr 2, 2010			Qtr 3, 2010			Qtr 4, 2010	
				Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov
1	<b>Data Gathering</b>	<b>01/05/09</b>	<b>23/09/10</b>																				
2	<b>Barbara</b>	<b>01/05/09</b>	<b>02/08/10</b>																				
3	Meeting	01/05/09	01/05/09																				
4	Recorded Interview 1, 2 and 3	07/05/09	11/06/09																				
5	My Observation	03/07/09	03/07/09																				
6	Barbara's Observation	07/07/09	07/07/09																				
7	Final Recorded Interview	02/08/10	02/08/10																				
8																							
9	<b>Ruby</b>	<b>19/05/09</b>	<b>10/08/09</b>																				
10	Meeting	19/05/09	19/05/09																				
11	Recorded Interview 1, 2 and 3	23/06/09	10/08/09																				
12																							
13	<b>Andrea and Alfred</b>	<b>08/06/09</b>	<b>19/08/10</b>																				
14	Meeting	08/06/09	08/06/09																				
15	Recorded Interview 1, 2 and 3	17/06/09	15/07/09																				
16	Alfred Final Recorded Interview	15/07/10	15/07/10																				
17	Andrea and Alfred Observation	15/07/10	15/07/10																				
18	Andrea Final Recorded Interview	22/07/10	22/07/10																				
19	My Observation	19/08/10	19/08/10																				
20																							
21	<b>Catherine</b>	<b>09/06/09</b>	<b>12/08/09</b>																				
22	Meeting	09/06/09	09/06/09																				
23	Recorded Interview 1, 2 and 3	30/06/09	12/08/09																				
24																							
25	<b>Tasmin</b>	<b>19/06/09</b>	<b>23/09/10</b>																				
26	Meeting	19/06/09	19/06/09																				
27	Recorded Interview 1	12/08/09	02/09/09																				
28	My Observation	04/08/10	04/08/10																				
29	Tasmin Observation	20/08/10	20/08/10																				
30	Final Interview	23/09/10	23/09/10																				

Project: PHD Timeline	Task		Milestone		External Tasks	
	Split		Summary		External Milestone	
	Progress		Project Summary		Deadline	

Following a description of the methods I have included vignettes which introduce each parent-participant and provide background information. This is because I wanted to include the parents' definitions of themselves and how they engaged with the research rather than write these on their behalf as this would have been inconsistent with my intention to give them a voice.

Through adopting an ethnographic approach, described in more detail below, I was able to give each parent's case study a unique identity (LeCompte and Preissle, 1993). Their stories helped me to consider the origin of their viewpoint rather than simply accepting that this represents 'experience' per se (Silverman, 2007). Each story emerged through a reflexive approach arising from radical listening (Clough and Nutbrown, 2007). Invited into their world I experienced multiple feedback loops teaching me about them and about myself and highlighting the role of the transactional model (Sameroff, 1987).

### **3.5 Plans to gather information from the parent-participants**

The design of the research was intended to gather stories that described, analysed and threw light on limitations, clarified suppositions and consequences and suggested new applications and theory that could improve current practice in support of parent-participants. I aimed to enable them to participate in creating and checking their story for accuracy. My intention was to share an account that bore the characteristics of honesty. To do this I wrote about the strengths and weaknesses of my decisions and was open about what helped and what held me back (Silverman, 2005).

To avoid the limitations of using a single procedure I decided to apply a combination of methods. To record parents' personal experiences in an authentic and trustworthy way that supported them I needed to match their needs. So that I could make a 'study of a singularity conducted in depth in natural settings' (Bassey, 1999:47) I agreed a convenient time for me to visit with each case study parent in their home. This environment helped them to relax and share information without being interrupted or observed by outsiders. The consent procedure was devised, given ethics approval by

the university department and shared with the parents at each meeting, setting clear boundaries for sharing experiences on their terms (see Appendix 1).

The research design was planned in two phases, approximately twelve months apart, funnelling down to capture how experience of support changes for a subset of the original group of parent-participants. During the first phase I met with each parent-participant on four occasions and audio-recorded semi-structured interviews at three visits, asking them to review and verify the resulting transcript (Denscombe, 2007). I also compiled fieldnotes which encompassed my participant observations and reflections of the experience after each visit. To help the parent to keep track of their sources of support I asked them to compile a visual representation, described to the parent as a picture (see Appendix 2). In practice this worked particularly well for Tasmin and Barbara but seemed less effective for Alfred, Andrea, Ruby and Catherine. To avoid the pressure of expectation I was careful to let them take charge of how they used this method.

As a result of coding and analysis four parent-participants from the original case study population of six emerged as important to revisit. This was due to their personal circumstances and the age and stage of their child. Tasmin was waiting for a diagnosis for two-year-old Tony and this meant she would have many experiences of exploratory appointments with professionals which I wanted to find out about. Barbara had reached a time of transition as three-year-old Bernard was about to receive more nursery education in a combination of settings that were mainstream and inclusive. I wanted to find out the impact of this for the family. Andrea and Alfred were waiting for four-year-old Amber to start in the nurture unit at the school and due to their complex personal life I wanted to return to find out how this changed or confirmed their views of support. Ruby with Reece and Catherine with Courtney were both in stable nursery and school placements and I therefore decided not to meet them again.

In phase two of the case study I visited the homes of Andrea and Alfred, Barbara and Tasmin to gain information that would add to their story in relation to the following questions:

- What sources of support do parents identify and how are these experienced?
- How effective is current legislation in ensuring the delivery of support to parents?
- Are all parents able to access the support they need?
- How do people's attitudes impact on the support that parents receive?
- How does the partnership between professionals and parents impact on their experience of support?
- In what ways do the support needs of the participating parents change over time?

To answer these questions each parent-participant agreed to record an encounter with a professional independently when I was not present. As a non-participant observer I watched them receiving support from a professional in their home. I then recorded a final interview during which they shared their experiences of the previous year. I added fieldnotes to convey personal and parent reflections.

The data collection plans selected for each phase embraced methodological triangulation which Denzin (1997) identifies as particularly relevant to hermeneutic interpretation because the use of several methods invites the audience to enter 'the circle of interpretation' (p319). The methods offered a number of channels through which to test out an emerging theory and question practice. The case studies provided the opportunity for me to find out more about each parent-participant's experiences and their attitudes and feelings about events (Ball, 1997), through discussion with me and independently as they reflected on the impact of support between interviews. I aimed to build a relationship of trust and sensitivity and was flexible, allowing parents' experiences to 'unfold, cascade, roll and emerge' (Lincoln and Guba, 1985:210). This was because I wanted to gather a full picture and ensure that the experience was positive for them.

I also applied methodological triangulation as a vehicle to question and corroborate findings rather than claim that I had got it right or found the truth (Denscombe, 2007; Patton, 2002). This was intended to lead to 'a fuller version or a version that incorporates different facets of the thing being studied' (Denscombe, 2007:138). The sources of data selected represented an attempt to 'develop interactionally grounded interpretations' (Miles and Huberman, 1994:438). As parent-participants became involved in 'member-check triangulation' (Stake, 1995:115) key features of their responses were illuminated (Guba and Lincoln, 1989).

The data enabled me to explore and compare the two worlds that humans inhabit: the 'external world of fact and the inner world of fancy'. The inner world described by Campbell (1988:52) as veiled or clothed by a 'garment' that appeared to be 'spun out of symbolic strands or signs'. This was not always visible through the transcript which made my reflections in the fieldnotes particularly important. In this way I was able to represent another dimension to each encounter.

In practice there were a number of pitfalls arising from using the methods described. These included the time taken, my limited skills and practise with each method and the quantity of data they yielded. My anxiety to get it right interfered with the process and was recorded in my fieldnotes where contradictions and interpretations were shared revealing benefits and limitations, capturing complexity for me and the parent-participant. The result of the experience showed that 'all social action is situated and unique, the same unit, behavior, or experience can never be observed twice' (Silverman, 2004:320). Therefore our encounters became 'a construct of the individual's particular biographical store of episodic memories' (Campbell, 1988:61). As this reflected a partnership of exploring I turn to describe how the participatory aspect worked in practice.

### **3.6 Including the parent-participants in the research**

I applied a participatory approach to each case study because I wanted to make the research open and honest giving every parent-participant the right to comment on the methods, interpretation and their final narrative. Like Goodley and Clough (2004:335) I wanted to 'break down traditional

relationships between researchers/participants', although unlike them I did not envisage my parent-participants becoming co-researchers themselves. Instead, I focused on what Byrne *et al.* (2009:67-68) propose: 'participatory researchers seek to engage in meaningful partnerships with the researched seeking meaningful data for social transformation'. Danieli and Woodham (2005) argue that a participative approach is often about empowering the participant. Although this was important to me, I was primarily concerned with making the findings authentic and trustworthy and recognising that as the parents were at the centre of delivering these intentions they should have a say in how their voice was portrayed. This plan resonated with Park's (1999) assertion that participatory research is about attitude as much as outcomes.

My implementation was limited because, unlike Bourke (2009) who worked with participants, sharing and deciding on methods, I had planned my research design in advance of meeting parents. However, I did follow Barbara's suggestion and omitted the word diagram from the participant information sheet because she said that it reminded her of school (B-FN:8). By Ruby's instigation I used a highlighter pen to direct her to sections of the transcript where I had posed questions (R-FN:12).

Nind (in press:21) makes the point that:

Academics need to adopt a competence discourse in which competence rather than incompetence on the part of the participants/co-researchers is the starting assumption, but to keep this balanced with a learning discourse in which no one is expert.

I could see that due to my lack of experience and concern to manage the research, like Byrne *et al.* (2009:75) I had a 'tendency towards the exercise of expert power'. This was exposed in the tone of voice I used in interviews and made explicit in my fieldnotes. In an effort to afford the parent-participants independence, they composed a visual record of support which acted as a kind of visual elicitation. Although the process helped the parent-participants to keep track of the subject and provided a useful reference point to help them to recall what they had shared at the previous meeting, the clarity of the message was mixed as shown in Appendix 2.

Barbara, Andrea, Alfred and Tasmin recorded an experience of receiving support as part of the second phase of data collection which provided their independent feedback. Their participant observations reflected personal preference, Barbara choosing to write a narrative account of how she felt before, during and after meeting the speech and language therapist; Tasmin writing a critique of two experiences of receiving support one negative and the other positive; and Andrea and Alfred, like the participants in Aldridge's (2007) research, choosing to take photographs to record an appointment at the hospital adding a brief explanation next to each (see Appendix 3).

Through comparing myself with other researchers who had used the participatory approach I realised that my application was limited, leaving me wondering whether the parents had been left stranded on the fringes. Although I had followed the advice of Byrne *et al.* (2009) offering parents the right to access all materials, in practice beyond the interview transcripts and narratives, this was not taken up. I did not involve the learners in the analysis as Goodley and Clough (2004) or Bourke (2009) had done, or invite them to take part in compiling their vignettes as per Howitt and Venville (2009). I recognised my reasons for this; firstly limitations on my own time and secondly because my approach seemed less demanding for the parent-participants who were also busy.

Nonetheless, because I did not want the participative approach to be a mere 'add on' (Bourke, 2009:458) I attempted to include and value feedback from the parent-participants each time I engaged with them. Although limited, like Howitt and Venville (2009:212&227), I heard 'experiences in a vivid and life-like manner' that brought to light 'subtle aspects' that without the dual vision process may have remained hidden. These were exposed in the responses to the questions I posed alongside incidents on the transcript, sometimes hand written and at other times raised when I arrived at the parent-participant's house. I realised that these would be particularly useful when I had made incorrect assumptions. Barbara and Tasmin chose to challenge these and I was able to respond by changing both my view and their story to reflect this. Through their

feedback I received both challenges and affirmation to my comments, adding evidence that the account and interpretation was trustworthy. This met the intention of the case study method in 'adding to existing experience and humanistic understanding' (Stake, 1980:72)

In spite of inevitable shortcomings each narrative aimed to capture experience by synthesising the parent-participants' stories as ratified by them. Silverman (2007) reminded me that the speaker is inclined to turn their story into 'something for us' (p61) which added particular significance to the checking process. In response to feedback from Barbara and Tasmin I revised small sections of their final story. The experience reminded me of what Lister *et al.* (2003:163) found, that participatory research methods and agendas are 'a complex and uneasy mix of theoretical, practical and financial compromises'. In the end I had to acknowledge that although each parent-participant had played their part in sharing the authenticity of what they had explored with me, the final decision of what was included and left out lay with me. Nevertheless I concurred that involving the researched revealed a more 'holistic understanding of realities' (*ibid*), which was something I was aiming for in this study.

### **3.7 How I gathered information from the parent-participants**

The methods I applied to this study are now described in detail.

#### **3.7.1 Recording interviews with parent-participants**

Semi-structured interviews, to gain what Cohen *et al.* (2007) describe as unstructured responses, became the main method I used to explore how parents experience support when they have a young child with a learning disability. I aimed to capture richness and depth, reflecting the ethnographic approach by adding '*prompts* and *probes*' (Morrison, 1993). The firsthand accounts meant that I could gather each 'respondent's accounts of experiences, events, attitudes, and feelings' (Ball, 1997:312). I aimed to make the interactions 'conversational', by asking open questions (Säljö, 1997), rather than using the same words each time. This was because applying specific questions can stimulate direct answers (Silverman, 2007) that then infer that the researcher has power over the researched. Patton (2002) recommends a conversational model to gain trust and confidence because it puts the respondent at ease so that

elaborate, subtle and valid data can be explored. Conversations are not a neutral tool, however, as both of us were involved in creating and shaping the subjects covered (O'Leary, 2004).

At each meeting, prior to interview, we reviewed the participant information sheet and consent form (see Appendix 1) because confidentiality, anonymity and support for parent-participants were my priority to keep them comfortable and safe (Lofland and Lofland, 1995). I agreed with Nind (2008) that their social and psychological well-being was very important. I reminded them of routes to further support (as advocated by the Joint University Council (2009)), including their family support worker. Parent-participants chose how to record personal information to protect their anonymity and when ethical dilemmas arose 'in the field, in their local and specific contexts, on a minute-by-minute basis' (Flewitt, 2006:31) I was conscious to respond. I avoided recording any of their personal details on my computer.

### **3.7.2 Preparing to hear each parent-participant's story**

As an introduction to the interview process I met each potential parent-participant with the family support worker they knew from their local Children's Centre. The exception was Barbara who met the family support worker informally while being given a tour of the Centre so that she could get to know her. Although I offered each parent time to consider whether they would like to go ahead as a participant they explained that they had already decided to take part in advance of our discussions. I therefore stressed their right to change their mind at any time in the process.

At the first meeting, in order to protect their anonymity, pseudonyms were agreed with the same first letter for the forenames for each family member. This helped me and the parent to use the pseudonym during our conversations and later to enable the reader to differentiate between each family (see Table 3.4).

### **3.7.3 Listening to the parent-participant**

Applying Pole and Morrison's (2003) idea I suggested that each parent compile a visual representation, a picture, to show the support they had received (see Appendix 2). In practice this presented a challenge to some

of the parents: Andrea and Alfred were concerned about spelling and Catherine wanted to get it 'right' both in selection and method. To avoid any pressure of expectation I reassured parents of their choice inviting them to put these to one side when they were ready. Overall, like Aldridge (2007) and Lutterell (2003), I found creating images became a useful vehicle in facilitating communication and interpretation of experience.

To avoid any unwarranted intrusion or unreasonable disruption to the life of each parent-participant we negotiated a time frame that would suit them. When I arrived, we chatted informally and I did not use the audio equipment until we agreed we were both comfortable. I wanted to avoid exaggerating the formality of what I was doing, which Denscombe (2007) advises may be daunting. By limiting notes to recording key words or ideas, I focused on active listening techniques identified by Asksey and Knight (1999). Showing genuine interest and concern is a natural part of my communication style and used regularly in my role as a family learning tutor which meant that the interviews proceeded fluently. By putting them at ease, I could gauge their feelings and 'coax out the most relevant information' (Denscombe, 2007:191). Having listened to parents describing the personal impact of sharing painful experiences, I was careful to balance my questions in a way that meant the parent-participant took charge of what they disclosed. I felt that applying pressure would lead to them feeling exposed and possibly vulnerable, something I was keen to avoid. I therefore planned to be sensitive to their needs and monitor their response to follow-up questions. Where any parent became emotional I decided to stay on after the recording to enable them to recover and feel cared for. In practice the combination of trust and confidence that grew and was recorded in my fieldnotes, meant I could provide a more authentic portrayal of experience (Kvale, 1996).

Applying the recommendations of Lister *et al.* (2003) I adapted my pace to suit each parent-participant, watching carefully for any signs of discomfort expressed in body language, tone or words, as well as tuning into the emotions beneath the surface. Beresford *et al.*'s (2007) procedures of checking verbal and non-verbal behaviour were a guide for on-going assent. I responded immediately when a parent-participant either said or

signalled to stop the audio recorder. I used my own body language and quietly said "right" to show I was listening and following their train of thought (Carspecken, 1996). At the same time I was conscious, although not always successful, in trying not to influence contributions by being over-enthusiastic. Weiss (1975) reflects relationships from two angles:

the closer the interview comes to a warm, intimate relationship, the better will be the calibre of data, [yet] ... too close a relationship reinforces the respondent's bent to seem more socially desirable than he is, and thus imperils the validity of the data (p367).

This meant that the participatory approach and mixed methods in the case study were significant in achieving 'negotiated accomplishments' (Fontana and Frey, 2004:91).

As revealed in the vignettes of Beth and John, personal information became transparent so that each case study shared their age, social status, education and family background (Patton, 2002). Cohen *et al.* (2007) remind the researcher to consider respect and to notice personal judgements which inevitably creep in; I needed to be aware of the tendency to stereotype individuals or portray them in a way that makes 'derogatory or damaging representations of service users' (Joint University Council, 2009).

Parent-participants were invited to share information such as the approaches they found helpful or unhelpful, improvements that could be made and changes over time (see Appendix 4). Although this moved towards a joint understanding, I realised that, as Mishler (1991:260) argues, 'the relationship between meaning and language are contextually situated; they are unstable, changing and capable of endless reinterpretation'. By using Silverman's (2007) recommendation of phrasing questions with positive rather than negative polarity, I used the words 'do you have 'some' examples of that', in place of the negatively themed 'any'. I occasionally applied low-inference paraphrasing to keep the conversation on track and non-leading responses that invited the parent to say more about the support s/he was describing (Carspecken, 1996).

To gain additional details I used Stainton and Besser's (1998) technique of asking if they could tell me 'more about that experience'. To mitigate the impact of my influence I left subjects open, aiming to be 'unintrusive ... introducing a theme or topic and then letting the interviewee develop their ideas and pursue their train of thought' (Denscombe, 2007:176). As a result I ran the risk of the parent-participants choosing to stray from the subject of support - something I was initially concerned about - yet when I examined the transcripts I could see how the examples and stories were cleverly woven together by them, giving me a more complete picture of their experiences. Looking back, a process of discipline and creativity (Wengraf, 2001) merged naturally.

By reviewing the content of transcripts I was able to provide opportunities to 'draw out information, attitudes, opinions, and beliefs around particular themes' (O'Leary, 2004:164) that could be checked in relation to what had been said on previous occasions. In comparing the results of each interview I found that there was commonality in the areas covered including: behaviour and experience, opinion, value and feelings, and personal knowledge linked to their background, that offered an insight into how each parent-participant in the case study viewed themselves (Patton, 2002). I developed the technique to explore responses by asking 'participants to reflect on the processes leading up to or following on from an event' (Bryman, 2004:281). Where I recognised contradictions in their story, I sometimes chose to resolve it immediately and at others I teased it out when sharing the transcript, or left it to see if the subject arose again. If I felt unsure of my understanding or wanted to check my interpretation of their position, I occasionally asked for clarification (Kvale, 1996).

The information that emerged showed me how parents made sense of, or reacted emotionally to specific experiences. This seemed linked to what they knew about their worlds and how they experienced them (Patton, 2002). This often led to them talking about the past and present in the same answer; thus I considered the advice of LeCompte and Preissle (1993:176) that 'temporal order can arouse sensitive issues'.

Although Silverman (2007) argues that we live in a culture that invites sharing of feelings, in this field work most of the parents tried to hold back emotions when recalling negative experiences and Barbara was very apologetic when she broke down in tears. As I compiled the narratives following the interviews, I realised that the process had meant 'getting beneath the surface of personal feelings and experiences of participants ... Thus it [became] sensitive, difficult and morally demanding' (Clough and Barton, 1995:143).

The interview technique has been criticised for creating manufactured data which does not represent the personal view that might be offered if the participant was chatting with a friend (Silverman, 2005). I concluded that I could not test this out, or claim that the information I gained would be either the same if I had visited on another occasion, or in different circumstances. As Wengraf (2001) concludes, interviews represent

a unique interaction between two anxious subjectivities, an interaction that has to be understood if you wish to make correct inferences to any extra-interview realities, as they are anxious incomplete interaction (p232-235).

LeCompte and Preissle (1993) argue that it is important to avoid taking one person's experience and projecting it onto another's implying a generalisation of the idea. I therefore valued each meeting as a unique encounter at that time.

Weiss (1975:356) proposes that in case study,

the combination of a "right" answer and the identification of the interviewer with those who have a stake in having the answer come out "right" presents special perils to response accuracy.

This meant that detailed fieldnotes were necessary to record how my conduct may have influenced answers and led to what individuals considered a socially acceptable response in place of what they felt. With this in mind the role of observation seemed particularly pertinent.

#### **3.7.4 Sharing parent-participant experiences through watching and reflecting**

As part of each case study, I applied observation by becoming a participant observer during each of the meetings with the parent-participant. I applied an ethnographic approach because I wanted to capture what and how each individual had experienced support. By visiting parents in their home I was able to do what Wellington (2000:171) describes as 'preserv[ing] a natural setting and [gaining] cultural empathy by experiencing phenomena and events from the perspective of those observed'. I used the short time that I spent in each home as an opportunity to become temporarily immersed in their world. Through observing them I began to have insight into what they knew about their worlds and how they experienced the world around them (Patton, 2002). Thus I noticed how the web of language, values and life style created the opportunity to interpret 'how differences in perception and in motivation affect what is reported ... to check the distortions against events' (Weiss, 1975:362). In this context I was able to explore experiences both directly and indirectly (Carspecken, 1996).

To witness and take part in each parent-participant's experience of support I used 'a multi-dimensional vision for both observing and interacting with research participants' (Shimahara, 1988:86-87). I shared observations by including comments on the transcripts and asked them to read, correct and ratify them, which led to parents having 'equitable access to data for reanalysis' (House, 1997:259).

At the end of the first phase I carried out a non-participant observation of Barbara with her Portage worker. In the second phase I observed Andrea and Alfred together with their lead professional and then Tasmin, with her Portage worker. I chose this technique as a reference point to compare their description of experiences of being with professionals. Although I realised that this was a snapshot in time and only represented one interaction with a professional, as shown in Appendix 5 it provided useful evidence of partnership models and the way the parent and professional were defined.

Due to a twelve month absence, organising the non-participant observations in the homes of Andrea, Alfred, and Tasmin involved re-establishing a bond with each parent. This was achieved through telephone calls and visits to Andrea and Alfred before the lead professional visited them. This was more problematic for Tasmin due to the pressure of her work and the fact that she had only recently met the Portage worker. I compared this to the observation I had done with Barbara at the end of the interviews in the first phase when she was at ease with me and had already established a long standing relationship with Bernard's Portage worker.

After my non-participant observations with Barbara, Andrea and Alfred I stayed on to gather their comments. This would have been inconvenient to Tasmin so she offered to give me her feedback six days later, when she was on a train journey. Although this presented challenges, meeting the needs of the parent was of paramount importance to me and meant that I had to relax my instinct to control the process.

Observation meant I could use the data to 'acquire firsthand, sensory accounts of phenomena as they occur in real world settings' (LeCompte and Preissle, 1993:3), that is, their home. The observations generated the 'thick field notes' Carspecken (1996:48) describes. This meant that the technique of observation had a key role in providing what Denscombe (2007) calls 'the subtleties, the complexity and the interconnectedness of the social world it investigates' (p217).

Each case study parent-participant participated in observing themselves through their memories during the interviews and independently between our meetings and through reading the transcripts. They also observed their responses to an experience of support they received. This gave them opportunities to re-live experiences (Bailey, 1994) verbally and in writing. I observed how 'personal outlook and socio-cultural forces' (Taft, 1997:72) seemed to play a role in information that was shared. I found that observation also became a means to self-understanding raising the 'hidden mix of personal experience, scholarship, assertions of other researchers' (Stake, 1995:12).

As a researcher seeking to be ethnographic, to some degree I became an explorer, temporarily immersed in the life of the family (Bassey, 1999). This enabled me to investigate and discern 'ongoing behaviour as it occurs' (Bailey, 1994:243-244) making notes about its salient features. As I read through the observations from each visit, issues arising from the previous observation prompted me to tease out the problems of the case, 'the conflictual outpourings, the complex backgrounds of human concern' (Stake, 1995:16-17). I later identified this as part of the transactional model (Sameroff, 1987). Through a process of withdrawing from and re-entering the homes between visits, I became aware that 'highly salient data may be overlooked just because it is so familiar' (Taft, 1997:73). As a way to counter this I attempted to approach each meeting with fresh eyes.

In reviewing observation data I conceded that rather than provide a life-like image it was more a 'snapshot frozen in time' (Woods, 1988:102). However, by recording the details after each visit, the rich description that emerged helped me to create something holistic in the spirit of ethnographic definitions where I identified 'processes, relationships, connections and interdependency among the component parts' (Denscombe, 2007:62). Despite this and taking into account as much detail as possible, due to my short visits to the home of each case study parent I was left unable to portray their experiences in a way I could claim as accurate (Weiss, 1975).

As I reflected on my role as a participant and non-participant observer I realised that my presence would be influencing the behaviour of the parent. To mediate this I made four visits over a period of between six and eight weeks for an hour-and-a-half so that each parent-participant became familiar and relaxed with me. Over time confidence developed and each parent began to question, amend and confirm my notes, either verbally or writing on the transcript, providing support for my decision to make the research participatory in this way (Lincoln and Guba, 1985).

I realised that my own history, biases, interests, experiences and expectations would colour what I observed (Weiss, 1975; Wellington, 2000), so I included the impact of my own interfering thoughts and how the

experience was challenging my assumptions and embedded expectations in the writing up (Silverman, 2007). Following an iterative process of self-evaluation, monitoring, questioning and continual re-evaluation, I increasingly acknowledged personal influences (LeCompte and Preissle, 1993). Although I was reluctant to be seduced into matching the observations to a theory, fearing I might use this as a filter that would 'frame and shape' (Barr, (2010:96) my perceptions, I instinctively noticed patterns and used these as a starting point. I did not immediately realise that the process I was undertaking was part of the theory I would eventually recommend in applying to support in the future.

The observations led to large quantities of data which required pruning without losing sight of my aim to reflect an 'authentic gaze into the soul of another' (Silverman, 2004:343). By involving the parent we discussed why certain things should be omitted in deference to others. Although I found these a benefit to my research, I was also concerned that the process would be positive for the individual (Joint University Council, 2009).

When I looked back on the decision to record my observations I realised that I was naïve as to their worth, thinking that the transcripts would carry more weight. Caught up in carrying out the research, the learning came later as explained by Kierkegaard (Westphal, 1996). Without the inclusion of these insights the fieldwork could have appeared shallow and open to Nisbet and Watt's (1984:91) criticism of being 'low level and banal'. The observations enriched my collection of verbal data and invited a closer look at the cultures and events of the lives of the case study parents. The technique I applied to capture this in detail was in fieldnotes which are discussed in the next section.

### **3.7.5 The role of my fieldnotes**

Fieldnotes became intertwined in my descriptions of the interviews and observations of the case study population. They provided me with the additional information that enabled me to complete a narrative for each parent-participant. To reflect the ethnographic approach I recorded 'sounds ... and most importantly, sights that will help the reader understand the research setting' (Zeller, 1995:76) offering them the chance to 'be there' (Stake, 1995). Blumefeld-Jones (1995) recommends the use of detail so

that it is possible to enter into a world that the reader has no direct experience of, becoming part of their story. To achieve this, the 'context of the location, the climate and atmosphere under which the interview was conducted' (Denscombe, 2007:195) were included in the fieldnotes. These along with 'individualized mannerisms, vocal tones, facial expressions' (Carspecken, 1996:101) reflected the interplay between influences of culture and personality (Taft, 1997). To enable me to capture the 'complex dynamic and unfolding interactions of events, human relationships and other factors' (Hitchcock and Hughes, 1995:316) I wrote notes immediately after each visit and then reviewed them a few days later to compare and enrich the description. Examples are shown in Appendix 5.

Following the advice of LeCompte and Preissle (1993), I placed a time limit on myself to retain the freshness of the scenes and events I was writing about, making myself a 'professional stranger' (Pole and Morrison, 2003:155). Fieldnotes were also used to record either something that had happened immediately before or something that was about to happen (Denscombe, 2007) to remind me of how this may influence the parent during the interview.

Thorne's (2004) experiences of picking up 'scattered leads and hunches ... instances that seemed to contradict an emergent pattern' (p274) helped to crystallise the advantages of my approach. As I explored with parent-participants their experience of support I identified with Thorne's intention to find out, 'when and how, does a difference make a difference?' (p275). This meant that the narratives were more than providing a voice for the parent they would also shape an understanding of support which could be altered to become more effective.

As I reflected on my position in the process, I saw my epistemological status combining both the 'emic', in seeing things from the perspective of the parent, and the 'etic', as I recognised my role as an outsider (Pole and Morrison, 2003). I identified with the challenge of establishing 'a voice that simultaneously represents participants' field experience while creating a research text that goes beyond the field and its field texts to speak to an

audience' (Connelly and Clandinin:85). Sharing each parent-participant's story through using fieldnotes meant that I gained

A narrative account, a story, a chronological presentation, personalistic description, emphasis on time and place provide rich ingredients for vicarious experience (Stake, 1995:87).

This information became instrumental in learning about me and the parent-participant.

My fieldnotes inevitably represented an incomplete record, however, reflecting my personal interest. Denscombe (2007) lists the personal influences for me and the participants including: politics, values, personal interests, experience linked to the topic, expertise and qualifications. Weiss (1975) adds physical barriers of tiredness and anxiety as well as distractions such as background noise. Although these examples were noticed and included I was sure that occasionally these would have been accidentally overlooked. In reviewing reflections a few days later I re-visited the scene in my mind in order to clarify natural behaviour and disparity.

The ethnographic, case study approach presented a challenge to accuracy because fieldnotes were 'idiosyncratic to the observer with all the associated limitations, eccentricities, and biases and is not matched by the interpretation of other observers' (Taft, 1997:73). The problems I encountered were: 'selective recall' attached to the way I remembered experiences, 'selective perception' as I applied particular filters through which to judge information, and 'accentuated perception' which referred to the way I was feeling at the time of the meeting (Denscombe, 2007). A further influence was my 'own expectations and motivational states' (Isaac and Michael, 1997:91), which were likely to effect preconceptions. Riessman (2008:29) notes that,

like all stories, it [the narrative] is selective and perspectival, reflecting the power of memory to remember, forget, neglect, and amplify moments in the stream of experience.

This had an ethical implication in overlooking the experiences that were most important to the parent in deference to the one I attended to. This could not be discounted, adding weight to my decision to make several visits and select a variety of methods.

I now turn to the vignettes which introduce each parent-participant and set a context for the narratives that are to come. They contain extracts of data which arose from the methods described above in order to give each individual a voice. They do not represent the findings as such, but instead provide a backdrop to the experiences of support which are told later in their story. Abbreviations are used to show the origin of the data: 'Int' indicates interview, 'FN' fieldnotes, 'O' my observation of the parent and A&A-O, B-O, T-O each parent's observation of support they received.

### **3.7.6 How parents describe themselves and their role as a participant**

#### **Barbara**

Barbara has a son, Bernard, who was two when I first met her and who has Down syndrome.

*I first meet Barbara when I invited her to the Children's Centre. Establishing a rapport by phone, I notice her attempts to reassure me saying 'let's go with the flow' (FN: 1). She presents herself as a graduate with an air of competence, clear values, dedicated to the process and getting it right. These observations lead me to judge that I am with an able parent (FN: 6). Later she tells me that her outward appearance of competence means that others judge her as an 'expert' in the field of education.*

*When I suggest meeting in her home she says "I was hoping you would say that" (FN: 2) and so I find myself entering a modern detached house in what Barbara describes as a "middle class, affluent" (FN: 13) area. We relax sitting on the floor using a low wooden table to rest against in the tidy living room, Bernard's toys hiding in neatly stacked perspex boxes. Modern art and studio photographs adorn the walls.*

*Barbara is no stranger to research and Bernard has been a participant in several projects because she "wants it to help other children" (FN: 9); "its part of helping the whole process to find ... to sort of help people with Down syndrome" (Int4:292-294). She is excited because this research is about her and she wants professionals to hear her story. In her final reflections of taking part I hear a different perspective as in the first instance she claims to have begun to wish she had said "no" as then "things may be easier" (Evaluation: 1).*

*Humour features in Barbara's communication style, laughing with Bernard, joking about a wig and hat to disguise her identity and calling herself superman (FN:6). She laughs about choosing pseudonyms that sound old fashioned. Laughter also slips in, as a source of relief. She can laugh with Bernard to guide him, but there are other laughs too; the ones that speak of pain, of isolation, of fear and of embarrassment.*

*Brian, her husband, is an important support in the background and has a different approach advising Barbara to challenge professionals and question for Bernard's sake. Apparently he thinks everyone is a moron until proved otherwise (FN: 13). His language is less 'pc' applying negative terms to describe Bernard, to prepare him for when he is older. The contrast helps to balance what Barbara describes as her inclination "to wrap Bernard in cotton wool" (FN: 12). In the year between visits Barbara tells me that things have changed and she and Brian read reports about Bernard together, an improvement on "Brian coming home from work and me having to tell him ... both of us are in the same position reading the report ... its nicer for us as a family ... we understand it together" (Int4:634-647).*

*Barbara tells me what she thinks of the parent information sheet (PIS), identifying my concern for her well-being, confidentiality, pausing if things get emotional (FN:2) which is reassuring because there will be "no hidden surprises later" (FN: 7). Barbara assures me that payment for participation would be unhelpful, because it would lead to pressure to both meet my expectations and take away her freedom to withdraw from the process. We discuss the idea of parents creating their own picture of sources of support*

*and she suggests that when I introduce the idea to other parents I avoid the word diagram because it sounds like school (FN:8).*

*When a question is difficult she asks if she can return to the subject at a later point. We share the common experience of having a difficult birth. In the final interview we discuss the emotional tussle involved in letting our children go (FN:20). Yet I realise our differences, as my three boys are almost adults and independent with the necessary skills to guide their path. Barbara may not have the same confidence that Bernard will find his way.*

*I recognise feelings of gratitude and pressure when, during our first meeting, she tells me she has asked the Portage worker if I can observe them together (FN:5-6). It is early days in my field work and I am trying to build confidence and feel that I am being rushed. This experience becomes instrumental in my learning as I review my practice. She offers unstinting commitment, making comments on the transcripts, saying that reading these helps her to 'take it all in' (Evaluation:2). She expresses confidence in our relationship saying 'Gina was very reassuring and I know would have stopped if I had wanted to' (Evaluation:2); she shares surprise that the process of being a participant in the study has been almost 'cathartic' (FN:18).*

## **Ruby**

Ruby has a son, Reece, with a speech and language delay due to a problem in the muscles at the front of his mouth. He was three when I first met her.

*Fifteen months ago Ruby moved from the outskirts of London to an "ex-council" house in "a really nice community" (Int3:483) with her partner Richard. Two months before I meet Ruby she has a second son Robbie.*

*Ruby's friendly and positive attitude with me seems to mirror the ease with which she makes friends. Prominent in her life, she mentions these friends at each of our meetings. She talks enthusiastically of her trips to see her mum who will help her out with the boys. Although she emphasises the practical help, she turns to her mum for emotional reassurance (FN:13).*

*Ruby and I discuss her experiences of support while sitting in her tidy living room, free from toys and clutter. Organisation seems a priority as she arranges all the interviews during our first meeting, only altering one so that she can tidy up after visitors have been to stay. Ruby enjoys chatting, telling me about her plans for the future; set out in stages becoming a childminder and then training to be a midwife. She would need to do an access course and aims to 'take qualifications while she can' (FN:5). In turn she asks me personal questions showing a natural ability to make connections. My fieldnotes often refer to her relaxed communication style, repeating "you know?", inviting me to participate in her thinking, laughing, sometimes hinting that she is a little unsure of herself.*

*Enthusiastic about participating in the research, Ruby announces during the first phone call, "I definitely want to take part in this study" (FN: 1), and she is "pleased that her name was put forward" (FN: 4). Happy with the support now, she wants her story to help other parents because she has been through a "worrying time" (FN: 6).*

*Ruby uses Richard, her partner to illustrate contrasts saying that she is "a worrier at the best of times and I think that is why, why he is so laid back" (Int3: 35-36) saying that if this was not the case "we just wouldn't work" (Int3: 38). Later she turns the picture upside down as Richard would "put his hands up for a fight and say "I'll go in and have a word with them" (Int3: 58-60) if he is unhappy.*

*Ruby's communication style presents me with contrasts: tension as she tries to apply the 'right' language, grappling with terms when referring to autism saying, "without sounding biased or anything in a form of being racist to children with disabilities" (Int2: 147-148). She tells me, "get over yourself" (FN: 5) when I express concern about taking up her time, intruding in her life so soon after Robbie's birth. Ruby highlights the different perspectives that parents have and why it is important to hear her views rather than to imagine I understand her position.*

## **Alfred**

Alfred and Andrea have a daughter, Amber, who was diagnosed with autism at the age of three. A year later they are told that she also has a chromosome disorder.

*Alfred lives with Andrea, his wife in local authority housing and in the first phase of the study he is unemployed. Central to Alfred's life are his family and the home they live in. There are hints of his interest in improving the home, a tube of plaster and some tools lie on the dining room table in readiness for the next little job to be completed (FN: 12). On one visit the ironing is on the door frame waiting to be noted as a chore he has completed (FN: 6). A scratch card win leads to more home improvements, decorating the living room, buying carpet and a trampoline to help with Amber's physiotherapy (FN: 20). He proudly tells the lead professional that the council think they are better tenants than the previous family because of all the work he has done (O: 6).*

*Alfred makes reference to his neighbours explaining that they are "brilliant ...so friendly we can't fault them" (Int2: 222-223). However problems lurk in the shadows, as he tells the family support worker of nuisance texts (FN: 1) and the lead professional that the neighbour's children are making nasty remarks and that the parents are threatening to contact social services (O: 5).*

*The relationship between him and Andrea shifts from deference to her superior knowledge to projecting an intention to protect her. Alfred's descriptions are laced with 'we' and 'our'. As a result of the family learning course where we first meet, he explains a change in role, supporting Andrea, changing nappies and "I do more things with the children, always have done, always will now" (Int2: 23-24). At other times they seem at odds with each other, as Andrea refers to herself as the one who does everything on her own, through which I hear hints of exhaustion, frustration and resentment (FN: 4).*

*Alfred enjoys social interaction, such as meeting friends while playing darts where he can talk about his problems. Energy, enthusiasm and authority accompany him as he shares his knowledge about darts, his family, his*

*previous employment as a paramedic and as a lorry driver. He chooses to stand when the family support worker and lead professional come to his house, perhaps to assert his role as head of the family. He explains that all the phone calls from the professionals come through him and "then I'll phone up me wife and let, let her know what's going on" (Int4: 198-199).*

*Alfred enthusiastically reminds me of the date of each meeting and shares his confidence with maths as a particular skill. He appears proud to choose the pseudonyms for each member of the family. Alfred tells me that taking part in the research is helping his communication with the family (FN: 6). At the final interview he relaxes sharing a joke (out of Andrea's hearing), saying that Andrea only holds a "licence to drive people up the wall ... don't let her know I said that!" (Int4: 281-283). He teases Amber in front of the lead professional and when she adds a year to Amber's age says, "don't wish that on us" (O: 2).*

*At other times, positive communication dips, perhaps linked to a self-image moulded by an education which failed to identify his dyslexia. Now 32 he decides "I wanna learn more and get more A' levels, GCSEs, everything" (Int2: 170-171). Peppered throughout the interviews are moments characterised by apologies about spelling, or explaining that he can't answer a question, but his wife will give me that information. In these fragments I see a change in his demeanour, his head down, consistent eye contact fractured and his voice drops. When unhappy, his sentences are clipped, to the point, with descriptions that while sometimes mirroring my ideas or those of Andrea seem to encompass his own views. There are hints of tension as he comments on a stiff back at the end of the first interview and leaving the room to have a cigarette during the lead professional's visit (O: 1).*

*At each visit he smiles and welcomes me to his home, insisting (against my better judgement) that I should put my bicycle in his hall (FN: 15). We laugh together as I try to make sense of using the audio equipment and he relates this to a colleague who couldn't use the tachometer in his lorry. I realise his efforts to put me at my ease and the respect I feel for his perspective on this study.*

## **Andrea**

*Andrea and Alfred's home is in a run-down area close to the Children's Centre, a place that seems a refuge for her as she is reticent to go out. Together we sit on the settee or at a dining table given to them by the neighbour. The home appears tidy. I am not sure if this is in anticipation of my arrival, but she and Alfred describe how they "quickly tidy up" the day of the observation with the lead professional (O: 7). Photographs are abundant, moved around, small snapshots recording significant events, such as their wedding. There are no toys in sight, instead the television, often on during my visits, takes centre stage, perhaps the main entertainment (FN: 16). The 'thick net curtains keeping the world at bay' (FN: 15). The family support worker (FSW) tells me that although social services are concerned about the family, the children are always clean and she is not worried about their welfare (FN: 2).*

*Andrea wants to take part in this research because the professionals "don't want to know or hear her side of the story" (FN: 6). She hopes that by reading my study professionals will change their attitude to families.*

*Andrea presents information using contrasts: Amanda, Andrea's six-year-old daughter helps and is able to get Amber to do things but due to her "anger issues" (Int4: 314) she kicks and pinches her. Defined in age order, "one who is very gifted, one whose, you know her problems and then we've got one whose got other problems" (Int4: 269-271). Andrew's 'other problems' are not discussed perhaps because they appear insignificant next to Amber's. She tells me she loves her children "very dearly" (Int2: 132). When the lead professional visits, she holds Andrew close on her lap and tucks Amber in beside her as if to say "these are mine, don't try to take them away" (O: 1).*

*Andrea's body language conveys her 'expertise' in managing the family, leaning forward slightly with her head up. She says she is "the main one to deal with support" (FN: 2). She enthusiastically tells the lead professional about the activities she has done with the children, glowing in the light of*

*her praise (O:3). There is 'quiet determination, which when combined with Alfred's support seems to bring out a confidence' (FN:4). She tells me she is confident when at home but feels threatened "especially by men" making it hard to go out" (FN:10).*

*As authority shifts between Andrea and Alfred, conflict and harmony hang in the balance. Silently Andrea guides Alfred, holding up the requisite number of fingers to show time or the number of professionals involved. At other times Andrea tells me that "Amber will not do anything for her dad" (FN:4). Apparently oblivious to the conflict, I note my discomfort in this lack of harmony, instinctively trying to pour oil on troubled waters, talking about the different roles that my husband and I have.*

*Andrea talks of taking GCSEs in year 8, and A'level in maths and a degree in law (FN:19). She describes herself as a 'walking dictionary' apologising when she makes a mistake in spelling (FN:5). Yet she is reticent to write, avoiding comments on the transcripts leaving her top ten hits dangling at seven. I am relieved that after some persuasion from Alfred she agrees to write notes beside each photograph which tells their story of an appointment with the consultant (A&A-O:1). I try to make sense of this, aware of the mis-match between action and expectation. Necessarily tentative, possibilities come to mind; 'perhaps this is because she is afraid that she cannot live up to the picture she has portrayed, or does not have the time and energy to write things down' (FN:10). (She teaches me to 'test assumptions and to look below the surface to challenge what seems obvious' FN:23).*

*There is a curious mixture of confidence and restraint in Andrea's communication style - passive, measured and composed. I look for small changes to her posture and notice the widening of her eyes to emphasise a point. Something lurks beneath the surface, hinted at in body language, left hanging following a negative statement. Life seems a huge effort. Searching for an interpretation I wonder if there is effort involved in the contradiction between who she says she is and her behaviour.*

*As trust grows she goes beyond giving me straightforward answers. Connections are forged, even a bond borne out of sharing our experiences of giving birth, mothering, having a partner. I catch glimpses of her early life; a troubled relationship with her father, being bullied, and she asks me not to probe deeper. She is afraid of anger and violence and her brother is called in to warn Amanda of the consequences of her temper getting out of control because he has been to prison. (FN:20)*

*The lack of consistency in Andrea's feelings leaves me anxious, wondering if this not only applies to how she receives support but to her life more generally. I recognise my personal impact and acknowledge it as seeing how 'like a shawl I am attempting to wrap her in my own values' (FN:21). I struggle to make sense of the conflicting messages and then she finally explains that her mood swings are linked to manic depression. Avoiding medication in preference to herbal remedies she finds that it affects her moods which rapidly change from happy to tearful (FN:18). Without expertise I hesitate to use the words "that explains it" and am left wondering how professionals manage the inevitable mixed messages, sometimes seeing her coping and at other times falling apart (O:3).*

*In listening to Andrea I find myself instinctively reading between the lines. Sharing disappointment with me seems to lead to her feeling "quite happy" (Int3:96), a contrast with her mood on my arrival. When at our final meeting Andrea is upbeat, talking about trips to the park with the children, losing weight and putting the past behind her (FN:20), I record my relief and leave wondering and hoping, if this could only last.*

### **Catherine**

Catherine has a daughter, Courtney, who was an elective mute with behaviour difficulties up to the age of three. These are resolved and she was four when I first met Catherine.

*Catherine lives with Clive who is in the forces, Courtney who is four and Christopher eighteen months, in "what's classed as quite a notorious road" (Int2:436) illustrated through a description of a recent drugs raid. She has a mortgage on this ex-council house and tells me that when disclosing the*

*address, friends say "Oh God you're brave" (Int2:485). She wonders if others see her as a "scag or a tramp" (F:6) because of where she lives.*

*The contrast between the exterior of houses in the neighbourhood and her garden is striking, well stocked with accessories for relaxation and play, decking and a full size trampoline. The tidy living room with leather settee, furniture and prints from IKEA and fresh flowers in a vase offer differences to the glimpses into the homes of other residents, in the area (FN: 1).*

*Catherine has recently given up work, is a student with the Open University and preparing to get married (FN:2). As I first met her in my teaching role I am keen that she recognises the difference in our relationship. She approaches the interview process in a business-like manner, sitting forward, attentive to the task, wanting to know if she needs to 'do anything' (FN: 1-2), she seems proud to be helping (FN: 3). Catherine illustrates her own high standards, writing on the transcript and criticising herself over the use of "you know?", asking if she has been okay and apologising for saying too much (FN: 4&7). My notes reflect the aim 'to limit the perceived difference in status and 'power' (FN:3&5). She wants to share her experiences of support because they are affecting her now and she hopes that professionals reading her story will change their approach to young mothers (FN:3). At the end of the process she writes that she 'felt like I was being useful' and 'it was really good to be able to discuss my experiences with an impartial person' (Evaluation: 1).*

*Catherine describes growing up with "always a lot of money but not a lot of time" (Int2:326-327). Both her parents are professionals which means she 'always put a lot more trust in people that are trained' (Int2:360-361). With apparent pride she describes being independent from an early age. Using the past tense she says she was "very, very judgemental" (Int2:453). Her new neighbours challenge previous assumptions as they are "helpful and friendly" (Int2:450). Her story contains ambiguities and contrasts, although she thinks "most people who are that age who have children aren't maybe as capable or as like I am, I was quite mature for my age" (Int1:28-31) she describes becoming more confident through having Christopher and buying a house making her 'a lot more normal' (Int2:238-239).*

## **Tasmin**

Tasmin has twins who were two when I first met her. One of them, Tony has a learning and physical disability.

*Tasmin, describes the modern detached house that she lives in with Ted, her husband, Tony and Tammy as in "a nice area ... quite a quiet area" (Int3: 331-332), within walking distance of the shops. She moved there seven years ago and notices that the house seems a lot smaller since the twins arrived (FN: 11). In talking about her home she becomes animated inviting me to enter into a rare moment of enthusiasm. In analysis I wonder whether she values this because it is an area of her life she has control over, which makes it special (FN: 15).*

*On each occasion, we meet in her living room, which reflects the central position that the children have in Tasmin's life. Toys are around us, a large family portrait dominates one wall showing the twins moving towards the photographer with Ted and Tasmin in the background. The presence of a baby monitor, stair gates and her comments about applying sun cream before they go for their afternoon nap all remind me of her care for them. She shares her relief in being able to stay at home with the twins until they went to nursery because "they were more, a little bit more independent" (Int2: 186-187). When I meet her she has recently returned to work part-time in a demanding role which involves travelling the country.*

*Tasmin is generous in sharing her struggles with me and I become acutely aware of the emotion that this involves. She seems to be hiding under a blanket of self control with the corners lifted at significant moments, accompanied by a mirthless laugh and a clearing of her throat. In our first four meetings she is having interrupted sleep as Tony wakes every night (FN: 14). The exhaustion she describes seems mirrored in her appearance which lacks energy perhaps, 'too tired to make an effort' (FN: 8). When I return the following year, the contrast is visible, reflected in her dress and general demeanour which seems more relaxed and energetic (FN: 18). In spite of this, each time I reflect on my meetings with Tasmin I have a feeling of a mother desperately swimming against the tide. Comparisons*

are made as I hear the story of an “ordinary” life before the twins, when things were under control - a “pretty uneventful sort of childhood and life really until this happened” (Int3: 75-78). Before the birth of the twins her friends and family see Tasmin as “very work focused” (Int2: 178) who, as she writes on the transcript is, ‘very stable/solid, people didn’t seem to be able to cope with me being different’.

In our relationship Tasmin is organised, booking our appointments in advance and at a time when the twins are having a sleep. She makes links between us, having done research for a higher degree. She appears competent and I respond to her request by giving her the agreements to sign rather than reading them through with her (FN: 4). She reviews each transcript and comments, without any prompting from me. I observe that she reinforces her written feedback by talking through the points leaving me wondering if this is because others have disregarded her opinions (FN: 11). She tells me that she wants to take part in this research because she knows from experience that it can be difficult to “get people to volunteer” and because she thinks it is a valuable area to research (FN: 4).

When we first meet I notice that she wants to know more about me, asking me where I live and then making a link between this and her experience of the area (FN: 1). She remarks on things we have in common in a way that suggests she is reassured, for example, problems in expressing breast milk and getting organised to go out when the babies are young (FN: 12). I am interested by the way she portrays social etiquette, asking for assent over areas she expects me to agree to, for example her choice of the visual record of support, asking if it will be alright if she eats during our conversations, even the apology for the ‘untidy’ room, all things that underneath she knows I will have no problem with. Her apparently casual attitude to the consent procedure leaves me wondering how much she cares about this until I read her evaluation of being a participant when she says ‘I found Gina to be a sensitive interviewer with a strong ethical focus and very thorough in her follow up’ (Evaluation: 1). I catch a glimpse of the impact of her situation as she tells me that reading her narrative, although accurate was both difficult and emotional (FN: 19).

As a result of selecting the methods which contributed to the vignettes above and the narratives to come, I needed to build a robust case for how I could claim that they represented a trustworthy account of the experiences of each case study parent. I therefore present how this was tackled.

### **3.8 Aiming to make the parent-participants' narratives trustworthy**

In this section I consider how the selection of methods contributed to making the study trustworthy. Although some researchers focus on validity and reliability of the findings, my work was less about measuring and more about capturing an authentic picture of parents' experiences. While I wanted to argue that each parent-participant's narrative was an honest and authentic account, I knew other influences, such as a desire to present themselves in desirable terms, or in a way they think is expected by society (Weiss, 1975), could have interfered. Their responses could contain, 'cultural understandings about what is right, wrong, good or bad' (Carspecken, 1996:85). Reissman (2008:50) explains that the researcher's 'presence, and by listening and questioning in particular ways' shapes the stories participants choose to tell. This meant that rather than claim the narratives represent a definitive reality I needed to argue the case for plausibility and credibility (Pole and Morrison, 2003), explaining how the story communicated 'fidelity' from their perspective (Blumefeld-Jones, 1995).

The audit trail shows how I reached conclusions but it does not suggest that the data would be matched by another researcher. The different relationships I had with each parent-participant led to results that showed the unique character of each case study that explored support (Simons, 1996). To explain, my fieldnotes show the dynamics of each relationship to illuminate my role and possible influence in the situation (Hycner, 1985). This meant that making my autobiographical presence transparent was essential to any claim of trustworthiness (Clandinin and Connelly, 1994). Although I noticed similarities in the responses of parent-participants I was careful to avoid making assumptions that all parents would feel the same but instead noted that there was a match 'between the conclusions reached and the assumed reality represented' (LeCompte and Preissle, 1993:331). These are presented in the discussion that follows the findings.

In seeking to claim the trustworthiness of an example of support I identified any contrary cases that reported 'negative instances, immediately and deliberately, before they [could be] glossed over and forgotten' (Parlett, 1980:244). These occurred in interviews with Andrea, Alfred, Catherine and Tasmin and at first sight led me to wonder about the accuracy of their interpretation. A review of their communication and its context led to contrary cases being linked to different relationships and connections they had with professionals, rather than portraying information that was less trustworthy and authentic. Acknowledging these meant I recognised the important role of interpretation in the entire research process (Hamilton, 1980).

I hope that each narrative encourages the reader to respond to the parent's story, inviting them into the conversation about appropriate action for the future (Silverman, 2005). This would mean that 'believability' could be based upon their 'own parallel, similar and analogous situations' (Blumefeld-Jones, 1995:31). A consequence, however, is that inaccurate conclusions can be drawn, which Riessman (2008) found in her narrative research. I understood that, like her, I could be left witnessing extremely varied responses. I hope to limit this occurring by making each story both plausible and understandable and being sensitive to the way it has been conveyed to me (Polkinghorne, 1995).

In order to portray each case study narrative with 'confidence, authenticity, cogency' (LeCompte and Preissle, 1993:323) I used extracts from the transcripts to include the voices of parents. The verbatim examples from the data, along with thick description were designed to reassure the reader of the authenticity of the findings (Silverman, 2007). Samples of the original transcript show how the sections I used in the narratives matched the experiences of the parent (see Appendix 4). As parent-participants became involved in checking there was less opportunity for what Barr (2010:100) calls 'blurring the ways in which meanings emerged'. This also became relevant in meeting Lincoln and Guba's (1985) standards of credibility, fittingness, auditability and dependability. However, the parents did not have the same investment in the accuracy as I had, which meant that the quality of their checking may have been less rigorous.

Although I witnessed and recorded the 'feelings, intentions and states of awareness' (LeCompte and Preissle, 1993:329) of parent-participants, occasionally I filled in gaps to complete the picture of their experiences of support. Where information remained hazy I avoided claiming "completeness", agreeing with Silverman (2004:354) that this would be an illusion in itself.

Through applying a thorough process of analysis described below, I aimed to present narratives in a form that provided the reader with the insight and understanding that I had experienced in my interactions with each parent (Polkinghorne, 1995). As Blumefield-Jones (1995:25) suggests, 'the narrative is believable when it can be credited with conveying, convincingly, that the events occurred and were felt in ways the narrator is asserting.'

Confirmation and correction arising from each parent-participant's reflections of the accuracy of events, interactions and interpretations add weight to the claims of trustworthiness, although as Riessman (2008) concludes, the final decision lies with the reader when they are prompted to 'think beyond the surface of a text, ... toward a broader commentary' (p13). In this case it was to influence practice in the future, along with a theory to make the recommended changes plausible.

In this section I have outlined how I aimed to achieve trustworthiness and authenticity. I now turn to explain the process of data analysis and its value.

### **3.9 How the information gathered became narratives**

The analysis of the data involved interrogating what Adelman *et al.* (1980) describe as 'a single instance locked in time and circumstance'. The parent-participants' narratives that emerged through the ethnographic case study showed patterns representing 'enduring truths about the human condition' (MacDonald and Walker, 1977:12). They indicated support for the assertion that when requiring support 'individuals actively make sense of life experiences by creating coherence and continuity to face the given complexity and ambivalence of life' (Stroobants, 2005:49). However the 'multiple realities arising from natural differences in the development of

human perception' flagged by Isaac and Michael (1997:218) were also present. To make conclusions credible, painstaking analysis was essential (Pole and Morrison, 2003) and the process undertaken is described in this section.

When analysing the events, behaviour patterns and interactions I tried to imagine how they would look if they were occurring on another planet to gain a fresh perspective and understand them in a new light (LeCompte and Preissle, 1993). As part of the process I was aware of the continual 'search for, and attempt to incorporate, negative or deviant cases into emerging conceptualizations' (Ball, 1997:313). Like Stake (1980), I found that 'what becomes useful understanding is a full and thorough knowledge of the particular, recognizing it in new and foreign contexts' (p.68-69). In common with Clough and Nutbrown (2007) and Silverman (2005, 2007), I chose to analyse my records of things that seemed mundane and ordinary, at the same time noticing subjects that each case study parent-participant avoided.

Through analysis I dismantled and reassembled 'conventional or common-sense meanings, altering the balance between what seems strange and what is familiar, striving to find new ways of looking at the world' (Walker, 1980:224). This provided the opportunity to be creative in the analysis to 'regard different ways of seeing as new ways of knowing' (Simons, 1996:235) the case study participants. By gradually working through the findings in this way induction from evidence rather than deduction from theory was the main focus of the process (Keeves and Sowden, 1997) and helped to avoid Skeggs' (1997) point that many theorists only see and hear from where they are located.

To ensure that the analysis of transcripts and fieldnotes was rigorous I followed a particular structure, firstly reducing the data to make it more compact. This involved listening to interviews, revisiting transcripts and making notes of what the case study parent-participant had shared and how they had shared it, summarising using key words and phrases that 'belonged' to each individual. As I re-listened to recordings of my interviews with each of the parents I noticed silences, or small joining sounds that

were particular to them, highlighting where things puzzled me. This helped me to recognise the significance of the mode of communication each parent used and led to a decision to avoid paraphrasing ideas or 'cleaning up' speech, instead keeping in all the additional sounds because I wanted to retain the voice of the individual (Silverman, 2005). Alongside these records I drew up a list of questions so that I could examine 'how' and 'what' arose from the combination of data from my fieldnotes, observations and transcripts in relation to the research and sub-questions (Silverman, 2005).

I applied the most intensive analysis to the parent-participants I re-visited for the second phase of data collection, Tasmin, Barbara, Andrea and Alfred, which meant careful scrutiny of the additional data arising from observations carried out by the parent and myself. I then compared the content of the final interview with the ideas expressed in the first meetings with them. The combination of methods assumed significance in building a more robust picture (Silverman, 2007). While Ruby and Catherine remained in the background, through analysis I noticed that their contributions added to the common themes arising from the data.

Throughout the analysis I used the CAQDAS package Atlas.ti to code the data so that I could view parent-participants' key statements and compare their method of communication. Fifty-three codes emerged (see Appendix 7), some of which had many statements linked and others only a few. Those subjects that included all the parents and were repeated most frequently were: *personal feelings* (250), *personal values* (201), *comparing* (193), *judging professionals* (130), *parent concerns* (130) and *the value of support* (134). A section of the data was coded by my supervisor and we compared our interpretation of the segment of interview with Alfred which is shown in Appendix 7.

Application of the Atlas.ti programme meant that I was able to identify common themes that showed connections, both within and between parent-participants' experiences. The specific examples meant that I could see ideas that did and did not fit together and draw out interrelationships (Lincoln and Guba, 1985). This complemented my role in 'seeing patterns,

hearing noises, in data, processes requiring fluidity, flexibility and multi-task capability' (Richards, 1997:288). This procedure helped me to see where 'there is a relationship between people's ambiguous representations and their experiences' (Hollway and Jefferson, 2004:2-3).

At times I found using Atlas.ti challenging as it ran counter to my instinct to regard each person as unique. It felt reductive to fit parent-participants' personal feelings into codes. I also found myself questioning the accuracy of my interpretations. However in spite of my feelings of resistance I continued to apply it as part of the discipline of the analysis and recognised its value as I compared my first impressions of what had been most significant to the parent with the transcript coded evidence. Thus it became a reality check to my assumptions.

Drawing on these methods I created an analysis journal that informed the writing of vignettes and narratives. This meant I could review themes and patterns for each of the six case study parent-participants. To evaluate the results I checked a variety of reasons for responses through internal questions such as "does this idea make sense?" (Keeves and Sowden, 1997). These became a guide for compiling both the vignettes and the narratives.

Each analysis journal contained quotes from the parent-participant that illuminated my understanding of the experience the parent described. To reflect each parent-participant's individuality in their vignette and narrative I included records of 'body movements, vocal tones, and facial expressions in addition to verbatim speech acts' (Carspecken, 1996:49). The intention was to provide an authentic and detailed picture of each person, so that the reader could get to know the parent. Through applying a systematic method of condensing the data using informal and formal coding, then compiling an analysis journal and finally selecting key information to write a vignette and narrative I aimed to reflect a more authentic and trustworthy portrayal of each parent's story. To maintain the integrity of my practice and research I conducted a final check to make sure that the narratives did not have 'juicy snippets' or snap shots in the way a journalist might describe an experience (Silverman, 2007). This would have challenged the

scholarship of this piece of work and more importantly have implied a lack of respect for each parent, something I had made a commitment to avoid.

The snippets that had been taken from each interview, observations and fieldnotes were 'knitted' together to present each story coherently. This showed how the iterative approach reflected Stake's (1995:44) intention to pass along 'an experiential, naturalistic account for readers to participate themselves in some similar reflection'. Within each vignette and narrative I invited the reader to join me in its interpretation, noting Kemmis's (1980:126) idea that through case study 'self reflection provides the reader with the means for reconstructing the study and, critically, demonstrates its rationality.'

The techniques described show how, as part of the analysis procedure, I became submerged in the data. They explain the benefit of adopting an iterative and reflective process to produce findings that reflected a portrayal that was trustworthy (Bassegy, 1999). I wanted to mirror the concern I had shown for the parents during the data collection by sharing the final results with them. When I returned to meet with Alfred, Andrea, Barbara and Tasmin I asked them to read their narrative and vignette. I felt the shock of recognition in each of them as they told me their story described their experience. Small amendments were made in response to Barbara's and Tasmin's feedback and the narratives otherwise remained intact. To ratify my portrayal of the parent-participants' experiences was important because I hoped that what they had shared would influence practice and I believed that they were in the best position to say what could be improved or edited.

According to Keeves and Sowden's (1997) categories of sample, the small number of case studies in this research mean I could not generalise experiences beyond a specific case. Denzin (1989), though, argues that generalisation is not a goal for the interpretivist. Instead as an ethnographer I was aiming for 'comparability and translatability of findings rather than for outright transference to groups not investigated' (LeCompte and Preissle, 1993:83).

The interpretive analysis described above reflected a hermeneutic approach that looked for 'the social nature of meaning ... interpreting cultures from within given situations and contexts' (Per-Johan auOdman and Kerdeman, 1997:186). My purpose was to analyse how present, past, cultures, groups, conditions and lifestyles had influenced support for each parent in order to understand their position more clearly. I understood my role in the 'hermeneutic circle' as a process of examining, pre-understanding and reflective understanding (Per-Johan auOdman and Kerdeman, 1997:190) for me and for the parents who had shared their experiences with me. Through analysing what they had shared I learned how they re-lived the journey from diagnosis or first noticing their child's disability. They portrayed this in graphic, emotional detail that enabled me to enter their interpretation based on both theirs and my pre-understanding and reflection. Analysis of this revealed 'the intimate connection between experience and expression' (Per-Johan auOdman and Kerdeman, 1997:188), reminding me of Kierkegaard's (Westphal, 1996) proposition that we live life forwards and understand it backwards.

Through entering and identifying with each parent-participant's story I began to see glimpses of a transactional model (Sameroff, 1987) in action in a new context. As this arose from an inductive procedure I needed to show how conclusions were drawn with examples so that the journey to the theory was transparent (Miles and Huberman, 1994). This not only required a detailed review of all the data using Atlas.ti to identify how the parents had shared definitions of themselves and professionals, but also for me to step back and consider my role in defining myself. Arising from this process, themes, patterns and concepts emerged revealing some consistency (Hycner, 1985). Conclusions were set alongside aspects of my reading and experience, raising my awareness of the natural tendency to look for things that confirm rather than disconfirm our thoughts (Silverman, 2007). In my case I saw the connections later which meant that I had left space in the interpretive cycle for this to emerge rather than forcing myself to see it. As I became more sure, ways to anchor these conclusions to explain consistency as well as assist in elaboration and refinement (Silverman, 2007), became apparent. This reflective process represented a

search and gradual unfolding of a theory rather than finding a definitive truth.

To understand the role of the transactional model in practice I revisited my data identifying my role in connecting with each parent-participant using the perspective-display series (PDS)(Silverman, 2007). Evidence was present as I had sought common ground via a question and statement to build a link. These showed examples of Cohen *et al.*'s. (2007:23) term 'the interplay between all social encounters exposing them as "mutually interdependent"'. This process meant that I became part of the learning cycle, simultaneously noting similarities and differences in my reactions and behaviour towards each person. The analysis highlighted that in each interaction either positive or negative definitions become a key part of the transaction model (Sameroff and Fiese, 2000). This awareness had the potential to guide me and other professionals in future encounters with parents.

Through a review of the learning journey above, I saw how the radical listening I had committed myself to at the start of this study had enabled me to grasp 'an inchoate sense of the whole text' (Per-Johan auOdman and Kerdeman, 1997:187). Until this point I had been unsure of its significance or impact. This had not led me to one conclusion as the transactional model offers the opportunity to continue questioning in the moment. Rather than being a means to an end, it left the end dangling in front of the parents for them to take control of in their own way. My choice of ethnographic case study had enabled me to apply 'perceptual freshness and openness, comparing, contrasting, aggregating and ordering, establishing relationships, and speculation' (LeCompte and Preissle, 1993:277).

Although the process of analysis had been painstaking, I was equally aware of its limitations because my interpretation was unique to me and, as Cohen *et al.* (2007) suggest, both the researcher and participants are open to false consciousness making their subjective contributions incomplete. In spite of this, the result led to 'the most 'grounded' set of hypotheses about their experience and response'

(Wengraf, 2001:232-235) I could realistically gather. As Pole and Morrison (2003:155) observe,

This does not mean that we can say that ethnography provides 'the truth', but it may mean that we are in a better position to judge whether it provides a convincing version of a truth. Is any form of research able to more than this?

The next chapter presents the findings in individual narratives.

## CHAPTER 4: PARENT-PARTICIPANT NARRATIVES

The narratives of each of the parent-participants, and my engagement with them, are presented in the order in which they were interviewed as shown on table 3.4. I use the present tense to draw the reader into their experiences and into their telling, indicating how they are drawn from a mixture of sources.

### Barbara

At the age of thirty, four days after Bernard's birth, Barbara is told that he has Down syndrome. When Barbara begins to tell me of Bernard's birth, emotion is in the background: *"a bit of a difficult labour and obviously the shock of having something unexpected at the end"* (Int2:299-301). Perhaps to escape the pain she tells me of the coinciding move into the house. Returning to the subject of diagnosis I hear that the doctor was positive and that there was *"nothing that particularly scared me or that he implied we needed to do"* (Int2:552-553). To clarify what she means by this she writes on her interview transcript *'not keep Bernard'*.

There is a four day wait for confirmation of his condition and Barbara recalls a conversation with Brian, *"what's your gut reaction about this? What do you feel? Does Bernard have Down syndrome? And we both went yeah he does"* (Int2:578-580). The memory triggers tears, a moment of poignancy for both of us, as I stop recording and pause.

As we resume she tells me, *"I think I wanted someone to say "no he hasn't got Down's", probably, but looking back I don't know what I wanted"* (Int2:610-612). Entering her world, I share feelings of isolation, confusion and fear that waiting for the results conjure. Staff, at a loss, bring leaflets and Barbara wonders what else they can do? It is all *"quite upsetting, all the big thoughts, nobody there to talk to about it"* (Int2:585-588). These are set alongside the pre-birth conversations *"all the questions about what he is going to look like, his personality and 'how brainy they're going to be"* (Int2:644-645), reinforce pain. When Bernard's condition is confirmed *"all confidence of being able to be a mother drained away"* (FN:15).

Barbara apologises for her tears, sharing surprise at the emotion because she does not feel sad today. She reflects *'it was due to Gina's nature that I could openly and be open with my emotions, and again, it helped me to re-read the transcript to be able to 'take it all in'* (Evaluation:2). She avoids emotion in front of professionals though, (FN:13) saying *"I don't want to get upset when I'm saying it, I want to be smiley and confident"* (Int4:563-564). The exception is the Portage worker as she *"burst into tears in front of her"* (Int3:519-520) when she explained that Bernard had bitten his key person at nursery and that she found the Portage worker's gentle response reassuring.

Once home from hospital there is a swathe of feelings, *"a mixture of 'absolutely brilliant...absolutely ridiculous...absolutely mad"* (Int3:68-109). Hundreds of cards and lots of visitors arrive, there is chaos as she attempts to express breast milk, surrounded by babies and mums. Barbara reflects on the period of adjustment, not knowing *"what to expect"* (Int3:194-195) and finding it *"strange, so I was quite bewildered"* (Int3:200-201). The appointments with the health care professionals are *"quite a big pill to swallow"* (Int3:199) as she realises *'none of this would be necessary but for the fact that Bernard had Down syndrome'* (FN:14).

Encounters with other children leave Barbara *"thinking God, you know? I wish that was mine, I wish that was my son"* (Int3:303-304). I find my feelings merging with Barbara's words, *"it's quite a turmoil thing, it's not very nice to think"* (Int3:305). Every day life, it is hard at first; she can't *"face it"* (Int3:49). Then she decides *"I've got to do it, make myself do it"* (Int3:51-52).

Perhaps due to the time lapse and because of the shock in adjusting, details and vagueness merge. Jottings on the transcript reveal *'personal feelings would get in the way of taking it all in. At the time, that part of me felt neglected by professionals'*. When she fails to follow professionals' suggestions she feels, *"a bit like a bad parent"* (Int3:208-209) thinking, *"Ooh I should be, I'm obviously terrible"* (Int3:212-213).

The local support group for parents of children with Down syndrome, whose co-ordinator visits Barbara in hospital, provide her with a place to go. It is *"brilliant, absolutely fantastic"* (Int2:136-137) [I could] *"just waffle on err and wasn't judgemental or anything and was absolutely fab"* (Int2:170-171). Barbara chooses to place this in the corner of her 'picture' of support because the support group is used less, however, she tells me that the co-ordinator is still on hand and knows about *"fighting for things"* (Int2:149).

The health visitor sees Barbara daily and is *"fab...brilliant, absolutely fab...they were lovely"* (Int2:233-238). Later when she goes to the surgery they say *"pop in but come and see us don't just pop in and pop out again"* (Int3:146-148). These reflections set up a theme that explains the importance of making connections. Barbara appreciates any commonality, finding that the first-time mum's group whose children have a variety of additional needs are, *"really at ease, just ask me questions, I've gone 'this is awful'"* (Int3:38-39).

At her first visit to DownsEd she confronts the reality of what Bernard will look like. With other Mums, she learns to look at the child not the disability. When it is time to say goodbye to the friends she has made, she cries saying *"I'm not upset, not upset, I'm crying because in the beginning I didn't like coming ... looking back they had the biggest impact on how we viewed what Bernard could do (err) and what his potential was"* (Int4:512-516).

Barbara is *"quite overwhelmed"* (Int1:102) when she receives the Early Support folder. In the early days she says there is *"lots, had lots of information"* (Int3:205) and later writes, *'just completely different activities – so many'*. Gradually confusion gives way to confidence and knowledge of Bernard so she can say, *"I am his mum, so I don't think he'll enjoy that activity and I would be better at saying that"* (Int3:235-237). As she confesses to occasions when she is *"upset about things and [so does] not say anything at all"* (Int3:239-240) I realise this confidence is unstable. When I meet her a year later the mixed feelings remain as she writes about meeting a speech and language therapist in her home, *'Even though I feel more confident about sessions like this one, it doesn't stop the same*

*thoughts popping in my head, but I am more likely to feel positive and proud, (rather than negative and upset) and that is a lovely feeling to have'* (B-O:3).

The Portage worker (PW) arrives when Bernard is nine months old and is - *"the light, the sort of light at the end of the tunnel"* (Int3:400). Drawing *"a little bit of sun"* (Int1:50), on her picture Barbara tells me it is *"brilliant"* (Int1:22), *"its consistent, individual, they know Bernard and Bernard knows her, he looks forward to it"*. It is *"completely valuable"* (Int1:30) and she will be *"quite gutted when that finishes"*. Barbara uses the Early Start folder, showing high standards, dedication and pride (FN:13) and referring to *"targets"*, repeatedly telling me Bernard is now up to number 78. As the PW visits weekly Barbara tells me she feels less pressure to show Bernard is progressing (Int3:438). When I observe them working together I see a *"collusion"* that speaks of common unspoken goals, Barbara defines herself as the learner still needing to build confidence (O:2-3).

Alongside Barbara's dedication and commitment to help Bernard to reach his full potential, I sense anxiety. She writes of her 'relief when B achieves a milestone, which is 'extra amazing' as he has usually tried so hard to get there' (O:6). Facing Bernard's limitations is 'not great for confidence' (O:3). The nursery he attends is designed to give him a *"boost before he starts school"* (Int1:369 and Int4:17). She explains the difficult mix of wanting Bernard to be treated as normal and making him the best she can under the circumstances (FN:15-16). Barbara identifies this as *"my controlling part"* (Int4:264-265). Looking forward to when he starts school she says she has to, *"let that control go and trust in somebody else"* (Int4:256), taking *"a step back...let them do that...take a bit of a back seat"* (Int4:308&312-313). Barbara wants to avoid becoming *"teacher/mum [or]... special needs mum, 'cause they're the worst two"* (Int4:325-326).

When Bernard is in childcare, Barbara has time *"to be me again"* (Int1:327), something she underlines with '! ☺'. I am surprised by her escape route from things connected to Down syndrome. She finds that Facebook is *"positive"* and *"lovely"*, not serious, and not *"you know? Horrible"* (Int2:118). She makes friends via an internet forum for parents

who have a child with Down syndrome, and pops *"on there every day"* (Int2:18). In this arena Barbara feels in control, saying *"it's nice just to lurk actually and have a read"* (Int2:17). She says, *"you think you know people"* (Int 2:32) and *"everyone knows what, you know, what you can go through"* (Int 2:39-40). In this way she celebrates Bernard's milestones, discusses options for managing behaviour, or just makes a connection and puts *"the feelers out"* (Int2:88). A year later she says Facebook is in place of the forum, building up *"a large sort of Down syndrome err kind of family, friend group"* (Int4:541-542). However there are drawbacks because it is not as safe as the forum with people sometimes *"writing inappropriate comments"* (Int4:554-555).

Family and friends feature on Barbara's picture of support in block capitals surrounded by 'sun' offering *"100% ... massive"* support, (Int1:259-262). Going to a concert with a friend means 'doing something 'special', which helps her feel 'ordinary'... (O:12). Her husband Brian, is *"slightly stronger"* (Int2:421); they are at opposite *"ends of that sort of spectrum"* (Int2:429-430) and a good team. The extended family *"absolutely adore Bernard, think he's amazing, which he is"* (Int2:505-506). However, *"they don't see the bits that are maybe not so great"* (Int2:509-510). Friends and family do not really comprehend what it is like. Cracks appear in the facade as she shares her desire to have an existing friend who *"just happened to have another child with Down's"* (Int1:274-275). Quickly, Barbara whispers, *"I know it wouldn't be lovely"* (Int1:283).

With passion Barbara shares her priorities, that professionals 'treat him as Bernard first' (FN:32) with *"an element of (umm) definite caring as if it's just me"* (Int 2:398-399). They *"must see B first and DS second but ... must concentrate on development to give him the best opportunities in life and to ... 'fit in'..."* (O:14). Although support could be bad for *"whatever reason"* (Int2:469) the word *"awful"* is in contrast to being a *"happy lady"* (Int2:476) because when things are good *"you feel on top of the world and you feel you can achieve anything"* (Int2:470-471). When professionals don't understand *"it is much more upsetting than you can imagine"* (FN:9).

Throughout our interactions Barbara demonstrates an underlying reluctance to criticise professionals, when disappointed she avoids confrontation, *"If I felt I had to be mean ... that's not in my nature"* (Int2:436-437). She sees this as a weakness to be overcome for Bernard's sake (FN:13). At her final interview Barbara describes her progress, *"I'm better at it, for example in secure, in nice secure environments like DownsEd"* (Int4:489-490) but she hides her disappointment when the optician fails to help her find glasses to fit Bernard.

When Barbara has no personal connection with a professional they are described in an unenthusiastic tone as *"very helpful, very nice people"* (Int1:155) but *"I would sometimes be a bit, not particularly partial to going to that one"* (Int1:160-161). The six monthly check ups are *"like an MOT"* (Int1:229). Sensitive subjects are punctuated with short bursts of laughter or a dramatic tone. In her first approach to the day nursery, she describes their enthusiastic response *"yeah bring him in"* (Int 1:346) and then she lowers her voice, slowly saying *"just want to let you know that my son has Down syndrome" - and I know I was waiting for the pause on the phone"* (Int1:347-349).

Barbara shares pain and frustration when professionals compare Bernard to a typically developing child saying that this *"is never good news"* (Int3:276). She views Bernard's development in *'larger ... bigger windows'*, telling me that she does not like the term *'normal'*. Comparing Bernard to other children means *"wishing it was something else, then you know you can't move forward"* (Int3:290-292). When she hears other mums discussing their child's progress she says *"I'm glad I'm not in this. I used to feel a bit smug"* (Int3:318). Although admitting that, *"hand on heart, I do it when I go to DownsEd"* (Int3:321). To conclude she says that every child with Down syndrome is an individual who *"can do things, can't do things, struggles with things, loves things"* (Int3:390-391).

Barbara is hesitant about the future, *"I'm pretty sure it will be fine 'cause they will help to make it, make it, you know, fine"* (Int1:359-361). She is pleased that the catchment school are happy to take Bernard because *"some are, can be rather, not so keen if your child has a certain special"*

*needs and make it kind of quite clear that they (um), they might not want, particularly want them*" (Int4:69-72). Part of Bernard's preparation for school is the assessment for his Statement of special educational need which she describes as *"bewildering"* (Int4:81), *"it's harder, it's huge, it's a huge area"* (Int4:90-91), and *"a bit of a cloud ... six weeks of horribleness"* (Int4:122-123). Although she receives support from the pre-school, writing the parent contribution was *"quite hideous ... I found it quite upsetting, again because you're focusing on the things he can't do"* (Int4:112-113). She receives the result *"Shaking"* (Int4:214) finding that it recommends more hours than she expected and is *"totally, absolutely, really pleased"* (Int4:136).

Before we part company Barbara sums up her journey; the first year is crazy due to adjustment and a feeling that everything is coming towards her. In the second year, a gradual settling, getting used to the pattern of appointments, almost establishing a flow and acceptance that this is what having a child with Down syndrome involves. In the third year inclusion begins as Bernard is embraced into a pre-school environment, mixing with children, becoming part of a community. Looking forward to the fourth year, Barbara sees that they are finally going to be a 'normal' family with Bernard going off to school and being more independent of both his parents (FN:20). Behind these reflections I am reminded of her comments recorded at our second interview *"Bernard is my son, he couldn't be anything else"* (Int2:655).

### **Ruby**

At the age of 31, when Reece is sixteen months old, Ruby begins to worry about his lack of speech. He is three when I first meet her (and as I write he attends KIDS and a mainstream pre-school).

Ruby's concerns about Reece's lack of speech arise when she compares his language development with her friends' baby girls. Rationalising this she says, *"girls always excel quicker than boys"* (Int1:60-61), but she decides to share her observations with the health visitor, who says:

*wait 'til they're over two years old, and I think, I think that if they have a speech delay, children, it should be, it should be picked up earlier, especially to get the help and support that you need*  
(Int1:21-25)

Information she finds on the internet contradicts the health visitor's advice, leaving her feeling that Reece is entitled to support before he is two (FN:8). When she moves house she finds that several parents at the toddler group have children with speech and language problems, one whose child attends KIDS. Although the health visitor makes a referral, she says *"I would say the support was mostly from a friend"* (Int1:52-53). Reece begins to have speech and language therapy and is placed on the waiting list for KIDS, six months later aged three he is offered a place.

Although relieved when Reece is offered a place at KIDS Ruby questions her image as a parent, she tells her mum she *"could have done a bit more"* (Int2:85). Prompted by the media *"mentioning about, you know - switching the telly off ... I started beating myself up"* (Int2:93-96) leaving her wondering if she is to blame. Later she challenges these feelings telling me all parents feel the same and that the television helps Reece to learn. When the television is left on during my second visit, I record it being both a distraction and something I judge as negative for the child (FN:7).

Ruby turns to the internet for information and punches *"in speech delay and it brought up autism"* (Int2:46-47). She tells me *"it would have been awful"* (FN:7), *"I was worried about the whole autism thing"* (Int1:57-58). When she talks to other mums whose children have a speech delay it *"started to put my whole mind at rest about the autism thing"* (Int1:63-64). However the fear continues as she describes being *"beside myself with worry"* (Int2:48) and although she reminds herself that *"there's nothing we can do about it, we just work with it"* (Int2:50-51) she is still *"an emotional wreck"* (Int2:55). Attempting to gain perspective she explains he hasn't got it *"severely because he does interact"* (Int2:152-153). On the final transcript she writes that *'I was 'OTT with autism but the internet can give a lot of negative info, hence where I got it from'.*

At each meeting Ruby raises the subject of her fears that Reece has autism, telling me *"it would have been awful if it had been that"* (FN:5). Worried *"that he wasn't normal"* (Int2:120) she asks the speech and language therapist who tells her *'no way'* (Int2:133). Requiring further reassurance she consults the manager at KIDS who says *"don't worry he's, he's definitely not"* (Int3:411-412) a comment accompanied by the relief of laughter. She explains, *"I often need reassurance in certain, certain areas"* (Int3:414). Looking back she tells me *"I sometimes get emotional now"* (Int2:136). Her explanation for these feelings is that *"every parent, you want your child to develop normally"* (Int2:145-146).

Ruby is very pleased with KIDS: *"The support with them is just, you know? Been brilliant"* (Int1:165-166). Ruby is sure it is the right setting for Reece, attracted by the atmosphere, friendly staff, organisation and a speech therapist, *"on site and obviously you can use them to your advantage"* (Int3:188-189). Delighted she tells me Reece's *"confidence has shot through the roof since being there"* (Int1:192-193); she has observed *"massive improvement"* (Int3:198) and reflects *"he's come on leaps and bounds"* (Int3:356). She is proud that although limited in speech his understanding is not impaired and *"he's been so good at making himself understood"* (Int3:209-210). However, I also become aware of the challenge of waiting *"it's only now he's starting to come out and communicate a lot more so that's nearly a year on"* (Int2:23-24). She shares her expectations with intensity searching for evidence of progress, and when it's missing she says to herself, *"hang on a minute something's not right here, what's going on?"* (Int3:353-354). She shares her role to *"go that step further"* (Int1:275), using *"parrot talk"* laughing, *"even though it drives you mad, it's got to be done"* (Int1:277-278).

Reece attends a mainstream pre-school to enable him to mix with children he will go to school with and be around *"children that were talking really well, to help encourage him"* (Int1:235-237). She compares the communication between KIDS and the pre-school. Able to *"approach KIDS a lot more"* (Int2:314-315), using a home-link book as *"a three way conversation with me in the middle"* (Int3:339), she never has to think

twice about asking them a question at any time. This leaves the termly updates from the pre-school sadly wanting.

As Ruby compares the two settings that Reece attends she says that KIDS have *"more staff and stuff"* (Int2:300) and at pre-school *"they're gagging to get home"* (Int2:329-330). She wonders if she should take Reece out of the pre-school and decides to approach the manager. The result is weekly reports *"just roughly ... a quick scan on what he's been doing and a few words he's been saying"* (Int2:383-386). This means that she can celebrate his progress and does not find herself saying *"Oh come on Reece, do this, do that' but he's already doing it"* (Int2:259-260).

Close behind the first, a second problem with the pre-school is lurking, as Ruby asks the staff to change Reece's nappy. She raises the subject several times finally saying *"you take the other children to the toilet when they need to go don't you? Why can't you change his nappy at the same time?"* (Int2:402-405). Her decision to confront leaves her thinking she is labelled as *"being [an] over the top kind of mother"* (Int2:320-321). Laughing, she describes imagining them thinking *"oh here we go"* (Int2:410-411) when she phones. Barely concealing the fear, she reflects *"I was worried they would treat him differently because he had that delay"* (Int2:414-415), hesitantly saying

*I didn't want them to sort of pick on him and ... I know that sounds terrible, but (um) you know I didn't want them to sort of, you know? Not focus on him as much, you know?* (Int2:426-429).

The 'horror stories' in the media leave her thinking they might *"isolate him as such"* (Int2:436-437). I relate this worry to my experience, recalling the times I have challenged professionals, later, wondering whether they may take it out on my children. However, unlike Reece my children would be able to tell me. Ruby shakes the kaleidoscope saying now, *"the way they talk to me is fine and it's all, sort of well understood and everything so..."* (Int2:472-473). At our next meeting sounding relaxed she tells me that pre-school offered all the children an activity recommended for Reece by the speech and language therapist using bubbles. Ruby is relieved that

*"obviously Reece didn't feel excluded"* (Int3:291). I hear Ruby's surprise that the relationship is now positive, an outcome she did not expect from confronting them with her concerns (FN:13).

Ruby defines support as *"getting the help and advice you need"* (Int2:444). In contrast she has found health visitors ignoring problems and *"throwing it in our faces"* (Int3:248) perhaps slipping into the plural to express her concern more forcefully. On the transcript she writes *'H.V. was no help at all. All I was given was "he's a boy, he's being lazy etc" but deep down I knew something weren't right'*. She describes them as *"by the book people"* (FN:6). This means she tries to avoid health visitors, explaining that *'her friends are sometimes more helpful'* (FN:6). She identifies possible improvements as being listened to, taken seriously *"we may be over the top, over protective but they do need to listen to our concerns"* (Int3:449-451).

The expertise of the speech and language therapist means *"their support is good"* (Int1:136-137), however, Ruby is disappointed by the initial lapse of three months between appointments. Because Reece will start school next year Ruby thinks *"it needs to be more like maybe every other week"* (Int1:118-119). The advice seems limited, perhaps even inadequate, *"she just told us to do these different things"* (Int1:110-111), and Ruby wants *"a bit more of that information, support on what sort of games to do and you know?"* (Int1:131-132).

Driven by a desire to see for progress, Ruby regularly raises the subject of early referral. Her argument is that:

*I think that if they have a speech delay children should be, it should be picked up earlier especially to get the help and support that you need* (Int1:22-25)

Restated in the final interview, she says that *"you want to get cracking on it straight away so they're able to go to mainstream school, start early"* (Int3:461-463). Although Reece is clearly her central concern these points are put in the third person *"to give them a chance to catch up before going*

to school" (Int2:17-18). She portrays the tension in her relationship with KIDS who hold back when she wants them to begin speech therapy (FN:10). In her anxiety to see action she thinks, *"I probably drove them a bit mad"* (Int3:369), saying *"but he is settled now, are you going to start him on his speech therapy?"* (FN:10). At our last meeting she tells me enthusiastically, that following a meeting with the speech therapist at KIDS he will have weekly sessions during the summer as *"there is still quite a bit of work to be done"*. I interpret this as a need to make him 'right' and 'cure' him (FN:11).

Reflecting on telling me her story she enjoyed the experience *'it's helped me to talk about Reece's and my experience throughout this roller coaster journey'* (Evaluation). I am left with the central message that support was essential for Ruby and Reece and that getting private treatment would have been a *"ghastly price...believe me, you know? If I was working we could afford it, we would've done hadn't we found KIDS"* (Int3:49-51).

### **Alfred**

At the age of thirty, Alfred's daughter Amber is eighteen months old and is referred to the community paediatrician to find out why she has a physical and communication delay. This leads to a diagnosis of autism. I meet the family when Amber is three years ten months and again a year later when she has just been diagnosed with a chromosome abnormality.

Using a dart board to grade his relationships with professionals, Alfred begins with those he regards as *"brilliant"*, the family support worker (FSW) who he trusts and goes to when he can't speak to his wife Andrea. He explains that as part of the Common Assessment Framework (CAF) process he needs someone to speak up for them and when she offers he is pleased (FN:1). He explains that it is only the FSW and me who want to hear his opinion; the *"real professionals"* (FN:7) do not.

The staff at KIDS are regarded as: *"friendly, brilliant, well mannered"* (Int1:260). They work together and when I ask, an example immediately springs to mind: *"we've had leaflets on how to help Amber walk on her tiptoes and everything else and stand on one feet ... um I've also passed*

*the leaflets over to the key worker and she's helped her at pre-school"* (Int2:109-113). Alfred sums up good support saying *"you've got that key worker that understands what's going on, how to work on it and what to do"* (Int3:153-155).

Alfred tells how interactions with other professionals, for example the health visitor, got off to a bad start, *"because at the first time, they didn't believe us, what was going on"* (Int1:217-218). A recurring theme is the attitude of the professionals who *"don't want to listen..."* (Int2:50-53). He explains,

*they tend to curl up in their selves, within their selves and won't ask you any questions and then you get frustrated 'cause they are not asking any questions and you've got to do all the asking and answering as well* (Int2:57-61).

Alfred expresses frustration: *"there's not enough working together!"* (Int3:27-28). His conclusion, counters earlier positive examples, *"there's no one around who wants to help the parents, they will try and help the children, but then it's very difficult because we haven't been getting the help that we should have been getting for our children"* (Int3:119-123). This point is reinforced when he describes being unable to get an appointment with the GP saying that it is *"like getting blood out of a stone"* (O:4). He hopes that I will write down some of these things, because he wants the professionals to know about their experiences (FN:12).

Alfred talks of how *'he finds it difficult to be "told what to do" by someone who has never had children'* (FN:14). He raises this point again a year later adding that professionals are *"cold hearted, disinterested and lacking in understanding"* (O:7). He is angry that they are only now being told about their entitlements for Amber, two years after her first diagnosis of additional needs: *"we've been kept in the dark"* (FN:3). He describes the things that make a difference; the outcomes of the behaviour management course range from spending more time together as a family, to taking the decision to stay with the family.

The attitude and background of professionals is important to Alfred. He illustrates the dichotomy of searching for information and advice from the pre-school alongside having his own observations and opinions sought. Collaboration over instruction is clearly communicated as a way forward. He gives examples of working together, which not only help him to feel he has an important role in Amber's progress but also enable the setting to get to know her likes and dislikes. He tells them that Amber loves animals and *"if they can't find our daughter then they look in the farm area and she's there interacting with all the animals, cuddling up"* (Int2:136-138).

Describing Amber's communication difficulties he notices the pressure she is under to make herself understood, suggesting that Makaton is a "Godsend"; he feels strongly that people on the streets should learn Makaton *"so they could translate and they could talk to people whose got the same problem as Amber"* (Int3:65-67). As I reflect on this idea I wonder if this links to his own frustration with a school that did not find out about his dyslexia until he was leaving and did not do *"something about it"* (Int2:182-184).

There are examples of how proud Alfred is of Amber *"we are amazed to see the progress of how Amber's doing"* (Int1:250-251); *"It makes me feel really confident and proud of my own daughter"* (Int2:146-147). Conscious of her difficulties and in his role of supporting her development he says *"it's a bit hit and miss and then she does it"* (Int1:101-103). In the final interview progress is *"yes and no"* (Int4:214), clarified as physical improvement, communication and her growing independence, choosing what she wants to do. He explains that when Amber chooses to be on her own outside they feel *"upset"* (Int4:227). He also explains that although she is tall for her age she has the mental age of a two-year-old. He thinks that this is good because she can get into places free *"ducking and diving"* (Int4:247-248). This phrase seems to sum up his relationship with professionals avoiding him, or he misses them, or the point they are making, leaving me concerned about the impact that this has on him and the family.

A year later Alfred explains that he has not been around much, away *"nine times out of ten"* (Int4:25). I hear a contrast in opinion about support, improvements and disappointments; he identifies a lack of support based on having to *"step in to help my own daughter"* (Int4:71) at sports day, something he had not expected and complains about to the lead professional (O:2). Another disappointment is in not receiving a letter about a Team Around the Child (TAC) meeting, saying *"it's unprofessional not letting us know what's going on and they rearranged the appointment without me and the wife being there"* (Int4:108-110). Things changed after he lost his temper, so that they now negotiate the times and dates, which means that *"there's a bit of communication going on there"* (Int4:122-123). He also identifies improvements as there is more support and professionals *"talk to me, they won't talk over me or around me. They talk directly to me over the phone"* (Int4:200-202).

Alfred's story portrays a rich tapestry that builds a picture to show how and why it is important to understand and work with him and his family. He gives me clues about what he values: being respected, listened to, consulted, taken seriously and treated as an expert in the needs of Amber.

### **Andrea**

When Andrea is 24 her daughter Amber is diagnosed with autism and three years later with a chromosome abnormality.

Andrea chooses to record her picture of support by writing a list of what she calls *"top ten hits"* (Int1:3). When Andrea is twenty two Amber is born and she is already caring for Amanda who is two. Thirteen months later when Andrew is born the health visitor is consulted about the apparent physical delay in Amber's progress, *"she could not sit up or anything"* (FN:4). I hear her frustration that the first health visitor *"didn't believe her"*, she had to put in a complaint (FN:4). She explains, *"You know when babies coo and babble and all that? ... [Amber] was dead quiet"* (Int1:64-66). Her tone is very calm and measured, *"it was very upsetting at the time"* (Int1:69). As if inadvertently hammering a nail into a water pipe, different aspects of support pour out. Reminding me of a musical box, the tune represents memories flowing without a pause, leaving me feeling Andrea's earlier

description of Amber having *"huge behavioural problems"* (Int1:7-8) is the tip of the iceberg.

When a manager steps in *"then we've got all the help we've needed really"* (Int1: 51-52). The paediatrician is put at number three on her list of support people as she is responsible for the assessment process. Someone from London comes to help complete the *"fifty-page form"* (FN:10). KIDS are at number one on the list of best support as they focus on Andrea's priorities for Amber by supporting a change in her daughter's behaviour and offering advice about how to manage her better. She tells me that they focus on teaching Amber life skills which, she sees as more important than education.

To illustrate Amber's difficulty in forming relationships Andrea says she only interacts with a few people, naming herself, Alfred and her key worker at KIDS. As if to underline the importance of this connection she provides the example *"if she's wet herself or anything like that, then yeah, that's the person who she goes and sees"* (Int1:36-37). I find myself questioning the accuracy of this assessment, knowing Amber lives with siblings but check myself as I recognise Andrea is communicating that this is a serious problem.

At number four on the list the Portage worker is someone they *"got on quite well with"* (Int1:184-185). Remembering her role in helping her to manage Amber's reluctance to eat, Andrea reflects that *"she helped us out a lot"* (Int1:193). Regular contact with the family support worker is valued because of Amber's complex needs. She says *"it's nice to bounce ideas off someone"* (Int2:111-112), in contrast to others who *"seem to tell us what to do"* (Int2:121-122). Although Andrea chooses not to include the lead professional in her top ten she tells me that she is a *"lovely lady"* she *"is not judging, she is helpful"*. She describes how she organised help within ten minutes of a phone call when their boiler broke down during the winter (O:7).

I am surprised when Andrea enthusiastically tells me about the short two-week course she attended at the Children's Centre. As she presents this

alongside having to leave another course because the crèche failed to manage Amber's needs, I almost dismiss its significance. This prompts me to challenge my tendency to under-estimate the impact of the short courses I teach. She explains how it has led to her changing her diet, providing details of the content and the impact. Thus Andrea teaches me that it is not the time span (in this case just four hours) that counts, but the impact of the experience. Andrea is clear that too much information is overwhelming and I wonder if this is why two weeks was long enough.

Andrea includes Amber at number five in her top ten of support and says at the end of our final meeting *"I would probably put her at the top of the list because she's the one doing most of the work ... she's very, very good"* (Int4:414-415). During our meetings she lists a litany of Amber's problems from physical to communication and intellectual difficulties. The tone remains even, almost distant, while the detail reflects respect and pride. I am surprised when she tells me that Amber's tantrums are a measure of her progress because she is making herself understood. Andrea says *"it helps her out in her own little, little way of how she works and everything"* (Int2:46-47). I notice the contrast with the reactions of many parents I work with who regard tantrums as negative. She communicates acceptance of Amber who on the one hand likes to be on her own and on the other is described as *"bubbly and always a happy child and enjoys doing stuff and loves being about"* (Int4:384-386). Andrea leads me to question my assumptions as I thought I knew what she would find difficult and how she would interpret Amber's behaviour. Now I wonder how many times I may have got it wrong with other parents.

Andrea adds the school to her list of support in July 2010 showing me how ratings can change. At the first meeting with them in July 2009 Andrea is very disappointed that they have not read Amber's report (FN:7). This implies a shaky beginning to the relationship but a year later they are described as *"very supportive"* (Int4:16). They help to manage Amber's needs for speech and language and physiotherapy, which means that the hospital appointments have *"dwindled down"* (Int4:18). They treat Amber as *"a normal person ... as any other child and they are very good at that and I'm very pleased. That's the only people that I know that have helped"*

*us out, they are very, very good"* (Int4:150-154). The quality of relationship seems to have led to her saying that they are getting *"more information out of them than we are from our own doctors"* (Int4:177-178).

Disappointment often plays on Andrea's lips; professionals: *"do not know your up from your down and your left from your right or anything like that"* (Int3:180-181). It often feels like they are giving Andrea *"verbal diarrhoea"* (Int3:197). They *"never answer what you need them to answer"* (Int3:210-211). She notices the *"funny look"* (Int3:205) they give her when she repeats a question. Without the information she wants, she reflects that *"we felt a bit put out and a bit confused"* (Int4:140). This continues in the TAC meetings where she feels they are not allowed to have an opinion, saying that it is like *"a butting wall"* (Int4:266). This implies a lack of trust which becomes evident when in July 2009 the health visitor is unable to contact her, *"looking for the worst case scenario"* (FN:13). Andrea sees the resulting enquiry as a complete over-reaction. The statement she is asked to give is like one provided to the police.

Using emotive language, Andrea tells me it feels like: 'professionals slamming doors in their faces' (FN:10) and then *"being talked over"* (FN:11). As I listen I wonder if I could be accused of this, being too quick to bombard parents with ideas, coming up with instant, yet perhaps unhelpful solutions, instead of listening carefully. Andrea teaches me that this does not help.

I hear that missing out on benefits is a bitter pill to swallow, as money, short breaks and the use of a wheelchair are all things that would have improved their lives. Andrea's story expresses a mixture of resentment, confusion, disappointment and helplessness as she thinks they question *'her social phobia, thinking she is "talking out of my bottom"* (FN:11).

At our third interview Andrea angrily waves a letter that explains her application for support is being processed and I notice a contrast in interpretation, as in my own naïve way I see this letter as positive - the family being kept informed, given reassurance that they have not been forgotten - then checking myself because if I was feeling the pressure

Andrea describes I may well be equally disappointed by the apparent lack of action.

When I visit the following year she tells me social services helped them to find out about their entitlements and they are very grateful to be receiving extra money to meet Amber's needs. Although disappointed that they cannot apply for respite care until Amber is seven they intend to use the extra money from a grant to have a family holiday next year (O:8).

Andrea shares her fears for the future, unsure of *"how we're going to cope with her [Amber] when she's out of education"* (Int3:8-9). Without any information or reassurance *"we look into the future, we don't know"* (Int4:123). Andrea is left feeling it is *"a huge worry"* (Int3:18), *"we've got to put aside our future near enough and think about hers really"* (Int3:21-22).

There are moments when Andrea shares feelings of desperation, showing me marks on her neck inflicted by Amber 'as though, words were not enough to make a simple plea to be listened to with care' (FN:13). A year later she tells me that due to her depression she kept *"asking and asking people to help ... and nobody came and helped me"* (Int4:246-248) she was *"on her hands and knees begging for support"* (FN:19). The results of being ignored are stark. Andrea finally snaps and *"exploded"* (Int4:251) hitting Amber. When support is provided she says *"it kind of worked on a good way but it came from a bad thing"* (Int4:254-255). Andrea almost loses her children and a TAC is created, something she views as both a blessing and a burden: 'A blessing because more support is provided, but a burden because she sees it as a type of surveillance and feels the threat of her children being taken away from her, permanently lurks in the shadows' (FN:21). She now has to do it 'their way' to *"keep them happy, keep them sweet and they stay out of our lives really ... so I have no opinion really, none that matter"* (Int4:238-241). She says that she doesn't care as long as *"I can keep my children"* (Int4:244).

In the first three interviews Andrea tells me what she does not want, which is to be told what to do. The vital role of relationship and positive

interaction gradually unfolds. Being told what to do leaves her feeling *"worthless, not good enough, very defensive"* (Int2:130-134). Professionals seem to lack understanding and are *"not in tune"* (Int2:139). Andrea wants advice and information presented as a straightforward answer to a straightforward question. Instead, she finds them saying *"go and get on with it, get on with your life and ... hopefully nothing serious happens"* (Int4:75-76).

The behaviour management course which is part of the condition, imposed by social services, of her keeping the children, gives her ideas to put into practice (O:7). However, I wonder whether her plea to professionals to *"listen ... don't keep imposing your ideas ... don't keep repeating it"* (Int2:155-157) has been implemented or whether she has given up on this due to the threat of losing the children. She explains that the previous year the health visitor *"put pressure on me to go to counselling"* (FN:11) saying she would have liked her to say *"maybe you could do it, if you feel like doing it"* (Int3:107-108). I realise that like me she would have been trying to help, but that it is important to find out, rather than imply that the parent should do it my way.

Comparing her situation to families in India Andrea tells me she has no extended family to help her (FN:20). Her father is depressed and has withdrawn from the family and her mother is not mentioned. Her mother-in-law provides transport but does not visit her at home (FN:17). As she describes people as living on *"little islands"* (FN:20), I am touched by feelings of isolation. The previous year I try to find out how she connects with others and hear that she attends coffee mornings, family picnics etc with parents who share common experiences and are organised by KIDS. This means that Andrea compares herself with other mums, *"I just think, Oh my God, my life is so easy compared to theirs"* (Int3:142-143). The following year I feel relief as she tells the lead professional of a new friend who lives locally (O:3).

In July 2010 I find Andrea clutching at straws to make sense of her child's condition. She appears energised by the discovery that Amber has a very rare condition because of a lack of a chromosome. She thinks that this may

hold the key to explaining her behaviour, giving them some answers and expectations for the future. The experience leads to a trap of too little and too many facts and information from the specialist that is '*confusing and useless*' (A&A-O:1). She tells me that they are directed to a database and then "*out the door, see you later*" (Int4:38-39). The experience leaves them feeling "*we are kind of in the dark*" (Int4:142-143). Keen to manage the uncertainty she says that she wants a book to tell her that "*this is what could happen, this is the reality of the situation*" (Int4:71-72). In listening I become confused by contradictory messages, information from a database is unacceptable, a book would be good. These feelings draw me into Andrea's world of wanting to know, left waiting, wondering, confused, feeling powerless, in need of a clearer definition.

Andrea is generous in sharing her opinions and providing examples of her experiences. When I attempt to elicit what it has been like to participate in this study she says "*Fine, nice to talk about my feelings, how we've been treated but even now we feel like we are being treated like idiots*". Although Andrea tells me that much has changed between one year and the next, I feel the tension of hope and disappointment that are never far apart.

### **Catherine**

At the age of nineteen Catherine seeks support because Courtney, who is two, is refusing to eat, having tantrums and not speaking. When I meet Catherine, Courtney is four and she no longer requires support.

Catherine is unsure of the root of her daughter's problems, making a tentative connection between their onset and a serious bout of cryptosporidium arising from the nursery giving Courtney tap water to drink. Deciding to move Courtney she looks for a nursery "*more local which is why we moved her to that one*" (Int2:13-14). In place of a formal complaint she observes

*to be honest they just wanted us to go because they were aware that it was their fault that she'd got ill and they just, it was sort of a bit unpleasant and they didn't really want to be involved with us anymore I don't think* (Int2:52-56).

Stifling my surprise during the interview, on the transcript I ask if she shared any of the concerns, she writes 'not really as I didn't want to appear to be causing a fuss'.

In the early days Catherine takes Courtney out to groups and writes that 'I was standing out, being very young I felt I looked incapable'. As she engages with professionals they seem *"patronising"*. She imagines they see her as *"some sort of dysfunctional, you know, teenager and that I needed things I didn't"* (Int1:57-58). The health visitor *"kind of rushed off and bulldozed down one track and it wasn't necessarily the right one for us"* (Int1:60-62). In frustration she says *"nobody asked any sort of remotely sensible questions really in my, in my opinion anyway"* (Int2:277-278). She writes on the transcript that 'she wanted to go out shopping and visiting friends; not to groups'. Instead she finds herself invited to a young parent or other group and that the experience *"was just a bit, almost a bit pointless really"* (Int2:310-311).

Catherine shows a pre-occupation with being judged for being a teenage mother, sharing feelings that appear to run deep perhaps intensified over the intervening 12 months. I wonder whether some experiences are exaggerated, due to emotions that have been suppressed and because of a fear that they may be rejected, judged as unimportant if they are not powerfully communicated. She explains her own contradictions, *"I would look like I'm completely in control even when I'm probably not"* (Int3: 75-76).

Catherine includes Clive, her partner, to reinforce the point about feeling judged, describing the nursery viewing him as *"a criminal"* (Int1:222-223), she reasons that had he *"turned up in a suit"* (Int1:219) *"I can't imagine they would have batted an eyelid"* (Int1:219-220). At parents' evenings she feels Clive is not *"really taken seriously and that his opinions weren't actually important"* (Int3:354-355) which she interprets as *"quite sort of hurtful really"* (Int3:366).

Catherine's examples of interactions imply an undercurrent of resentment, when professionals arrive late for an appointment she feels they are *"not really that interested in me and that I'm not a priority"* (Int3:389-390). When the nursery nurse says *"this is what you need to do next, off you go"* (Int1:168-169) telling her that *"this works for everybody"* (Int3:165-166) she feels undervalued. She writes that the speech and language therapist ignores her *"for most of the interview"* and thinks that because she sees so many parents *"they didn't really remember anything they'd said to you last time"* (Int3:118). When the speech and language therapist agrees that Courtney no longer needs support Catherine comments that *"she was pleased to see the back of us, it would give her another slot for someone else"* (FN:5).

In explaining Courtney's refusal to eat she says professionals were *"focusing on other things"* (Int3:83) such as food allergies. Catherine is unhappy when the behaviour therapist fails to share information with the speech and language therapist so that she

*couldn't really, really grasp that and couldn't really understand the sort of child that she was dealing with. She just thought that she was a late speaker, she didn't really understand the whole picture.* (Int1:246-250).

Catherine explains that she did not tell the speech and language therapist Courtney has a problem with eating because *"I thought that's probably a bit too much"* (Int3:156). Yet, Catherine feels that she was not *"sort of listened to as much as I feel I should have been"* pointing out that *"no one knows my child like I do, you know?"* (Int1:253-255). The complexity of managing the relationship is stark and highlights the importance of building a rapport with parents like Catherine.

Catherine defines the role of support as something that makes *"our life easier"* (Int3:7), in order to achieve this she is looking for something *"structured"* (Int3:13). She writes that being told *"Oh just let her get on with it"* (Int3:49) is *'dismissive and unhelpful'*. She wants professionals to *"help me with whatever problem it is and then go away"* (Int2:373-374),

*“be the expert and leave it at that” (Int3:225). Feeling “quite happy to never speak to whoever it is again” (Int2:386-387), she is “not trying to kind of collect friends” (Int2:400-401).*

Delving deeper I find that although statements are forcefully communicated, they are occasionally ambiguous, she says she wanted *“to do it on my own, I wanted to actually be independent even though I didn’t know what I was doing” (Int2:258-260)*. She wants professionals to say *“okay this is the problem let’s go and sort it out” (Int1:39-40)*. At other times she wants the nursery nurse *“to actually take her [Courtney] in hand and do something about it” (Int1:83-85)*. On other occasions she wants professionals to accept *“I actually do know best and I know what I need help with and what I don’t” (Int3:395-396)*. Returning to her own role she wants to be *“shown how to deal with, with Courtney” (Int3:41-42)* to *“feel a lot more in control” (Int3:48)*.

When Courtney is three she says her first words, a moment Catherine finds emotional to recall. Clive returns from a tour of duty with an injury and within an hour of his arrival Courtney says, *“I love you Daddy” so it is a big moment” (Int1:450-451)*. As she tells the story I sense a mixture of emotions, pride, wonder, puzzlement and overwhelming relief.

When I ask about positive experiences of support Catherine tells me that the nursery nurse *“was great, in as much as, she was, she didn’t patronise me so that was the first person I had had that hadn’t done that” (Int1:85-87)*. She compares the second nursery with the first saying she prefers the organisation and the fact that staff *“knew what they were talking about, it really, really helped” (Int2:79)*. They manage Courtney’s eating problems by *“sort of make[ing] sure that when I collected her at the end of the day she would have had something to eat” (Int2:88-90)* by trying *“really, really hard” (Int2:90)*. They are unable to help with Courtney’s speech problems and Catherine thinks *“there wasn’t really, really much they could do” (Int2:95)*. She did not share the suggestions of the speech and language therapist because she saw them as *“irrelevant really” (Int2:106)* because they did not work. Although the nursery follows the advice of the behaviour therapist when Courtney has a tantrum, Catherine says that there are no

noticeable improvements. Catherine tells me that she feels relaxed and is *"more chatty"* (Int3:136) with the key person, because she sees her regularly and as Courtney is at the nursery for the whole day, *"it looks like the holistic approach"* (Int3:144).

The support Catherine's family provide is helpful; her mother takes Courtney so she *"can completely sort of relax and probably have an early night actually"* (Int3:253-255). Her great aunt offers consistent care and visits professionals with Catherine so that *"rather than me explaining it, someone else explaining it, and sort of more of an authority"* (Int1:144-146). Her father helps Courtney with her learning *"but not much of anything else"* (Int3:334).

During our meetings I catch glimpses of the emotional impact of Courtney's learning disability, as she says *"no one really ever asked how I felt ... so that was really tough"* (Int1:169-171). She feels *"worried"* thinking there is *"something terribly, terribly wrong"* (Int2:128). Her concerns are fuelled by her family telling Catherine that she was talking when she was really young. She concludes that Courtney's *"not normal"* (Int2:137). She discloses her fear, seeing *"a sort of dreadful, dreadful time trying to look after her"* (Int2:141-142), acknowledging that at the time she was getting *"carried away"* (Int2:143). On the transcript she writes that she feels embarrassed about this, perhaps because the problems are now resolved and Courtney who starts school in September, no longer requires any additional support.

Reviewing the simple picture of support that Catherine produces during our meetings I see that the 'flow diagram' (FN:4) shows four professionals, two nurseries and three family members. This seems to reflect the limited extent of her experiences of support in which she portrays herself as judged or isolated and disregarded. Although outwardly unscathed by her experiences of support, I am left wondering how deep the phrase *"I've sort of almost lost faith"* (Int3:190) reaches.

## Tasmin

At the age of 38 Tasmin gives birth to twins at 26 weeks gestation. One of the twins, Tony, who is now three has a learning and physical disability.

Tasmin describes the twins arriving thirteen weeks early as, *“obviously quite eventful”* (Int3:78). When recollections of this time become too much she changes the subject promising to return to it without acknowledging the pain she is experiencing. Looking back to the first interview she tells me she is surprised by the powerful emotions provoked through reliving those early days when the twins were in hospital, at times fighting for their lives (FN:10). I hear that the experience is *“horrendous”* (FN:6). There are the practical difficulties of travelling, the uncertainty, along with the reactions of her friends suggesting that with the twins away she could have an uninterrupted night, saying *“but of course I didn’t..., so I was kind of sleep deprived”* (Int1:134-135). The extended period the twins spent in hospital combined with post-natal depression *“all kind of took its toll in the end really”* (Int1:112-113). She recalls a moment of desperation feeling *“I can’t really cope anymore”* (Int2:625-626) and contacting the TAMBA helpline.

As I listen to the physical challenges I notice the presence of the emotional issues. Tasmin explains the reactions of friends and family that leave her feeling misunderstood and isolated. Even professionals dismiss her and anger and resentment simmer. Her strong feelings are moderated during our interviews and spill out in her writing on the transcript, explaining she is *‘very frustrated’* and *‘I just find it very irritating that they don’t accept there are problems – I am with him the majority of the time but apparently I don’t really know what he is like...’*.

Well meaning comments from friends and family who tell her everything will *“be alright”* (something she repeats three times) followed by *“it’ll be okay”* (Int2:501) lead to anguish as Tasmin says *“so don’t tell me”* (Int2:509). She expresses disappointment and frustration saying *“I think the issue I have with his sister and his mum in particular is they don’t really accept that there’s a problem with Tony”* (Int1:26-28). She explains how she tries to convince her husband Ted that there is something wrong with Tony saying, *“I don’t think he’s quite right, I don’t think he’s quite all there...it*

*took him probably a good couple of months to think that actually maybe it wasn't quite right"* (Int1:294-296&298-299). Family and professionals tell her that Tony's behaviour is due to his gender; she concludes that the consultant was not listening, because *"he is significantly worse than any of them, so I know its not just that he's a boy"* (Int2:576-578). She concludes, *"there's definitely something else...I know there's something else...I know there's something else"* (Int2:581-585). When she recalls these examples, they seem to throb like a wound that had been knocked and opens the partially healing scar. As she tries some of the recommended techniques for managing behaviour, she concludes that *"I don't think his, think his behaviour is kind of normal, I think it's worse than normal"* (Int3:23-26). In my absence these feelings build, so that when the educational psychologist visits her in December 2010 she breaks down in tears because she is desperate for help (FN:20).

Recognition that there is a problem comes slowly as the registrar at a neonatal appointment responds to Tasmin's question saying that *"some of his problems are related to, maybe not enough oxygen, you know, soon after he was born"* (Int1:66-68). He says that because of this Tony is more susceptible to ADHD. I hear Tasmin cling to this, describing it as *"that's the closest anyone has ever come to saying actually he might have something like..."* (Int1:341-343). She repeats the encounter in the next interview, saying she thought, *"thank God somebody is actually saying something"* (Int2:590-591). Although as yet, a tentative diagnosis that cannot be confirmed until he is five or six, she says *"it's nice to think that somebody actually is, has listened and said "well it could be because of this"* (Int2:602-604).

To further support her concerns, Tasmin tells me that when she attends a course, the speech and language therapist agrees with her that Tony has a problem with his development. An assessment from Portage leads to Tony being placed on the waiting list to which Tasmin repeats this is *"exactly the sort of support he needs"* (Int1:457&473). These examples leave me thinking that when someone hints that they agree with her, she gathers up examples and treats them like jewels to negotiate with, in the hope that they will lead to the support she needs.

Alongside the concerns sits an internal struggle, a feeling that she should look upon things differently: *"[it's a] miracle that he's here... if he's got learning difficulties, that's the worst thing that he's got, then I actually think that we're quite lucky"* (Int2:519-522). I wonder if this rational, calm aspect of her communication, suggesting acceptance rather than asking for help, leaves professionals with the impression that this is not a serious problem. As she aims to, *"try to kind of keep it in perspective really..."* (Int1:88) I hear her doing her best to explain his behaviour saying *"he's still not really ever going to be like, what like a normal fifteen-month-old child"* (Int1:243-246).

Tasmin portrays the subject of learning disability as something she has always been accepting of, suggesting that she has never had *"an issue with that"* (Int3:105-106). She links this to the fact that *"we were brought up fairly liberally I suppose in that way"* (Int3:106-107). When she compares herself to another mum she met in the neo-natal unit, she says it could have been so much worse (FN:7), so as far as she is concerned *"there are worse things to worry about"* (FN:12).

The subject of diagnosis re-emerges in the final interview, some twelve months later. Tasmin is almost grateful when Tony hits his key carer at nursery and her sister-in-law, because it shows *"its not just me"* (Int4:249). However the attitude of the family has not changed *"significantly"* (Int4:452) because she *"does not think they properly accept there is a problem"* (Int4:458). However, she is clear that Tony has not been given an SEN place *"because he's a boy and a bit naughty"* (Int4:467-468). Tasmin laughs at herself because she is now attempting to reassure the family, telling them that after a year in the nursery he will be fine. She wonders why saying, *"maybe I'm just trying to make myself feel better about it, I don't know"* (Int4:484-485). I question this point and she tells me that it is because she wants the twins to go to the same school.

Tasmin's experiences of support are presented as a mixed blessing. There are examples of positive experiences that emerge from regular contact with the health visitor who was *"really, really good ... helpful, ... very supportive"*

(Int1:167-169). As the health visitor retires Tasmin begins to forge a connection with a Home-Start volunteer, who visits half-day a week and *"has been really helpful actually"* (Int2:389-390). Tasmin focuses first on practical examples and then the emotional support saying, *"I've talked to her about Tony and how difficult I find, you know, find him"* (Int2: 418-419). The practical help continues as she goes to some of the appointments with Tasmin, which she finds helpful, as taking the two of them is *"just horrendous"* (Int4:309-310).

When the twins are six months old, to help with her post natal depression the health visitor *"sort of put me onto the twins club"* (Int2:259-260). This becomes a source of making new friends with the practical advantage of being predictable and not too far from home. To highlight the benefit of the twins club, she compares it to a toddler club where she felt other mothers were quite *"judgemental"* (Int2:326) about Tony's behaviour, whereas here *"one might be running riot and nobody kind of flickers really"* (Int2: 335-336). Her tone becomes reflective as she considers the reassurance of seeing *"that other people have kind of survived my experience, I suppose"* (Int2:346-347).

Tasmin shows that she wants to give the twins other social opportunities, taking them to a toddler play session organised by Home-Start. She says she *"enjoyed taking them to that"* as *"they deliberately keep their groups small"* (Int2:441-443) and Tony *"didn't stick out like a sore thumb"* (Int2:448-449). Also, other adults tried to guide Tony in his behaviour so it was not just her saying *"no, no, no"* (Int2:452-453), which she thinks he switches off to. She is also afraid that he will think that she is the only one *"kind of picking on him for want of a better word"* (Int2:458). As she talks about this I find myself aware of the struggle between trying to get control and a fear that Tony will fail to recognise that she loves him.

When Tasmin describes finding something that Tony enjoys, her voice lightens and her body relaxes: she recalls using the sensory room at the Children's Centre as *"lovely it was really, really nice"* (Int2:265-266), because Tony liked it and it gave her a *"bit of chill out time to be honest"* (Int2:280).

Tasmin shares her disappointment in the delay in receiving Portage support saying *"I think it's a real shame...there's such a long waiting list"* (Int2:22-24). When she arrives, she is pleased by the approach of the Portage worker who has nine weeks with Tony, thinking that had she come earlier *"I wouldn't have had half the difficulties I've had with him"* (Int4:168). She describes Portage as *"getting as much in...it wasn't an emotional support...it was very much more sort of factual"* (Int4:381-185). I see this in action as the Portage worker takes the lead and Tasmin follows, providing an echo to her requests saying to Tony *"what else is there?"* (O:2). She describes the improvement in his ability to sit down and concentrate saying it *"has been really, really helpful"* (Int4:178).

Tasmin values the regular one-hour appointments with the neo-natal unit which have been every six months since the twins left hospital. However although it was here that the idea of ADHD was muted, she describes the appointments as supporting Tony's *"general development"* rather than focused on *"his sort of learning problems"* (Int1:50-51).

When sharing factual information I feel Tasmin settle on sure ground. She details her thorough approach in finding a nursery for the twins, describing how she *"trawled round quite a lot"* (Int2:147) visiting ten or eleven before making the final decision for practical reasons. Later she writes on the interview transcript that it was also important to see 'how the other children seemed'. Tasmin discusses the early connections with the nursery and her anxiety about them meeting Tony's individual needs. Moving him from the baby unit to the toddler room is debated in a tussle of questions about his well-being and development defined in the word *"concern"* (Int2:60-85) being repeated four times. Together with the area inclusion co-ordinator, the nursery reassure Tasmin that he will receive additional support. She describes how they have been working together to support Tony's language skills following the advice of the speech and language therapist, in nursery and at home; so it has actually *"started to make a difference"* (Int4:274).

Tasmin describes how professionals gradually increase as the health visitor refers Tony to the community paediatrician, joking, *"cause we didn't have enough appointments!"* (Int1:350). I hear of the practical difficulties in

getting to appointments that are in different cities as *"a real pain in the neck"* (Int1:361), and having to take Tammy along too, an added pressure. When the community paediatrician suggests setting up a TAC she challenges this because Tony is already seeing the professionals that this would involve.

For her observation Tasmin chooses two examples of support to write about, one where a health care assistant is present which goes well because it *'allowed me to talk sensibly to Dr. without losing my train of thought'* (T-O:1), and the other with the occupational therapist which is *'a nightmare'* (T-O:1) because she has to manage alone. This point is reinforced as she describes taking Tony to appointments and feeling *"constantly on edge"* (Int3:388-389) and *"in a state ... so I tend to lose the thread"* (Int3:394-395). In a final review of the web she has drawn to show examples of support, Tasmin comments on the number of different people she sees saying, *"I'm not surprised that I have stress around all these appointments to be honest"* (Int4:570).

Tasmin values support that provides practical ideas identifying the community physiotherapist as more helpful than the one she sees at the neo-natal unit. She wants to put ideas into action so that Tony makes progress. When podiatrist appointments are cancelled she says, that with this *"intervention four to six months ago...it would have been a bit further down the road of improving his walking"* (Int3:131-133).

Tasmin identifies improvements by telling me what is missing; services are *"bitty"* and *"not joined up"* (FN:4), *"services very disjointed"* (Int3:121-122), *"it's just awful...not easy"* (Int3:125-126). Now she is working, *"the lack of flexibility is difficult"* (Int3:306-307). At the final interview I hear that she would like appointments consecutively where she sees more than one professional on the same day, pointing out *"I can't believe I'm the only person who needs to see all three"* (Int4:604). She expresses frustration at being unable to communicate with professionals, who do not have a secretary, via email, writing *'Why not?'* (T-O:1), comparing this to her own work where she emails customers to make appointments. Other practical details such as the limited size of the room and lack of parent/child car

parking create problems (T-O:1). As I review this I see the solution as stretching a piece of elastic which retracts and stings her when she considers the reasons why she cannot expect help.

In embarrassment and shame I recall how, because of the lack of a diagnosis for Tony, I had questioned whether Tasmin was an appropriate participant for this study. As I listen to her story, the reality of my misjudgement hits me. Tasmin's worries are real, acute and clearly defined as she talks about the impact that Tony is having on the family. She describes how Tammy, his twin, misses out. She *"is starting to become restricted because of his behaviour really"* (Int3:441-442). On a personal level being woken at night and attempting to manage Tony's behaviour by day is *"just exhausting"* (Int1:433). The implied, rather than openly stated, impact on her relationship with Tony as she almost whispers the confession that her friends do not want to look after Tony saying, *"I don't blame them to be honest Gina, 'cause I think sometimes if I didn't have to look after him (laughs) I probably (begins to laugh), I wouldn't want to either"* (Int3:195-197). She explains that there are times when she is 'at the end of her tether and screams' (FN:16). Later when Tony is enrolled for a special needs place, an outreach worker from the Centre comes to visit because she offers advice *"to families who have kids with behavioural difficulties"* (Int4:138). She welcomes her ideas as *"quite useful"* (Int4:159).

Throughout my encounters I try to identify things that help Tasmin, I find that she regards being at work three days a week, *"a bit more breathing space"* (Int4:363). She is also grateful for friends she has made since having the twins (FN:10). Recently Ted has begun to take Tony out to a football club for an hour on a Saturday morning which means that Tasmin can spend time with Tammy, *"that's quite nice that it gives, at least that's given me that time to spend a little bit of time with her"* (Int4:541-543).

Tasmin defines quality of support as someone who *"accepts and [is] accepting"* in contrast *"to someone who 'Tries to brush it off really"* (Int3:66-67). This, I realise, is something that is missing in so many areas of her life. She continues to think that the professionals either believe that

she is exaggerating or cannot diagnose the problem due to Tony's age, and the fact that his behaviour does not fit an obvious pattern such as autism (FN:18-19). It is only through these intimate conversations, briefly becoming part of Tasmin's world, that I feel able to shed some light on the impact of her experiences of support. I wonder who is more disturbed by this, her or me, as when I explain that this study may not lead to change, her comment to me is "*changes often occur slowly*" (FN:4), leaving me feeling that in her case I wish they would hurry up.



## **CHAPTER 5: DISCUSSION**

The final chapter in my research involved returning to the sub-questions identified as a result of reviewing the literature and carrying out a cross-case analysis with the parent-participants' stories.

### **5.1 Sources of support and how these are experienced**

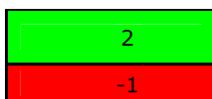
I asked each parent to record their sources of support in a way that was meaningful for them which led to personal visual representations (see Appendix 2). There were similarities in sources of support as shown in Table 5.1.

<b>Table 5.1a Sources of Support Identified by Parents</b>							
<b>Support</b>	Andrea	Alfred	Barbara	Catherine	Ruby	Tasmin	<b>Total</b>
<b>Education</b>							
Nursery 1			1	1			<b>2</b>
Nursery 2				1			<b>1</b>
Pre-school			1	1	1		<b>3</b>
Pre-school - KIDS	1	1			1		<b>3</b>
School	1	1	1				<b>3</b>
SENCO						1	<b>1</b>
<b>Specialist Services</b>							
Audiologist			1			1	<b>2</b>
Behaviour therapist				1			<b>1</b>
Community nursery nurse				1		1	<b>2</b>
Home-Start						1	<b>1</b>
Occupational therapist			1			1	<b>2</b>
Physiotherapy	1		1			1	<b>3</b>
Play therapy	1						<b>1</b>
Podiatry						1	<b>1</b>
Portage	1	1	1			1	<b>4</b>
Speech and language	1		1	1	1	1	<b>5</b>
<b>Health Care</b>							
Community pediatrician	1		1			1	<b>3</b>
Eye hospital			1				<b>1</b>
G.P.		1					<b>1</b>
Health visitor 1	1		1	1	1	1	<b>5</b>
Health visitor 2	1						<b>1</b>
Heart Consultant						1	<b>1</b>
Neo-natal						1	<b>1</b>
<b>Children's Centre</b>							
Children's Centre	1					1	<b>2</b>
Family learning courses		1			1	1	<b>3</b>
Family support worker		1					<b>1</b>
Outreach worker						1	<b>1</b>
<b>Support Group</b>							
1st Time Mums Group			1				<b>1</b>
Down Syndrome Support Group			1				<b>1</b>
DownsEd			1				<b>1</b>
Home-Start Group						1	<b>1</b>
Twins club						1	<b>1</b>
<b>Family and friends</b>							
Extended family		1	1	1	1	1	<b>5</b>
Friends		1	1		1	1	<b>4</b>
My child	1						<b>1</b>
Partner		1	1	1	1	1	<b>5</b>
<b>Computer</b>							
Internet					1		<b>1</b>
Internet forum			1				<b>1</b>
Facebook			1				<b>1</b>
Tamba						1	<b>1</b>
<b>Total</b>	<b>11</b>	<b>9</b>	<b>18</b>	<b>8</b>	<b>8</b>	<b>21</b>	

Table 5.1b shows the value that each parent-participant placed on the source of support.

**Table 5.1b Overview of Parents' response to support**

<b>Support</b>	Andrea	Alfred	Barbara	Catherine	Ruby	Tasmin
<b>Education</b>						
Nursery 1			2	-1		
Nursery 2				2		
Pre-school			2	2	1	
Pre-school - KIDS	2	2			2	
School	1	1	2			
SENCO			2			2
<b>Specialist Services</b>						
Audiologist			1			
Behaviour therapist				2		1
Community nursery nurse				2		1
Home-Start						2
Occupational therapist			1			2
Physiotherapy	2		1			1
Play therapy	2					
Podiatry						-1
Portage	2	2	2			2
Speech and language	2		1		1	2
<b>Health care</b>						
Paediatrician	1		1			2
Eye hospital			1			
G.P.		2				
Health visitor 1	-1		2	-1	-1	2
Health visitor 2	2					
Heart Consultant						2
Neo-natal						2
<b>Children's Centre</b>						
Children's Centre	1					2
Family learning courses		2			2	2
Family support worker		2				
<b>Support Group</b>						
1st Time Mums Group			2			
Down Syndrome support group			2			
DownsEd			2			
Home-Start Group						2
Twins club						2
<b>Family and Friends</b>						
Extended family		2	2	2		1
Friends		2	2		2	1
My child	2					
Partner		2	2	1	2	1
<b>Computer</b>						
Internet					1	2
Internet forum			2			
Tamba						2
Facebook			1			
<b>Total</b>	<b>16</b>	<b>17</b>	<b>33</b>	<b>9</b>	<b>10</b>	<b>35</b>



Helpful Support  
Unhelpful support



A mixture of helpful and unhelpful support

Health professionals were identified as the first support to each family. This was positive for Tasmin and Barbara. Catherine was disappointed that the health visitor failed to listen to her; while Ruby, Alfred and Andrea found their concerns were dismissed, which echoes the findings of Statham and Smith (2010:11):

Parents themselves are often aware when they need help, and there is some evidence that opportunities for earlier intervention are being missed when parents approach services asking for support which is not forthcoming until their problems have escalated.

This point was particularly pertinent to Andrea and Tasmin who became emotional when their requests were ignored. Their stories enabled me to challenge my first response to a parent's approach and in place of providing solutions, to spend more time asking questions so that I could hear their perspectives and priorities.

Bernard, Amber and Tony were referred to the community paediatrician, prompting referrals to other specialists. Dowling and Dolan (2001:28) identify the problem of parents attending many appointments with schedules that can be 'very punishing for children and parents who often have to travel considerable distances with the child and possibly siblings'. Tasmin expressed the impact of this when, instead of viewing appointments as a help she looked at her visual representation of support and said, *"I'm not surprised that I have stress"* (Int4:570). The parent-participants' experiences demonstrate why multi-agency support needs to be in one location (DfES, 2004a).

Support in the home was appreciated above outside appointments. Barbara and Catherine described how a natural environment enabled them to relax, which as Schmalzer Blanklin (1998) contend leads to advice that empowers the family to solve problems and manage behaviour more effectively. However, an added ingredient was the attitude of the professional, as Barbara illustrated when explaining that the speech and language therapist 'had ideas that were specific to Bernard based on what she had been told, what she had seen and what I told her [leaving her]... more likely to feel

positive and proud' (B-O:3). Catherine and Tasmin thought the home environment would enable professionals to see their child's behaviour so that their concerns would be taken seriously, because in Tasmin's case she thought that *"they think I am exaggerating the situation"* (Int4:232). My decision to carry out ethnographic case studies in the home gave me important insights into how each source of support had been experienced. Entering the world of the families, I saw that the quality of support is often defined by the quality of interaction and this led to me acknowledging my role and looking for ways to improve my techniques.

As Barbara and Andrea described their relationship with their Portage worker, I began to gather examples to guide me in the future. Barbara and Andrea's responses matched Clare's (1995) findings that regular contact with a caring person was the most significant aspect of the support. When Andrea was worried about Amber's food phobias her Portage worker *"would give us advice ... she would come round at dinner time and give her different things to eat"* (Int1:188&191-192). Barbara found that she could share her anxiety about Bernard biting his key person, and be reassured.

Tasmin helped me to see that her need for support was multi-faceted, which meant that the regular visits from the Home-Start volunteer provided her with a range of emotional and practical help - the 'instrumental support' described by Assher *et al.* (2008) and Frost *et al.* (2000). Her examples included getting some sleep, preparing meals and providing an extra pair of hands so they can go to the park, which had *"been really helpful actually"* (Int2:389-390).

I noticed the important role of the nursery and pre-school environment and how carefully each had been selected. I could see how Ruby's and Barbara's rationale for selecting two settings for Reece and Bernard, matched reasons that parents gave Flewitt and Nind (2007:440): to 'enable children to grow up with fluid identities able to juggle contrasting school and societal cultures, belonging everywhere.' Responses to each setting were mainly positive, with each parent providing evidence of positive communication with the setting. When problems arose the parent showed how their character and confidence played a role, with Ruby approaching the pre-

school head-on and Catherine avoiding the issue of Courtney being given tap water which had led to her illness.

The outcomes each parent wanted from education varied, apparently linked to their personal values; Barbara to reach Bernard's potential, Andrea to develop Amber's self-help skills, Alfred for him and Amber to be understood, Ruby and Tasmin so that their children could enter mainstream education and Catherine, a secure place to play. This broadened my hitherto narrow view that parents chose education to ensure that their child performed well at school.

Parent-participants shared examples of how they had benefited from meeting with other parents. Barbara made many connections through DownsEd, first-time mum's group and a local support group for parents of children with Down syndrome. Tasmin went to the twins club and Ruby made friends with other mums at the local toddler group. As they spoke enthusiastically, I considered how I could facilitate this for parents I met in the future. However, Catherine and Andrea's stories warned me not to generalise.

When I interpreted Andrea's position as being isolated, I also noticed my concern and joy when she talked of making a new friend (O:3). This personal response raised questions of other possibilities. Andrea may have been happy to have less social contacts or perhaps had more friends than I realised and chose to separate that part of her life from me. I prefer to give parents the freedom to decide what they want to talk about and in future I need to check my assumptions when I become aware of omissions, instead of feeling sorry for them as I had in Andrea's case.

The mixed responses that the internet provoked struck a chord with my feelings and experiences. I could see how instrumental forums had been for Barbara, helping her to make new friends and enabling her to *"put the feelers out if there was something I was stuck with"* (Int2:88-89). Facebook had enabled her to connect with others outside of the subject of Down syndrome. Her reflections in the final interview resonated with my concerns: *"You get people writing inappropriate comments"* (Int4:555-556).

However I, like Tasmin, could see the worth of websites to access information (in her case TAMBA and in mine a myriad in relation to my research). As I listened to how Ruby *“punched in speech delay and it brought up autism”* leaving her *“beside myself with worry”* (Int2:46-48), I thought about the importance of finding accurate information and the need to reassure parents in a similar situation.

Like the parents in this study, as a researcher I had found friends and family a positive and necessary part of my sources of support. Andrea had intrigued me by listing Amber (her daughter) as support, saying *“with all this we wouldn’t have had any sort of contact with (err) any of these professionals if she didn’t do any of the work”* (Int2:5-7). Through her I learned a new perspective on the position of the child in support. Tasmin’s anger and sadness in having her concerns rejected by friends and family provided the stark reality of what it feels like to be misunderstood.

Reviewing what the parent-participants had listed as support and how these had been experienced, was an essential ingredient to my exploration. Through them I learned that in addition to the practical implications, the professional’s attitude shaped the value of the support. As the ethnographic case study approach provided an opportunity to temporarily enter parts of their lives, I gathered unique perspectives that would shape my practice in tuning into the parents’ agenda more carefully in future. This would challenge my previous inclination to use my values and beliefs as a primary guide. When their priorities were different to mine, or the picture was incomplete, I would need to see when negative judgements were creeping in simply because their focus and behaviour did not match my own. These evaluations are unravelled further as the remaining questions are addressed.

## **5.2 Effectiveness of current legislation in ensuring the delivery of support to parents**

Through the case study approach I found the narratives opening up a view of the ‘wider socio-historical, political and cultural events’ (Goodley and Clough, 2004:349), which helped me to make links between experiences and current legislation. Ruby referred to this, complaining that when the health visitor failed to acknowledge Reece’s speech problems she was

ignoring the government's commitment to early diagnosis (FN:10). She interpreted a rationale for early support as enabling her son to be ready to enter mainstream school, a point embedded in the Children's Plan (DCSF, 2007a). Tickell's (2011:60) report endorses this, as a local authority representative told her that 'early identification is a must. The difference to a child's learning can be greatly affected if a child is not identified until they reach school age'.

Barbara's and Catherine's experiences reflected a policy commitment to respond quickly to vulnerable parents. In Barbara's case it was because Bernard had Down syndrome and in Catherine's, because she belonged to one of the government's target groups being a young parent. While delivery of support was effective, the impact was individual. Barbara was offered access to early intervention programmes (DCSF, 2009) receiving the Early support folder which led to her feeling "*panicked ... and quite overwhelmed*" (Int1:99-102). Later she valued this as a way to record Bernard's achievements, matching Smidt's (2007) and the DfE (2011b) rationale. In contrast, Catherine heard professionals say, "*this is what you need to do*" (Int2:274), which led to her feeling pressure to accept the support they chose for her. This showed me that enabling a parent to take control of recording their child's achievement was more productive than telling them what to do.

During the research I found out that the government were keen to support low income families such as Andrea and Alfred in order to prevent future problems as reported by Glass (1999) and Smith (1999). This is embedded in the Children's Plan (DCSF, 2007a). When support was delivered they found it complicated and incomplete, leaving them with questions unanswered. Like the parents in the study by Beresford *et al.* (2007), they wanted to feel skilled and informed. Alongside them I felt the frustration and impotence of missing benefits and opportunities, such as a place for Amber on a holiday play scheme (FN:10), offered as part of the government's 'Aiming high for disabled children' scheme (DfES, 2007b). When I listened to the story of a professional from London assisting Andrea and Alfred in completing paperwork for benefit claims (FN:1&10) and the family support worker offering to be an advocate during the Common

Assessment Framework (DfES, 2006) process, I caught a glimpse of myself attempting to support parents' to gain access to the services they need. Atkinson *et al.* (2002) endorse this joint assessment process to meet children's needs and enabling a better understanding for parents, yet I could see how easy it is to set something up and walk away, believing the questions and concerns have been resolved and leaving disappointment in my wake.

Because Andrea "*exploded*" (Int4:251), having been "*on her hands and knees begging for support*" (FN:19) I realised that policy does not always lead to the action a parent needs. The response from social services brought threats, creating unrelenting fear that Andrea's children would be taken into care. I viewed this as tragic and yet the Lord Laming report (2009:83) was there to remind me that the 'profile of child protection across children's services' should be raised; a response to the cases reported in the news.

Although 'Improving Life Chances' (DfES, 2005) identifies many of the constraints contained in Tasmin's story, she was pleased to access a local government-sponsored parent-toddler group for families with additional support needs and then disappointed when a year later it was later closed "*cause of funding*" (Int2:461). Since 2004, due to the Disability Discrimination Act, hospitals are required to make reasonable adjustments to include disabled children and Tasmin's story told of a partial response when three of her appointments were supported by a health assistant. However, when she is left unsupported the encounter with the professional becomes difficult (T-O:1). I heard about the benefits of having a health assistant who integrated the play into the assessment so that the doctor could see what Tony could do, '*he is happy and relaxed and so am I*' (T-O:1). This apparently met the policy outcomes and could represent a rationale that this support is cost effective.

The difficulties that Barbara, Tasmin, Alfred and Andrea encountered in travelling to many different appointments links to the findings of the Children's Trusts (DCSF, 2007b:9) report which recommended 'Having a specialist early intervention and prevention service organised around a

central hub ... Using a multi-agency team working through a Children's Centre' . These issues were identified in 'Removing Barriers' (DfES, 2004b:12) when a commitment was made to 'refocus funding to support earlier intervention'. Since December 2010 when a cut of 11% for early intervention was announced, Allen (2011) has compiled a report that argues for its presence, proposing an Early Intervention Foundation that is funded independently of the government. The parents who spoke to me helped me to see the benefit of this becoming a reality.

Through listening to each parent's description of what they were looking for, I was able to compare the delivery of governments targets with their effectiveness. Once again priorities were individual, for Catherine, support needed to be structured, professional and delivered competently, using a detached style. Andrea wanted support that responded to her with respect and consistent action. Alfred (like Abberley (1987), communicated concern about society's lack of acceptance of learning disability. He described his daughter being expected to conform, but he wanted her to be appreciated for her different skills which would reflect the affirmation model proposed by Swain and French (2000). Barbara regularly returned to the point about wanting support to be personal, with professionals really knowing her and Bernard. Ruby defined support as *"getting the help and advice you need"* (Int2:444). Tasmin wanted professionals to listen and take her problems seriously, considering the impact that Tony was having on the whole family. Although the expectations are reflected in Routledge and Sanderson's (2002) government targets for the twenty first century and 'Aiming High' (DfES, 2007b), I realised that this exploration revealed gaps in practice. I saw that although the proposal for individual budgets (DfES, 2005) would offer more autonomy, it was the interactions when encountering professionals that influenced the effectiveness of support. This implied that more details about approaching parents, which is currently more opaque in policy documents, is needed.

The children's experiences of education broadly reflected the priorities set out in the Ten Year Strategy (DfES, 2004a:7) that 'Parents want to secure the best for their children, and to see them fulfil their potential in later life.' Each parent valued the concept of working in partnership set out in the

Early Years Foundation Stage and described in the Tickell (2011:60) report combining the input of 'practitioners, parents and carers, professional organisations, local authorities, health, early years and other children's services, and inspectors' to improve the quality and effectiveness of the early years provision. Listening to the parent-participants' stories had revealed a deeper understanding of the personal nature of their views and perspectives.

Comparing the commitments embedded in government policy with parents' experiences showed both consistency and inconsistency in delivery and effectiveness. Listening, I heard of negative examples, including delay in diagnosis, disjointed and inaccessible services and the impact of lack of funding, alongside opportunities that led to positive interaction with selected professionals. The government Green Paper on Support and Aspiration says that giving families more support and control would end the 'frustration, complexity and confrontation inherent in today's system, which in itself can undermine family life' (DfE, 2011b:41). This is also acknowledged by the parents in this study.

### **5.3 Are all parents able to access the support they need?**

Before I began this research I was concerned about the accessibility of support for parents; the narrative approach meant that I gained personal accounts by which to assess this judgment. As Bernard had been diagnosed with Down syndrome in hospital, Barbara was provided with an avalanche of options presented in a *"pile of leaflets"* (Int2:137-138). When Barbara left hospital she felt that she *"didn't want to go out at all ... and then I thought I've got to do it, make myself do it"* (Int3:49-51) and she knew where she could go. Catherine gained access to support via her health visitor, who told her that she needed to join parent groups saying, *"this is what you need to do and go to this group"* (Int2:274-275), something Catherine resented. Tasmin's health visitor identified her post-natal depression and recommended the twins club, where a parent suggested she apply for a Home-Start volunteer. Ruby's friends at the toddler group told her about KIDS. These examples explained that access to support comes through a variety of channels, written, professional and from other parents.

When access to support provides too many options Andrea, Alfred and Barbara showed me it can be unhelpful and overwhelming. The response of Alfred and Andrea matches the findings of Barnes (2003a:13), that 'too much information can often lead to confusion, uncertainty and apathy, and so be dis-empowering,' clearly illustrated in the annotated photograph of a document provided at a hospital appointment *'which really was confusing and useless'* (A&A-O:1) (see Appendix 3). This showed me that when information is a vehicle of support it needs to be succinct, relevant, focused and accompanied by an explanation when the parent wants it.

Professionals dismissing Andrea's, Alfred's and Ruby's concerns, exposed a barrier to accessing to support. Ruby applied a tenacious approach, quizzing other parents about where to get help for Reece's speech delay and then persistence in getting him a place at KIDS, making her own referral and asking the health visitor to give her a letter. Andrea floundered, experiencing similar difficulties that Kathleen Croucher (Chapman, 2005b) described, not knowing where to go due to a lack of clear information. She later relied on the Portage worker and the community paediatrician to signpost further support. These stories demonstrated that access can be affected by the character and approach of the parent.

Ruby and Barbara's emotional tussle regarding confrontation helped me to see that access to support could be affected. Barbara avoided conflict, afraid of being labelled *"mean"* (Int2:434), perhaps, like the parents who talked to Prezant and Marshak (2007:32) afraid of 'biting the hand that feeds them'. Ruby was reluctant and thought that professionals would judge her as *"over the top"* (Int2:320-321), afraid they might *"sort of pick on"* (Int2:426-427) Reece. Finding the right time for Ruby to approach the pre-school staff was a problem because *"it all seemed a bit rushed, you know, 'cause ... they had to get all the children out the door and they had other children coming in, so it was like a conveyor belt and I felt as though I couldn't sit down and talk"* (Int2:243-247). She continued that when she collected Reece she had the impression that *"they were gagging to get home (um) and they haven't got time to speak to you"* (Int2:329-331). As Andrea attempted to gain access, being ignored left her feeling *"worthless"*

(Int2:130). Later as things began to implode she described *"asking and asking people to help me out because I suffer with depression myself and nobody came and helped me ... I got nothing in return"* (Int4:246-248). These extracts revealed the role of the internal dialogue in shaping access and personal identity. They shed light on the impact of interactions which left the parent feeling judged and disappointed in the professionals.

Accessing emotional support was important for each parent-participant. Barbara identified the greatest variety of sources including; professionals, family and friends she made on the internet, either via a forum or through Facebook. Ruby turned to her mother and Catherine, a great aunt. Alfred focused on Andrea and other family members. Tasmin found sources were limited to the health visitor and then a Home-Start volunteer. She was disappointed that professionals failed to talk *"about us as a unit, so you know, what effect his behaviour is having on me and on his sister and his dad as well, I mean we never really get the opportunity to, to talk about anything like that"* (Int3:412-415). This showed me the significance of making positive connections with others which was something which matched my personal experiences and enabled me to identify with parents' feelings about the need for this support and how it feels when it is missing. Their significance meant that in the future, when I found that parents wanted more emotional support, I could help them to access it.

Although I only met with one dad, Alfred, each mum identified their partner as a source of support. Alfred positioned himself on the sidelines, having less involvement with professionals, which matched the other mums' portrayal of their partners and was accepted without question. Ruby, Barbara, Catherine and Tasmin all reasoned that their partner's job had to come first and were grateful for any concessions that their employers made. Tasmin claimed that Ted was *"not really bothered about going to the appointments"* (Int3:272-273). Ruby and Barbara compared their approach with their partner's, thinking they were 'a bit too soft', wondering if this affected their access to support. In contrast to Barbara she told me Brian is *"very, very gung ho"* (Int2:414) and straightforward in his judgement. Ruby told me that Richard would *"put his hands up and fight and say I'll go in and have a word with them"* (Int3:59-60). As I observed Alfred standing

when professionals (the family support worker and lead professional) were in his home this seemed to communicate a need to project 'an air of authority' (O:1). Catherine described professionals' attitudes to Clive, claiming their prejudice towards his age suggested that they saw him as a 'criminal' for wearing "jeans and a T shirt" (Int1:221-222). These snapshots positioned each father on the fringes, brought in as a back up, indicating less access to professionals. This troubled me more than them and helped me to see why my assumptions need to be acknowledged and challenged.

The narratives suggest that access to support is influenced by the parent's approach and their child's condition. Where positive experiences were shared, confidence was apparent and in contrast negative encounters led to difficulties, challenges to self-esteem, identity and at times moments of desperation. I concluded that my role was to listen, to find out what support parents wanted to access, rather than assume that the values of the parent would match mine.

#### **5.4 How attitudes impact on the parents' experiences of support**

The parent-participants' stories showed me that attitudes become entangled in relationships and that they have an impact on individuals' experiences of support.

Through their narratives parent-participants exposed how personal and perceived attitudes influenced themselves and the professional. When professionals asked questions about what Barbara was doing with Bernard she criticised herself for being over sensitive, at the same time interpreting their questions as judging her parenting skills. She described thinking, "*I'm obviously terrible ... I'm not good enough, I'm not doing enough for him*" (Int3:212-215). During home visits she wondered whether '*they will make assumptions ... think I'm a slack mother*' (B-O:2).

Through listening to media reports, Ruby took the attitude that she might be responsible for Reece's speech delay due to him seeing too much television (FN:7) and thus displaying a feeling of guilt portrayed in the findings of Rix and Paige Smith (2008). In three of the four interviews with Tasmin she explained that friends, family and professionals told her that Tony's behaviour was because he is a "boy" (Int1:29, Int2:510 &

Int4:465), attitudes that contradicted her observations, leaving her confused and unsure about her judgement. Allan and Owen (1993) also describe how sadness and frustration arise when concerns are not acknowledged. When Tasmin repeated her story of finally being taken seriously as a registrar told her that Tony's behaviour may be linked to a lack of oxygen at birth, which meant *"a higher susceptibility for having something like ADHD"* (Int2:594-595), the relief she felt became poignant.

Parents' reactions to professionals' manner and tone of voice sometimes communicated unhelpful attitudes; Catherine, found the health visitor *"patronising"* (Int1:28). Catherine and Andrea described professionals taking charge, Andrea felt professionals try to *"push"* (Int3:102), Catherine was *"sent along"* (Int2:310) to groups. When Andrea disclosed her social phobia, she thought that professionals' reactions implied that *"I was talking out of my bottom"* (FN:11). She was perplexed when questions were unanswered, explaining *"we do get that a lot from professionals, especially like the health visitor and stuff. We can continuously ask the same question and they never answer what you need them to answer"* (Int3:208-211). Catherine had failed to connect with the speech and language therapist and concluded that her attitude was that *"she was pleased to see the back of us"* (FN:6). These comments made me wonder whether the professionals had been aware of the impact of their body language and tone, making me more conscious of my reactions to information shared by parents.

In other examples the parent-participants showed how their attitude reflected their expectations. Ruby, relying on the speech and language therapist to enable Reece to make sufficient progress to enter mainstream education and Barbara's observation that she felt *'positive that she will be able to help Bernard ... and that he will like working with her'* (B-O:2). In these stories I heard echoes of the findings of Rix and Paige Smith (2008) that parents search for professionals who can improve the child. I saw that in the past I had a tendency to respond to parents by providing a list of ideas, creating expectations which may be unrealised or were inappropriate to their circumstances.

As reflected in the literature review, the word 'normal' appeared to have currency in shaping attitudes. In company with parents in Bishop and Swain's (2000) research, Ruby, Catherine and Tasmin used it as a benchmark for their child's behaviour. When Tasmin's concerns were rejected she almost shouted that Tony's behaviour was *"worse than normal"* (Int3:26). Like the parents in Beresford *et al.*'s (2007) research, Barbara fought against Bernard being compared to a typically developing child. In common with Browne (2010), Barbara questioned the validity of how 'normal' measures of development are agreed. Tickell's (2011:33) report showed that 'normal' is portrayed in the EYFS age bands, and recommended that they are 'broken down into much smaller steps to help them to recognise the progress of children with developmental delays'. Alfred was concerned about the attitude of the education board, thinking they believe everyone is *"normal"* (Int3:102) and do not choose anyone to represent people with learning disability.

The responses of Barbara, Catherine and Ruby reflected Stainton and Besser's (1998) proposal that the individual's beliefs and values are determined by their own experiences and what society tells them. Barbara told me it would be lovely to have a friend whose child just happened to have Down syndrome, quickly retracting this saying, *"I know it wouldn't be lovely"* (Int1:283). Catherine, distressed by the idea that Courtney *"was autistic or any of all that sort of thing"* explained, *"so I was just saying 'she's not, not normal, that's the biggest worry ... that I was going to have a sort of dreadful, dreadful time looking after her'"* (Int2:136-137&140-141). She asked herself, with Clive away *"can I cope on my own?"* (Int2:159), while Ruby *"worried about the whole autism thing"* (Int1:57-58) saying she was *"beside [her]self with worry"* (Int2:48). Although she was reassured by speech and language therapists and the key carer at KIDS who said *"no way"* (Int2:133) and *"definitely not"* (Int3:411-412) I could see the legacy of negativity towards learning disability. In these encounters I shared the emotional turmoil of the experience and realised that it was important to enable the parent to express this and give them time to move on in the way Barbara's story revealed and is described above in Cunningham's (1979) model of psychic crisis.

Undercurrents of negative attitudes to learning disability occasionally came to the surface, as Barbara was afraid that Bernard's Down syndrome would affect the attitude of staff. When Bernard bit his key carer, Barbara was "devastated" (Int3:513&519) and thought he would be thrown out and labelled "the Down syndrome boy who bit everybody" (Int3:522-523). Catherine noticed the attitude of her family as they compared Courtney's development to hers at that age, implying that Courtney was "abnormal" (Int2:176&177) and that there was something "dreadfully" (Int2:141&157) wrong. Ruby linked her descriptions of learning disability to being "racist" (Int1:234&2:148), afraid that her remarks might be interpreted in this way. These examples heightened my awareness of the impact of applying the term 'normal' and that, although I might avoid its use, the word had emotive connections that may shape attitudes.

Although parents recounted incidents of professionals' unhelpful attitudes directed to them personally, there was no evidence of these extending to their child. However the fear of this occurring was expressed by all the parents, suggesting that they believed there is an undercurrent of intolerance to unconventional behaviour in society. This led to me taking on an active role in challenging this attitude in my practice.

### **5.5 How partnership with professionals impacts on the experience of support**

Within these stories I heard how encounters led to shifts in relationships, apparently influenced by the assumptions, expectations and life experiences of the individual at the time of interaction. The examples from the narratives are shown in table 5.5 below. Through reviewing parents' experiences of partnership, I noticed Dale's (1996:12) observation that there is 'considerable overlap and consensus between definitions' in practice. Mittler and Mittler (1983) describe the *expert* model, where the professional makes judgements and takes control, as being a long way short of partnership. Nevertheless each parent-participant gave examples of seeking advice and information which placed the professional in the role described by Case (2000) and Dunst *et al.* (2002) of 'expert' or 'professional centred'. As Atkinson *et al.* (2005) contend, this can lead to the professional defending their role as 'fixer', forgetting that sometimes

there is no 'fix' other than to let the parent express their emotions and gradually find their own solutions.

Expert guidance could be argued as appropriate because of the physical problems that Amber (mobility), Bernard (eyes and co-ordination), Reece (strengthening muscles in his mouth) and Tony (mobility and co-ordination) had and that could be improved. However when this was the primary focus, the individual model of disability where the problem lies with the child (Oliver, 1996) was on display. Although 'amazing medical and technological developments' (Davis and Meltzer, 2007:2) are a product of our age and can be justified in improving quality of life, I also realised that it fuels an attitude that to be different is to be imperfect.

Barbara showed how the *transplant phase*, identified by Jeffree (Mittler and Mittler, 1983) and closely linked to the *family allied model* described by Dunst *et al.* (2002), meant using parents' skills. In her interactions with Portage and DownsEd this was made transparent as she combined her knowledge with the advice of experts. At the same time, observations and her descriptions of working in collaboration reflect *family centred* and *negotiating models* described by Dale (1996), Dunst *et al.* (2002), Davis and Meltzer (2007), and Espe-Sherwindt (2008). This shows that in one interaction a number of models are observed according to the relationship and requirement of the parent at the time. This shed light on my role in seeking to establish a partnership relationship which matched the position of the family at that time and introduced the *transactional model* as making a useful contribution to enhance this.

The narratives of Alfred and Andrea further illustrate the range of partnership models and their impact. The community paediatrician and later the specialist at the hospital became the experts and diagnosed Amber's problems. The family support worker, the lead professional and Portage worker, helped them to access benefits. Andrea grew to accept social services as their inquisitors saying "I don't really care how they want to do it as long as I can keep the children" (Int4:243-244). This left me disappointed, yet within their stories I glimpsed hope, as Alfred worked in collaboration with Amber's key person and influenced the communication

style of professionals who now phone him up, giving insights into how the *negotiating model* (Dale, 1996), the *consumer model* (Cunningham and Davies, 1985) and the *empowerment model* (Appleton and Minchom, 1991) impact on family lives.

Catherine described herself as inherently independent and therefore she wanted *"to be able to do it by myself"* (Int2:263-264), which implied that she wanted a *family centred approach*. Yet on other occasions she expected the professional to say, *"okay this is the problem, let's sort it out"* (Int1:38-40) implying that she wanted to be told what to do. At other times she clearly resented being *"bulldozed off on one track [which] wasn't necessarily the right one for us"* (Int1:61-62). Ruby needed reassurance through action, requiring the *family focused, consumer model* (Cunningham, 1983) of partnership. She repeated the question *"when's the speech therapy going to be starting?"* (Int3:367-368), and told me that *"if the child has got a severe speech delay, you want to get cracking on it straight away so they're able to go to mainstream school"* (Int3:460-462). She therefore worked with professionals to see that this happened to Reece. These examples illustrate that a parent's agenda may alter and is linked to their priorities, which it is essential to unravel with them, because 'support is undermined if it doesn't reflect each family's unique circumstances' (DfE, 2011b:41).

Tasmin found working in partnership problematic until her concerns were acknowledged by the educational psychologist who said *"he [Tony] would probably benefit from going, going to (um) an SEN pre-school"* (Int4:38-39). She preferred professionals who encouraged her involvement in supporting Tony's physical, language and intellectual development, behaviour linked to the *transplant* and (Mittler and Mittler, 1983) and *empowerment model* (Appleton and Minchom, 1991). However, she also showed an example of Dale's (1996) *negotiating model* when organising a blood test to avoid an additional appointment (F.N:13) and clearly desired a *family centred approach* (Davis and Meltzer, 2007) in appreciating the impact of Tony's behaviour on the whole family. However at other times there was a quest for advice to deal with her son's *"worse than normal"*

(Int3:25-26) behaviour which linked to the *expert model* (Mittler and Mittler, 1983).

Partnership in educational settings represented corporate decisions reflecting a combination of the *negotiating* (Dale, 1996) and *family partnership model*, in which solutions were agreed through 'an interactive process' (Davis and Meltzer, 2007:7). Alfred offered suggestions to improve Amber's physical skills, whilst Ruby and Tasmin asked the pre-school and nursery to include activities recommended by the speech and language therapist to improve Reece and Tony's communication. Although Barbara did not want the nursery to get "*bogged down by things*" (Int1:324), staff supported Bernard by following the advice of the Portage worker and improved their skills in Makaton signing. Staff in the nursery responded to Catherine's concerns about Courtney's eating, ensuring that she ate some food while in the setting, providing examples of the *consumer* (Cunningham, 1983), *negotiating* (Dale, 1996), and *family partnership model* (Davis and Meltzer, 2007). I was encouraged by the parents' description of working with their children's educational setting and saw the benefits of using a holistic approach to the child's welfare which involved collaboration I could practice.

Table 5.5 summarises how a mixture of partnership relationships were exposed in each parent-participant narrative, described in detail above.

<b>Model of Partnership</b>	<b>Parent experiences that reflected the model</b>
Professional centred 'Expert' model	See: Barbara (p.118,120,122,123), Ruby (p.124,125,127,128), Alfred (p.128,130) Andrea (p.132,135,136,137), Catherine (p.138,139,140), and Tasmin (p.142,143,145,146,148,149)
Transplant and family allied model	See: Barbara (p.118,120,123), Ruby (p.127) Andrea (p.132) and Tasmin (p.147)
Consumer or family focused model	See: Barbara (p.122,123), Ruby (p.127,128) Andrea (p.132)
Family centred partnership model	See: Barbara (p.119,120,123), Ruby (p.125-127), Alfred (p.128,131), Andrea (p.132,133), Catherine (p.140,141) and Tasmin (p.145,146)
Empowerment model	See: Ruby (p.126) and Alfred (p.128,131)
Negotiating model	See: Barbara (p.119), Ruby (p.126,128), Alfred (p.128,131) and Tasmin (p.146,147)

**Table 5.5 Parent-participants' experiences of partnership models**

The parent-participant narratives demonstrate that partnership is complex, unstable and has unpredictable positive and negative outcomes. It is fluid and influenced by the individual's character and priorities and open to change according to how they are feeling at the time of the encounter. When the parent's circumstances alter, the relationship is portrayed in an

ambiguous manner because expectations and definitions change. The findings provided some insight into the various environments that the parents inhabit, a rationale for partnership identified by Mittler and Mittler (1983). The aims of family achievement, hopefulness and optimism set out by Nunkoosing and Phillips (1999) are reflected in the *family partnership model* (Davis and Meltzer, 2007). Through analysis of the stories and challenging my position however, I came to the conclusion that the *transactional model* could offer a new way of understanding and enhancing partnership with parents. This idea resonated with McConachie's (1983) contention that there is a need to apply imagination and commitment to the partnership process.

### **5.6 How support requirements change over time?**

As this thesis tells my story of change, so each parent helped me to see how support needs altered with the passage of time. Immediately after Bernard was born, Barbara needed help to adjust to the fact that he had Down syndrome and as a result the local support group was the first place she felt comfortable to go to. This gradually faded into the background as she made many connections with parents through other avenues such as DownsEd, the internet forum and first-time mums. As she prepared to enter a new phase of her life with Bernard starting school, she realised that her identity would alter again, perhaps affording the chance to experience being part of what she called, a "normal" (FN.20) family. Although her attitude to Bernard changed, reflecting a similar journey to that of parents in Murray and Penman's (1996) book, her need to have a personal rapport with those supplying support remained constant.

Ruby showed how her support needs changed from acknowledging her concerns about Reece's speech delay, to receiving regular appointments with the speech therapist to develop his communication. She continued to feel anxious, illustrated at the end of the final interview, when she hoped for further progress over the summer due to the planned speech and language therapy sessions at KIDS. Her story contained an undercurrent of fear that Reece would be rejected due to his learning disability.

Andrea and Alfred found that once Amber was diagnosed, many professionals became involved in tackling her complex issues. Their stories

included snippets of positive experiences with individuals, the key carer at KIDS, family support worker and the Portage worker. Over time things changed and they became disheartened by the attitude of professionals and felt that with each encounter they were neither understood, nor helped to manage their situation. When I re-entered their lives for the second phase of the study, Amber had been diagnosed with a rare chromosome disorder. They felt let down when their hopes of information about her long term development were left unrealised. While Andrea found that *"the school's been very supportive"* (Int4:16) in all areas of her development, Alfred and Andrea lived in the shadow of fear of losing their children. They therefore worked to *"keep them [professionals] happy, keep them sweet, and they stay out of our lives really, and it makes our lives a lot easier"* (Int4:238-241).

When Catherine first approached professionals she wanted to gain advice on how to manage Courtney's behaviour; to improve her eating, her communication and manage her tantrums. As time went on the problems were gradually resolved, leaving Catherine wondering whether, apart from the community nursery nurse, there had been any benefits to the professionals' input.

Soon after the premature birth of the twins, Tasmin was most concerned that Tony's physical needs were being met to ensure he survived. This gradually gave way to issues relating to his behaviour and how this impacted on her relationship with him and in meeting Tammy's needs. Later her hope was that, through support in the pre-school, he would enter mainstream education with Tammy because *"it's nice for him that they'll be able to go together"* (Int4:520-521).

Reviewing and summarising each narrative enabled me to share the 'nomadic' quality of identity which offers regular opportunities for transformation (Braidotti, 2003). In reality, I realised that this process happens more regularly than in the phases described above, as each time I entered the home small changes had occurred and as I left each encounter, I realised that the interaction had altered my views (as shown in Appendix 6). In acknowledging this I saw that a transaction had

occurred, which drew me to the tentative conclusion that the transactional model (Sameroff, 1987) had more to show me. To conclude this chapter, I turn to discuss this further.

### **5.7 Applying the transactional model to the narratives**

The literature review contains research which explained how the transactional model is defined and applied in practice. Within the transactional model Sameroff and Fiese (2000) identify three factors which can affect change in the parent-infant interaction. These are all shown above and include remediation, redefinition and re-education. When I related this model to the relationship between the parent and the professional, redefinition offered a way forward. Each parent-participant's story contained records of how single events shaped how they viewed themselves, enabling me to pinpoint examples of critical incidents (Simons, 1980) shared above. These arose from interactions between the parent and a source of support and apparently set up a chain of expectations. By revisiting my own brief encounters with the unnamed mother, David, Beth and John in the vignettes which introduced this study, I was able to see how definitions have an impact.

The encounters shared in the vignettes had led to particular reactions, interpretations and definitions. The emotional outpouring of the mother who had just been given the diagnosis of her child's Down syndrome prompted sadness and pity, defining her as helpless and perplexed, influenced by my experience of looking after David. When caring for David, the response I thought I saw in other adults meant I defined myself and those who care for a disabled child as outsiders. Beth's story of struggles, fighting for support in a world of scarce resources and campaigning for the rights of other parents in her position, left me defining her as a 'saint for coping', something Morgan (2006) and Murray (2000) describe as frustrating and unhelpful. I had defined John as choosing to ignore his child, concluding that becoming involved with his son was a step too far. I now wondered if his reactions could be linked to Rix (2008), who had felt guilty about his son's disability. These reflections enabled me to see the transactional model in practice, as I had used my personal assumptions to define and shape other people as Sameroff and Fiese (2000) describe in parent-infant relationships.

Each parent-participant in this study assumed an identity when meeting with me, leading to a definition that shaped their interpretations, influencing my responses. Applying an ethnographic case study approach meant that I aimed to meet each in their own space and discovered new ways to understand myself as a researcher and practitioner. The parent-participants' narratives showed that experiences of assumptions and judgements lead to definitions and that in the future I would be in a better position to challenge these in myself. Writing detailed fieldnotes and meeting the parents at two different moments in their lives, a year apart, I observed the role of continual transformation and change; Roets *et al.* (2008:6) discuss this as part of a nomadic existence which leads to 'complex and multi-layered identities'. I recognised myself in this, a nomad travelling with the parents and finding new things about my identity.

One outcome of applying the transactional model is to alter definitions in each party and I saw that when this is realised in practice, the expectations of both professionals and parents become exposed. This offers the potential to empower parents and celebrate difference. My reflections on definitions showed me that 'continuous dynamic interactions' (Sameroff, 1991:173), can shape relationship. This meant that my research had implications for policy and practice which was my rationale for selecting an ethnographic approach. As Geertz (1988) had promised through taking an interest in people, places and things that interest us, we are given ideas, views and images for debate and scrutiny. This debate and scrutiny is pertinent to current policy as the government strives to find ways for 'parents to feel well supported from the start' (DfE, 2011b:42).

The literature and an iterative approach to the data analysis revealed the role of my own values and beliefs, integral in partnership, which Dale (1996) maintains as important to differentiate as different to those of the family. I could see how the transactional model could enrich partnership moving closer to 'a full sharing of knowledge, skills and experiences [recognising] how much they have in common and how much they have to learn from one another', as recommended by Mittler and Mittler (1983:10). Sameroff (1991) suggests the application of 'attunement', (Stern, 1984)

aiming to connect with the other person subjectively, which could lead to a meaningful response enabling the parent to select targets that match their culture. When this happens the relationship becomes dynamic and bidirectional setting up what Combs-Ronto *et al.* (2009) describe as patterns of behaviour. This illustrates how the transactional model can be instrumental in influencing definitions. I could see how this process invites the parent and professional to become active partners, which Nind and Powell (2000) propose supports reciprocity.

### **5.7.1 Transactions that had a positive impact**

Each narrative contained examples of how the parent had defined her/himself positively. This was evident in the practice of professionals who listened and enabled the parent to view themselves as effective, illustrated in Mittler's (1996) evaluation of Portage.

As Barbara, Alfred and Ruby shared their joy and pride in their child (*"for a child with Down's he's doing brilliantly well"* (B-Int3:281), *"amazed to see the progress of how Amber's doing"* (Alfred-Int1:250-251), Reece coming on in *"leaps and bounds"* (Int2:199&Int3:356)), they showed how professionals created the feedback loops identified by Spano *et al.* (2009) and Bricout *et al.* (2004), which had led to positive definitions for the parents. Sameroff and Fiese (2000) explain that altering definitions becomes influential to both parties, showing how parents changing their opinion of the child led to the child altering in a positive way. In my study parent-participants defined some professionals positively and as a result gained more from the support. As a professional I learned that I could apply the feedback process in my role, an indication that this research had changed my thinking and practice.

Barbara and Tasmin illustrated how professionals' positive definitions arise from the bidirectional relationships described by Combs-Ronto *et al.* (2009). Barbara's *"health visitors were fab and came over all the time, came to visit the house and were brilliant, absolutely fab"* (Int2:233-235), later phoning every six months, providing *"just that little bit of sort of extraneous."* (Int2:249). The health visitor provided Tasmin with emotional support, an important feature as she had *"quite bad (um) post-natal depression"*

(Int1:109). In my own practice I saw how regular personal interest tailored to respond to individual needs, could make a difference.

When continuity of support exists, trust builds so that Tasmin could talk to her Home-Start volunteer about *"Tony and how difficult I find, you know, find him"* (Int2:418-419). Barbara told her Portage worker that Bernard bit his key carer and *"burst into tears in front of her"* (Int3:519-520). These parents showed me that trust and caring for them during the research had led to them sharing these intimate details and that I could extend this to further my practice in future. This illustrated the proposal of King *et al.* (2006) that both parties become contingent in making support effective. This was made possible when I applied 'attunement' (Stern, 1984) to my encounters with the parent-participants.

Tasmin showed me the importance of giving a parent *"some practical things to do"* (Int1:408); Barbara taught me that responses can transform, saying that her connection with DownsEd, had *"totally kind of changed how I view what Bernard is capable of, because their advice is so down to earth, it's not patronising these aren't special children, they're children"* (Int4:524-527). I learned that my response and definitions could mean that support dissipates doubt and uncertainty (Woodward, 2000), adding to the quality of partnership embedded in policy commitments (DfES, 2005).

Listening to Barbara, Ruby, Andrea and Alfred, helped me to see the importance of being able to share concerns with a professional, altering personal identity which as Major *et al.* (2003) show, empowers the individual when facing challenges. After Ruby challenged the pre-school asking for feedback and support for Reece, she found *"the way they talk to me is, is fine and it's all sort of well understood"* (Int2:472-473). Barbara gave herself *"a little secret pat on the back"* (Int3:279) because she shared her reservations about Bernard being compared to a typically developing child with the speech and language therapist. I came to see that by encouraging openness and honesty, negative definitions from either party were not inevitable. Reflection challenged my previous reactions to avoid inviting concerns about practice in case the parents blamed me, a similar

reticence shown by the pre-school staff in Clough and Nutbrown's (2005) study.

The parent-participants showed me that like them I compare myself to others in a quest for a positive definition. Andrea was proud to tell me that she knew more than Alfred, who also defined her positively saying that she was *"the main one to deal with the support"* (FN:2), *"my wife does most of it ... in fact my wife (err) knows all the names and everything else"* (Int1:89-90,96,167-168). As Catherine compared herself to other young mums saying *"most people of my age aren't maybe as capable or as like I am, I was quite mature for my age and that sort of thing"* (Int1:28-31) and being *"quite sort of independent and stand on my own two feet"* (Int2:344) from an early age, I noticed how her words jarred because they were challenging the way I compare myself, perhaps to improve my confidence. This was a point of honesty which was difficult to confront and yet necessary if I was to embrace my learning from this journey.

Sameroff and Fiese (2000) identify the role of education as one of the environmental factors which influence how the individual views the world and their transactions within it. The stories of Barbara, Catherine, Tasmin, Alfred and Andrea showed how education could be used to define an individual positively. When Barbara was asked to review a piece of research and comment on whether *"as a teacher, could you do it in your classroom?"* (Int4:447-448) she felt pleased and proud. As Catherine described friends *"off at university"* (Int1:119) and doing an *'open university course'* (FN:2) she communicated an image of intellect. Tasmin shared her experiences of research having completed a higher degree (FN:2). Andrea explained that having a law degree would mean she could become a barrister or a judge, (FN:7). Alfred regarded improving his education as a positive way forward saying, *"I wanna learn more and get more A'levels and GCSEs, everything"* (Int2:170-171). As they shared this part of their story, I entered their world, noticing the impact of my secondary modern school background and how I could use qualifications as part of the transactional model, either separating myself from parents, or identifying with them more closely.

Reviewing my practice, I realised that the recommendation of Cudré-Mauroux (2010) to care for yourself had an important role when caring for children with learning disabilities and in defining yourself positively. I encouraged parents to share their examples and Barbara told me she prioritised having *"time to myself, I get time to be me again"* (Int1:327), using Facebook, *"just for me"* (Int2:90) and going to a concert with a friend (O:12), while Ruby also spent time with friends (FN:13). Andrea was looking forward to going out with friends to celebrate her birthday (O:6). Both Tasmin and Alfred described the role of work, Alfred proud to be *"an ex-paramedic, so I can do things myself"* (Int2:48-49), and then getting work as *"a long distance lorry driver"* (Int4:26). Tasmin's work meant *"three days where I kind of go and do, normal conversations with people ... which has helped quite a lot ... it gives me a bit more breathing space"* (Int4:359-363). Catherine was able to *"completely sort of relax"* (Int3:254) when her Mum had Courtney for the night. Beresford *et al's.* (2007) research reinforces the importance of parents having time and space and I could see how this provided the opportunity to assume more than one identity and return to the child with a new perspective. To support them, short breaks and direct payments are recommended in policy and research (Arksey and Baxter, 2011; Blyth and Gardner, 2007; DfE, 2011b; DfES, 2007b). By applying the principles to myself I found that a break from work and study provided space to re-listen to parents' experiences, which informed both my writing and practice in a positive way.

Through reviewing my learning journey I recognised how definitions may have been influenced. Although Ruby and Tasmin felt more confident about their children attending mainstream school and Barbara looked forward to being a *'normal family'* (FN:20) I saw elements of pressure to fit in with society rather than celebrate difference. As Sameroff and Fiese (2000) contend, the culture at large inevitably has an impact on how we define ourselves. Yet I was uncomfortable with the notion identified by Culham and Nind (2003), that there continues to be pressure to conform or become invisible. I saw how the benefits of using the transactional model had transformed my views, which meant that it had the potential to do the same for others.

### 5.7.2 Transactions that had a negative impact

Parents provided examples of when they defined themselves and professionals in negative terms. Although Sameroff and Fiese (2000:136) were clear that 'no single factor is damaging or facilitating', these encounters seemed worthy of scrutiny to gather a deeper understanding of how the transactional model could be applied in the future. This would then have the potential to inform practice and policy, also showing the contribution of applying ethnographic and narrative methods to this research.

Although Barbara did not blame professionals for the fact that she failed to share her opinions, it left her *"feeling not very confident, then I'd come out feeling even worse but that's kind of me feeling not confident"* (Int2:253-255). Catherine also aimed to share her views but *"would sort of try and try to intervene but as I'm not a professional, you know, I wasn't sort of listened to as much as I feel I should have been"* (Int1:252-253). This accentuated the dilemma of how parents define the professional as superior, leaving them thinking that their point of view is less valid. It opened the debate as to how an approach informed by the transactional model could enable concerns to be released and confronted.

I recognised the impact of critical incidents as Barbara shared her experience of completing Bernard's statement of educational need finding it *"quite upsetting, again just because you're focusing on things he can't do ... a bit of a cloud, a bit of six weeks of horribleness"* (Int4:113-114&122-123). Through this she had shared her unique perspective. My research approach had helped me connect with her feelings, to consider this first-hand rather than situating myself as the researcher on the outside. In practice I would need to do the same, acknowledging a variety of approaches and impacts according to the individual, realising the difference for me or for Andrea if she was completing a statement for Amber.

I witnessed the complexities and discomfort that change and new identities prompt: Barbara, questioning her role as Bernard starts school, asked would it be *"teacher mum, special needs mum, normal mum"* (Int4:234,326,331)? She explored feelings of powerlessness, no longer able

to influence professionals, not *“able to add something in”* (Int4:613). I became entangled in her feelings as a parent of my boys, realising the difference due to their independence and smooth transitions. To provide support I needed to see the world through her eyes.

Just as Sameroff and Fiese (2000) contend, many factors impinge on the life and identity of the parent. Andrea illuminated this when sharing experiences of violence and bullying (FN:7&8) in her childhood. The remnants left her afraid when she was out and feeling intimidated by men (FN:10). This seemed to affect her interactions and interpretations, so that the report to social services which prompted an investigation, left her feeling like a criminal (FN:13). She likened their approach to bringing in *“the heavy machinery in sort of, you know? Made us feel very uncomfortable”* (Int3:227-228). This experience left Andrea resigned to the definition of ‘bad parent’, reinforced by the feeling that *“a lot of people seem to tell us what to do”* (Int2:121). She agreed to meet their requirements in order to keep the children (FN:21). I was shocked and saddened that she saw herself as worthless with *“no opinion really, none that matter”* (Int4:241). Woolfson (2004) used the transactional model to explain the impact of parents’ negative expectations of their child. This research showed me how it could also happen in a parent and professional interaction. Had I failed to listen to Andrea’s story and to review it in this context, I would have missed finding this out, leaving me, the professional and research community the poorer.

When I observed Andrea with the lead professional she showed me how views change within a conversation (see Appendix 5). Starting by giving positive examples, her position altered and her problems tumbled out; her daughter Amber was rough, had tried to strangle her and there was a lack of money to pay for carpets and school shoes for Amber (O:4&6). Although well intentioned the advice provided could also have represented *“imposing your ideas on someone who may not be as receptive or who has tried it out”* (Int2:153-156), something Andrea claimed she did not want. This behaviour was pertinent to my role and the process of reflection enabled me to see how it had defined the parent negatively. I could see how by using the transactional model and challenging my definitions, this approach

could lead to a different outcome. This is because transaction would enable me to review and substantiate the parent's expectations and the root of concerns, through asking questions in a different way and reviewing the answers from their perspective rather than my own.

Alfred shared concerns about negative transactions where neighbours sent abusive text messages (FN:2) and made *"nasty remarks"* (O:5). His frustration of not being listened to was clear, repeated five times in interview two (Int2:10,47,51,53,57) and a further three times in interview three (Int3:142,145,153). Analysis of his case study provided a rationale for applying an ethnographic lens and narrative because I was able to see how one behaviour can set up a pattern for another behaviour. When this is identified it could be altered (Llewellyn and Hogan, 2000). This became evident in the final interview where he claimed that professionals had changed and no longer talk *"over me or around me, they will talk directly to me on the phone"* (Int4:200-201).

Professionals' approach to Catherine led to a gulf between them, leaving her feeling *"bulldozed down one track"* (Int1:61), which became a *"hindrance"* (Int1:37). When there were no improvements, Catherine concluded that the nursery nurse didn't have *"quite the right skills to help us"* (Int1:89-90). Her experiences with professionals led to the conclusion that, *"although you've got a problem child, you've also got a problem too and they're not supporting you ... no one really ever asked me how I felt or how my partner felt or anything else, so it was really tough for us"* (Int1:163-165&169-171). She thought that professionals didn't *"appreciate quite how sort of stressful and upsetting it was"* (Int3:63-64). The transactions, in which the professional had defined Catherine as helpless because of her age, had left her feeling alone, misunderstood, angry and frightened. I could see how easy it is to focus on the problem and solution without exploring the background influences; importantly, this ethnographic case study gave each parent the opportunity to share experiences and expose this failing. I needed to embrace this in my practice in the future. I heard the excuses about lack of time, recognising that this approach would in fact save time because it was tailored to the family as recommended by McGuffin (2002).

Tasmin shared the practical, intellectual and emotional impact of support she regarded as *"bitty" and "not joined up"* (FN:4). Without the benefit of preparation ahead of the twins' birth, she felt vulnerable and misunderstood by professionals and those around her (F.N:6). Her rationale for negative feelings revealed a barrage of problems; *"I had post natal depression, I just felt I couldn't cope"* (Int1:192-193). She described being *"kind of sleep deprived"* (Int:134-135), how travelling to different hospitals *"kind of tipped me over the edge really"* (Int1:138), leaving her feeling that the whole experience was *'horrendous'* (FN:7). This explained how difficult, messy and uncomfortable it is to enter the world of the parent where there are many layers of need (McGuffin, 2002) and showed that professionals had uncovered these with Tasmin.

Anger and frustration escalated because Tasmin regularly encountered the explanation he's *"a bit of a boy"* (Int1:29), *"Oh well you know he is a boy?"* (Int2:569-570), *"Oh well yes he's a boy and that's what boys are like"* (Int4:464-465). Her interviews exposed inner dialogue, questioning her judgement and then deciding she was correct, but concluding that in the absence of an obvious diagnosis, professionals perhaps thought that she was exaggerating Tony's difficult behaviour (FN:19). She wanted professionals to listen *"in an accepting way and accept that what I am saying is how I feel it is, rather than you know tries to brush it off really"* (Int3:65-67). This study has taken me to a new level of listening and reviewing my well-intentioned responses to reassure parents and helped me to see the impact of our transactions.

#### **5.7.5 Conclusion**

The literature describing the transactional model identifies the complexity of defining and redefining relationships and shows that each party influences the other. The data brings this to life as these parents' stories expose the context of interaction which shapes the outcome (Sameroff and Fiese, 2000). This is relevant because the parent-participants' stories portrayed unique factors, such as the individual's social context. Bruner (1986) proposes that social realities are situated, negotiated and distributed, which means that knowledge of transaction can be applied in relationships

between professionals and parents. This influenced my understanding of the commitments in the government policies (DCSF, 2007b; DCSF, 2008; DfE, 2011b; DfES, 2006; DfES, 2007a) and provided a new practical context in which to apply them. The research provides practitioners such as myself with a guide to supporting positive definitions by applying Stern's (1984) 'attunement' - tuning into values, views and beliefs. The stories of Barbara and Andrea with their Portage worker and Tasmin with the Home-Start volunteer, showed that when an ethical framework, also applied in this research, is included as part of an approach informed by the transactional model, positive outcomes can emerge (Makau and Arnett, 1997).

The literature explains factors that influence how people define themselves, for example Llewellyn and Hogan (2000) identify the attitude of those in authority, while Major *et al.* (2003) claim the significance of self-concept and Cudré-Mauroux (2010) lists well-being, opportunities to achieve goals, and accessibility to appropriate resources. These, alongside the opportunity for parents to provide and receive feedback, could influence definitions positively (Woodward, 2000). When this leads to the multiple feedback loops that Bricout *et al.* (2004) describe, the active participation that Nind and Powell (2000) recommend means that both parties influence the relationship. Had feedback and an in-depth approach to identifying support shown in the research by Crnic and Greenberg (1987) and Spano *et al.* (2009) been applied, it may have avoided Catherine, Andrea, Alfred and Tasmin feeling stranded and misunderstood.

The narratives arising from the ethnographic case studies highlighted the dynamic, differentiated, multiple and changing entities that are situated and shifting in the context of support. This means that applying the transactional model can be messy and uncomfortable, requiring effort to identify with each individual as unique, in space and time, something I aimed to do by sharing parents' stories. Eisenhart (2001) argues that this can appear as a muddle and in my search for continuity there were many times when I was faced with the chaos of real life. However this became a moment of revelation for me, because I understood very tangibly that life was not neat and tidy and could not be controlled. The multiple encounters

with parent-participants showed me that our identity is 'nomadic [which] means you learn to reinvent yourself and you desire the self as a process of transformation' (Braidotti, 2003:53). As Brienens (2004) maintains, we continually shape the world and adapt according to the influences of that world. In the context of the transactional model both the professional and the parent have an influence on definitions. To apply the model successfully, complexity and change need to be embraced (Sameroff and Fiese, 2000). This involves 'looking for the ways in which otherness prompts, mobilizes and allows for the affirmation of what is not contained in the present conditions' (Braidotti, 2008:19), with the potential to make support a positive experience. It offers the opportunity to:

[draw] energy from the thinkability of the future [which] means that our desires are sustainable to the extent that they engender the conditions of possibility for the future. In order to get there, a nomadic subject position of flow and multi-layeredness is a major facilitator' (Braidotti, 2006:207).

This point reinforces the argument of Sameroff and Fiese (2000), that the most cost-effective approach to support is to target 'a specific child in a specific family in a specific social context' (p149). Although, demanding and challenging, the outcome opens the possibilities emphasised in Barbara's definition of support, *"the difference between having a good and a bad day, included and accepted and actually feeling isolated and abnormal"* (Int2:460-464).



## CHAPTER 6: CONCLUSION

This thesis tells of an iterative journey to explore, report and analyse parents' experiences of support when they have a young child with a learning disability. Conducting the research became a journey of self-discovery, informing my role at work and as a researcher. I began my journey unconsciously revealing my assumptions about learning disability through vignettes. Later, looking back I realised that these had an impact on the way I conceived the study (Clough and Barton, 1995) and became a starting point from which to transform my attitude and practice.

Each parent-participant presented a unique case study and through applying an ethnographic approach I found what Cohen *et al.* (2007:254) maintain, that each spoke for themselves rather than being 'largely interpreted, evaluated or judged by the researcher'. Their experiences became the narratives which enabled me to view the impact of support differently. Each story became precious because, as Flanagan (1949) explains, it may be that a single event sheds hugely important insights into understanding the issues that parents face and therefore becomes a critical incident. I wanted the reader to join me in listening to how these critical incidents had been woven into each parent's story inviting a way forward in the future.

The ethnographic approach supported my desire to make a personal connection with the parent-participants' experiences. Through the lens of making 'sense of the chaos of experience' (Clough, 1995:79), I found that 'the truth must dazzle gradually or every man be blind' (Dickinson, 1975:1129). This became a revelation, as I realised that the relevance of a transactional model had been waiting to be discovered from the beginning of this study, but would have blinded me had I noticed it too soon. Instead it crept up on me, gradually whispering its presence in my ear, giving me time to see how it could inform a working model of good practice in the future. As I reflected on the transactions that had taken place during my meetings with the parents, I realised that these had led to me exploring their experiences at a deeper level than I imagined possible. By entering into the world of the parent-participant in the way that I had, I believed

that other readers would, like me, 'move between the lines of my hesitant ideas, opinions, and viewpoints and there create their own' (Nouwen, 1976:158), with the parent at the centre.

Reflecting on the transactional model in the light of my data showed me how interactions lead to learning and could alter perceptions and definitions. As I considered this I was shocked by the number of parallels between my experiences and those of the parent-participants. The strange had become familiar. I began my journey expecting to find a particular result, just as the parents had when preparing for the arrival of their children. As I entered the world of research, I quickly became submerged in the quantity of information in the literature, on the subject of disability and later relating to methodology. Like Barbara and Andrea this was overwhelming, and for me, felt at times as though I was drowning. I saw the parallel with Andrea's feelings that her questions were not being answered and later as they were, the same lifebelt that information provided, as described by Barbara in her interactions with DownsEd.

When I explored definitions, they revealed our commonality in our hesitancy of whom and how to approach. Like me, parents' previous life experiences led to varying levels of confidence and competence. I found that when I felt confident in my role as a professional, a parent may find this intimidating. When I had to face the academic audience I recognised feelings of inadequacy, questioning my right to offer an opinion on how to conduct research. To share my findings meant exposing myself and others to the flaws I may and may not have noticed. Parents seemed to have had similar questions, feeling exposed when asked about their parenting and reluctant to challenge for fear of being judged incompetent or flawed.

As I re-listened to their stories about their background, I saw the influence of education and expectation. I knew my own embarrassment at failing my eleven plus and going to a secondary modern school, later turned comprehensive, later termed a failing school. Like the parents in this research I used my qualifications as a prop, something to pin a positive definition on and like Alfred and Ruby I wanted to do more, which had spurred me on to challenge myself at this level of study. My thoughts about

my education had become transformed from a source of shame and burden to a point of connection and understanding. I felt that I no longer had to apologise for the humble beginning that had been a gift to this study. However like the parent-participant, feelings fluctuate and even as I write this today I know that depending on the response that I have to this research and how I am feeling (defining) myself on a particular day, I may judge myself differently.

This research project became a part of my life - an extension of myself - something important and deeply significant. In this I recognised a comparison with the parents and their child; like them I was driven to learn and develop and to make a difference. My relationship dipped and soared as each parent's story was told and yet in the end they were as proud of their child as I am of this work. The fact that Andrea had added Amber to her list of support provided me with new meaning to the relationship. Like the parent-participants, I emerged from these four years of intense study a different person, transformed in my thinking and I would like to think in my behaviour. I was grateful that, like the parent-participants, I had never reached a point of either hating my work (in their case their child), or wanting to abandon it, but like them I had experienced many challenges along the way.

This journey terminates with the intention it began with, a change in my practice. I realised that I could use my knowledge to approach a parent differently, moving to their position rather than focusing on them as a problem to be solved. I now see this as essential to practice because, as Barbara told me, when professionals don't understand *"it is much more upsetting than you can imagine"* (B-FN:9). By altering my listening technique and entering their world, my intention to apply partnership with parents would be on their terms. My style of questioning would change from "what is the problem?" to "can you tell me more about the impact that this is having on you?"; from "have you tried?" to "what do you think would happen if you did this?"; from advising parents of areas of support, to finding out what sources of support they have and enabling this information to shape other ideas with them. I believe that changing my approach would alter the definitions that parents apply to themselves, empowering them to

own the solutions as recommended by the government (DfE, 2011b). My position would alter from being out in front, to alongside them, conscious of their values and priorities.

When I reflected on the role of the transactional model as a thinking tool in my research, I could see how my interactions with my supervisor and discussing my methodology with other students had altered my views and definitions. I entered the process believing that I already knew the problems that parents faced and that, were I to select the 'right' methods, I could prove this. The interactions that arose from applying an ethnographic approach showed me something different. I became aware of feelings of insecurity, searching for a definitive answer. Finally learning that this was the point, the more I clung to finding a final solution the weaker my research became. This was not about me controlling the data but instead the data becoming my teacher, a transaction that I had not expected or prepared for. I gradually grew in confidence to realise that by letting go of control, I could acknowledge the pitfalls of what I had done and move away from this research with a clear message that ethnographic case study, which adopts a participatory approach, will not provide a single solution but will provide insights that are unique and informative in a way that could transform.

The transactional model was not devised by me, it had already been applied in the parent-infant relationship (Sameroff and Fiese, 2000) and I offer it without the intention of describing it as something which will perfect every interaction between a professional and parent. This is not how it works between the parent and child, the outcomes may be aiding 'in general child development at one end and inhibiting it at the other' (Sameroff and Fiese, 2000:141). Therefore to claim a predictable outcome would be nonsense. However, as Gulson and Parkes (2010) and Sikes (2006) maintain, theory does work as an interpretive device to understand things better. This positive intention had the potential identified by Bricout *et al.* (2004) to alter behavioural patterns through providing positive feedback loops. In a similar way research could be influenced by applying the transactional model because it reminds the researcher that 'there is not one explanation for behaviour ... that people can and do modify, select, reconstruct and

even create their environments' (Llewellyn and Hogan, 2000:162), which is both a strength and weakness of what we conclude from interacting with our participants.

The strength of this research was that the parents who participated were prepared to share intimate details of their experiences of not only support but their reactions and feelings in relation to it. This occurred partly through my choice of methods, but also because of the bond of trust that I built with them, which Makau and Arnett (1997) contend is essential within the transactional model. Entering into a contract, which involved sharing my interpretations and inviting the parents to reflect on what they had said and its meaning, led to making sense of experiences through reviewing them, a way forward in understanding proposed by Keirkegaard (Westphal, 1996). The opportunity to re-visit homes a year after my first three recorded interviews, illustrated how definitions and perceptions alter over time, emphasising change, suggesting the role of nomadic paths of reflection and practice in our lives (Braidotti, 2006). Adopting a variety of methods, interviewing, fieldnotes and observations provided an opportunity for triangulation enabling me to view the data from different positions and to challenge my assumptions and interpretations. As these became exposed, so they were shared in the writing up following the advice of Silverman (2004), to make my position transparent. This went further than following a correct procedure for qualitative research and became an essential ingredient in my learning journey.

As I look back on this research its limitations also stand out. The study population is small and predominantly made up of mothers. Although more difficult to achieve, gathering the experiences of more fathers would have enabled me to compare the role of definitions, in a way offered by the five mothers. I imagine it would have revealed the same unique perspectives that they shared and would have been interesting to review. I was fortunate to be able to recruit parent-participants from different social and educational backgrounds, which, although not fundamental to the research design, offered the opportunity to see how previous experiences and social and economic conditions impact on interactions. However, these are only two aspects of what Sameroff and Fiese (2000:141) refer to as the 'broad

constellation of ecological factors'. To extend an understanding of these, parents from a diversity of ethnic background could have been included.

Within my exploration of literature I described how my attitude to disability had altered and that I had felt inspired by the 'affirmation model' (Swain and French, 2000). I had hoped to find out more about how the disability itself carried value as proposed by Abberley (1987) and reject negative stereotypes as recommended by Goodley and Roets (2008). However the findings of this research fell short of exposing this clearly, as although Barbara, Alfred and Andrea's positive view of their child encompassed their disability, the qualities brought about by Down syndrome and autism were less obvious. In the case of Ruby and Catherine they were keen to discard and move away from any visible impairment and Tasmin communicated the need to understand Tony's learning disability to manage, even control him. At the conclusion of the study she offered no indication of his differences having any worth in their own right. While this points to the recommendation for further research, I understood the paradox between wanting to give the disability a positive identity and inviting a stereotypical view of a particular condition.

Owing to time constraints for me and the complexity of the parent-participants' lives, I limited the number of interactions to four meetings, (3, recorded interviews) in the case of Ruby and Catherine and six (5, recorded) for Alfred, Andrea, Barbara and Tasmin. With more time and support, including a small research team I could have viewed perspectives from a greater variety of positions and possibly arranged to meet with the parent-participants on more occasions over a longer time span.

Comparisons are difficult and propositions limited because each child was at a different stage in their early education, which meant that the content of the stories are recollections shared at different times in each parent's journey. In the examples parents chose to share, the transactional model was not consistently visible, which highlighted the role of inconsistency. This was challenging, yet integral to understanding each interaction. As this research had highlighted the role of change, I knew that were I to return and ask the same questions to each parent in three years time, their

perspectives on the experiences that they shared with me would be different and once again I would need to tune into where they are at the time.

As in all research, the findings of this study leave questions that are unanswered and therefore prompt further exploration. A cross-case analysis could be undertaken to explore more about the factors that had led to the responses of each parent-participant. This has the potential to define the influences of transaction in more detail. Creating a focus group would stimulate conversation between parents and gather other perspectives. By delving deeper, as advised by Crnic and Greenberg (1987:357), exploration would offer the opportunity to 'assess both behavioural interactions of the family system and the perceptions of other family members [and professionals] to clarify these potentially related explanations'. This would involve meeting professionals and extended family to unpack the role of transaction more thoroughly.

This thesis speaks to two audiences: the professionals working with parents for whom I hope the research will influence practice, and the academic community. In the case of the former, it invites the application of the transactional model to enrich relationships of partnership, empowering the parent and making the support options better tailored to their needs; something which has the potential to make the investment in funds more cost-effective. It speaks to the academic community to say that whenever qualitative data is acquired in the ways used in this study, it is challenging and reveals not only information for the audience but also for ourselves. Each encounter with the participant becomes an example of the transactional model, through the assumptions that the researcher takes into the encounter. Ruby described her experience of accessing support as a "rollercoaster journey" (Evaluation:1), a phrase which resonates with my engagement in this research. In undertaking this work, I found unique insights into a subject which the literature shows has been lost and found many times. The lasting legacy lies with the parents who generously agreed to explore their experiences of support and helped me to redefine my role in the support I will give to families in the future.



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## APPENDICIES

### Appendix 1

#### **EP1 addendum: Protocol Gina Sherwood**

#### **Exploring families' experiences of support when they have a young child with a learning difficulty**

I seek approval by the University of Southampton, School of Education Research Ethics Committee and sponsorship by the university via the Research Governance Office to carry out the first exploratory phase of the fieldwork for this research project. Further ethical approval will be sought before commencement of the second phase.

The nature of the study and what it entails will be outlined in writing to all participants (see attached Participant Information Sheet: PIS). This information will also be discussed with the participants verbally and on more than one occasion. Potential participants will be encouraged to make suggestions about how and where the research is carried out and to ask questions about the role of the researcher and the possible impact of the research to themselves and to the wider community. The aim of this discussion is to help to address difference in power between the researcher and the participant. Information for participants will include: what the study is about; why they have been invited to participate; what will happen and when; who the study might help and how; any potential risks; who will see the data, what it will be used for and how it will be protected; right to withdraw and process for doing so; where to get more information; and who to go to if they are unhappy at any time. Potential participants will be encouraged by the researcher to identify additional resources should they need support during the process.

Potential participants who are the caregiver of a young child with a learning difficulty will be identified via personnel in the Children's Centre who know the individuals sufficiently to judge their possible agreement to discuss their experiences and benefit from participating in the research. Prior to the first meeting the potential participant will have had the opportunity to read the PIS and discuss the research with a member of the Children's Centre staff. At the initial meeting the researcher will discuss the PIS and its contents with them in the presence of the family support worker from the Children's Centre. A follow-up meeting will be arranged to allow time to reflect on what they understand of the role of the participant and make a decision as to whether they want to take part in the research. At the next meeting consent will be made through the participant recording their initials next to each statement on the consent form (see attached). Agreement to participate will be viewed as provisional consent, where consent is provisional upon the research being conducted within the outlined framework and continuing to develop within participant expectations. In addition to working within BERA and ESRC guidelines and Data Protection Act, my ethical duty to participants will be met through dialogue with the individuals and monitoring of impact on participants of involvement in the study.

Participants will hopefully benefit from involvement by developing greater self-awareness and understanding of their experiences of support, and through

reflection see themselves differently as a consequence of their participation, particularly from developing knowledge of the impact that services have on them and their family. Where this results in different but positive treatment of them by others, such as professionals, friends and family who provide support, further benefits may accrue. The researcher will be alert, however, to any less beneficial versions of this dynamic beginning to happen and respond, in the moment and in reflection, to minimise any potential detrimental effect. Where participants become attuned to any barriers to accessing support the researcher will respond by directing them to information and resources that may help them to overcome the difficulties they have identified.

The research will be conducted by Gina Sherwood who has worked with families for 18 years and supported by Melanie Nind who is very experienced in working with families where a child has a learning difficulty. Where necessary the supervisor will direct the researcher to others who are experienced in methods of participatory research including the importance of adhering to the ethics protocol.

In all reporting the research participants, networks and settings will be anonymised, through use of pseudonyms and additional devices, such as disguising the family, location or context. In the event of participants wanting to be named, this would be discouraged and the reasons explained. Care will be taken with audio data, limiting access only to the researcher and participant. The transcripts from each interview, recording what has been said verbatim will be anonymised. The content of field notes will be shared with the participants. In all cases the opportunity to amend, add and delete will be offered, so that the content represents an accurate portrayal of their views as they see them. Should I wish to share any specific section of the audio recording with anyone else I will seek informed consent on a case-by-case basis.

Data will be stored in locked facilities at the researcher's home and all electronic data will be password protected. The administrative database and the research database will be stored separately. The duration of keeping the data will be in line with the university data policy.

The outcomes of the research will be reported to participants via a written report supported with the opportunity to discuss the findings with the researcher in person.

One of the aims of the research is to contribute to methodological knowledge regarding participatory research methods. The researcher will be focused on exploring innovative aspects of the research for the second phase of the fieldwork and any associated ethical challenges, and will be reporting on these to, the participants and the research community.

## Ethical Protocol Guidance

### A ETHICS PROTOCOL GUIDANCE FORM

This guidance has been developed to assist you in drawing up an ethics protocol for a research project or bid for research funding. You are advised to also look at the following materials provided by the School of Education Research Ethics Committee, which are available on the School of Education Website:

- Student/Staff Research: Ethics Review Checklist
- Ethics Review Procedure Flow Diagram
- Ethics Reading List

The Revised Ethical Guidelines for Educational Research (2004) published by the British Educational Research Association are also useful (available on their website at <http://www.bera.ac.uk/publications/guides.php>).

**Title of Project:**

***Exploring families' experiences of support when they have a young child with a learning difficulty?***

**Name of PI/Student: Gina Sherwood**

**Student ID no: 222411402**

#### A. CHECKLIST

<b>HAVE YOU THOUGHT ABOUT HOW YOU WILL ADDRESS:</b>	<b>YES</b>	<b>NO</b>
1. your responsibilities to the <b>participants</b>	X	
2. your responsibilities to the <b>sponsors</b> of the research	X	
3. your responsibilities to the community of <b>educational researchers</b>	X	

<b>HAVE YOU CONSIDERED HOW YOU WILL:</b>	<b>YES</b>	<b>NO</b>
4. fully inform participants about the nature of the research;	X	
5. ensure participants agree to take part freely and voluntarily;	X	
6. inform participants that they can withdraw freely at any time;	X	
7. justify deception of participants if this is necessarily involved;	X	
8. offer protection for any vulnerable participants or groups in your study;	X	
9. manage the differential 'power relationships' in the setting;	X	
10. avoid any pressure on participants to contribute under duress or against their free will;	X	
11. guarantee that any research assistants or support staff involved in the project understand and adhere to the ethical guidelines for the project;	X	

<b>HAVE YOU CONSIDERED:</b>	<b>YES</b>	<b>NO</b>
12. what procedures to set in place to ensure a balance between a participant's right to privacy and access to public knowledge;	X	
13. how best to provide anonymity and confidentiality and ensure participants are aware of these procedures?	X	
14. the implications of the Data Protection Act (1998) particularly in respect to the storage and availability of the data.	X	
15. disclosure of information to third parties and getting permission from the participants to use data in any reports/books/articles.	X	
16. how you are going to inform the participants of the outcomes of the research;	X	
17. how to handle any conflicts of interest arising from sponsorship of the research e.g. a chocolate company sponsoring research into child nutrition, or your own vested interests if any;	X	
18. how you will protect the integrity and reputation of educational research.	X	

## Ethical Protocol Guidance

### A ETHICS PROTOCOL GUIDANCE FORM

Having considered these questions draw up specific procedures for how you will handle the collection and dissemination of data in your research study.

### B. ETHICS PROTOCOL – Student ID no: 222411402

**Ethics Protocol** (Please provide details here of the ethics protocol for your research and append your Consent form and Participant Information sheet)

This information is in 2 separate attachments.

**There are aspects to research governance that are outside the remit of the Research Ethics Committee, but which you must address to ensure that you are insured for the research you are undertaking. Before beginning to research you should complete an IRGA form and forward it to the Programme Office (students) or Research Office (staff), together with your CH1/CH2, EP1, Consent form, Participant Information sheet and research proposal.**

### Student Research Project: Ethics Review Checklist - Form CH2-Student

This checklist should be completed by the researcher (with the advice of the research supervisor/tutor) for every research project which involves human participants. Before completing this form, please refer to the Ethical Guidelines in the School's Research Student Handbook and the British Educational Research Association guidelines (<http://www.bera.ac.uk/guidelines.html>).

#### Project Title:

Exploring families' experiences of support when they have a young child with a learning difficulty

**Student:** Gina Sherwood..... Email: [ginasherwood@sky.com](mailto:ginasherwood@sky.com)

**Supervisor:** .....Melanie Nind.....Email:..... M.A.Nind@soton.ac.uk.....

Part One	YES	NO
1. Does the study involve participants who are particularly vulnerable or unable to give informed consent? (e.g. children with special difficulties)		X
2. Will the study require the co-operation of an advocate for initial access to the groups or individuals? (e.g. children with disabilities; adults with a dementia)		X
3. Could the research induce psychological stress or anxiety, cause harm or have negative consequences for the participants (beyond the risks encountered in their normal life and activities)?	X	
4. Will deception of participants be necessary during the study? (e.g. covert observation of people)?		X
5. Will the study involve discussion of topics which the participants would find sensitive (e.g. sexual activity, drug use)?		X
6. Will the study involve prolonged or repetitive testing or physical testing? (e.g. long periods at VDU, use of sport equipment such as a treadmill) and will a health questionnaire be needed?		X
7. Will the research involve medical procedures? (e.g. are drugs, placebos or other substances to be administered to the participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?)		X
8. Will financial inducements (other than reasonable expenses or compensation for time) be offered to participants?		X
9. Will you be involving children under sixteen for whom additional consent will be required?		X
10. Will you have difficulties anonymising participants and/or ensuring the information they give is non-identifiable?		X
11. Will you have difficulty in explicitly communicating the right of participants to freely withdraw from the study at any time?		X
12. Will the study involve recruitment of patients or staff through the NHS?		X
13. If you are working in a cross-cultural setting will you need to gain additional knowledge about the setting to be able to be sensitive to particular issues in that culture ( e.g. sexuality, gender role, language use)?		X
14. Will you have difficulties complying with the Data Protection Act (e.g. not keeping unnecessary personal data and keeping any necessary data locked or password protected)?		X
15. Are there potential risks to your own health and safety in conducting this research (e.g. lone interviewing other than in public space)?	X	

If you have answered NO to all of the above questions and you have discussed this form with your supervisor and had it signed and dated, you may proceed to develop an ethics protocol with the assistance of the Ethical Protocol Guidance Form which must also be completed. If you have answered YES to any of the questions, please complete PART TWO of this form below and adopt a similar procedure of discussion with supervisor, signing and proceeding to develop an actual ethical protocol with the assistance of the Ethical Protocol Guidance Form. Please keep a copy of both forms and protocol for your records. Only in exceptional circumstances will cases need to be referred to the School's Research Ethics Committee.

**Part Two** For each item answered 'YES' please give a summary of the issue and action to be taken to address it.

- Addressing point 3 - Through describing their personal experiences the participants may become distressed as having a young child with a learning difficulty may directly or indirectly provoke strong emotions. Managing this will involve developing a positive relationship based on trust and sincerity. On each occasion I meet the parents I intend to ask an open question such as 'How are you feeling today?' with the aim of putting the participant at their ease. This will provide me with useful information about how to approach the remainder of the questions in a way that is sensitive to their well-being. Throughout my visit I will be tuning in to their emotions through observing their body language and thinking about the impact that the subject is having on their internal responses. As soon as I become aware of either outward or inward distress I will suggest that we take a break from the interview or discussion. When the person is composed we will decide whether to talk about the subject again and if they wish to continue, we will negotiate a strategy that is chosen by them. If they require further support I will refer them to the sources identified in the PIS and recorded on the Consent form.

This support means that I can show the participants that their welfare is paramount and matches the concern that I communicate in my current work with parents as a family learning tutor. I believe that my 18 years experience of teaching and providing one to one support will enable me to manage this process in a sensitive and respectful manner.

- Addressing point 15 - As I am likely to conduct interviews in the family home and on my own, I intend to gain advice from the family support worker who I will accompany on the first visit to the potential participant. On every visit I will carry a mobile phone and make sure that other designated people know my location and the agreed length of the meeting with the family. I will aim to park near to the house and carry my car keys in my pocket. When I am in the home I will make sure that I am sitting in a position which allows me free access to the exit. I will select families who are already visited by a member of the Children's Centre's family support team as an added indicator of safety. I will also have an exit strategy planned which includes an appropriate excuse if I need to leave in a hurry. I have 15 years experience of making visits to people's homes as an assessor for the National Childminding Association and through my role as a course tutor in child care when I worked in Further Education. I will therefore use knowledge gathered over this time to maintain my safety in practice.

Please continue on a separate sheet if necessary

Signed :  
(Researcher)

Date:

**To be completed by the Supervisor (PLEASE TICK ONE)**

- Appropriate action taken to maintain ethical standards - no further action necessary. **This project now has ethical approval.**
- The issues require the guidance of the School of Education's Ethics Committee. **This project does not yet have ethical approval.**

COMMENTS:

Signed (supervisor on behalf of SoE Research Ethics Committee):

Date:

**There are aspects to research governance that lie outside 'ethics', but which are important for you to consider. These include data protection, insurance, and health and safety issues. You should seek advice re same from your Supervisor in the first instance, and then if necessary from your Programme Director.**

Appendix 1

Mrs Georgina Sherwood  
School of Education  
University of Southampton  
University Road  
Highfield  
Southampton  
SO17 1BJ

RGO Ref: 6404

01 April 2009

Dear Mrs Sherwood

**Project Title Exploring Families Experiences of Support when they have a Young Child with a Learning Difficulty**

This is to confirm the University of Southampton is prepared to act as Research Sponsor for this study, and the work detailed in the protocol/study outline will be covered by the University of Southampton insurance programme.

As the sponsor's representative for the University this office is tasked with:

1. Ensuring the researcher has obtained the necessary approvals for the study
2. Monitoring the conduct of the study
3. Registering and resolving any complaints arising from the study

As the researcher you are responsible for the conduct of the study and you are expected to:

1. Ensure the study is conducted as described in the protocol/study outline approved by this office
2. Advise this office of any change to the protocol, methodology, study documents, research team, participant numbers or start/end date of the study
3. Report to this office as soon as possible any concern, complaint or adverse event arising from the study

Failure to do any of the above may invalidate the insurance agreement and/or affect sponsorship of your study i.e. suspension or even withdrawal.

**On receipt of this letter you may commence your research but please be aware other approvals may be required by the host organisation if your research takes place outside the University. It is your responsibility to check with the host organisation and obtain the appropriate approvals before recruitment is underway in that location.**

May I take this opportunity to wish you every success for your research.

Yours sincerely



Dr Lindy Dalen  
Research Governance Manager

Tel: 023 8059 5058  
email: rgoinfo@soton.ac.uk

## Appendix 1

My name is Gina Sherwood and I am a student in the school of education at the University of Southampton. My research is looking at families who have a young child with a learning delay and the support they receive. You have been selected to take part because you have a young child with a delay in their development that affects their learning and have access to your local Children's Centre.

The aim of the research is to inform professionals who work with families about the impact of what they do, so that they can consider the way they provide support. I will use the knowledge you share to shape my role as a tutor working with both families and child care professionals. I believe that this research into support for families is important because it will also enable others to recognise what is helpful and unhelpful.

I hope that taking part in the research will enable you to raise any concerns and issues as well as celebrating positive experiences. During the process it is important to me that you feel respected and encouraged.

If you would like to volunteer to help me the procedure is as follows -:

- Arrange to meet with me for a short time with a family support worker
- Meet with me on 3 occasions over a period of 2 months at a place you select for a maximum of an hour each time

In these early stages I will ask for your permission to develop a picture showing the different sources of support you receive. During each of the meetings we will discuss your experiences of support (both past and present) and the impact they have on you and your family. I am aware that this information is personal and may be emotional for you to discuss. If any part of the experience becomes uncomfortable for you we will pause and decide together on the next steps. In the final phase of my research we will organise further meetings to examine particular aspects of support in more detail.

With your permission I will make an audio recording of our discussions; this is so that I can focus my attention on what you are saying rather than on writing notes. It will also enable me to pay attention to your well-being.

If you would like to help in the final phase of the study I will need to request the following help from you -:

- To keep records of support you receive from professionals or other people by recording your thoughts either verbally, or in writing or in a pictorial form.
- Observe you receiving support from a person you nominate and spending a maximum of 30 minutes after the meeting recording any impact that this has had on you and your family.

## Appendix 1 Exploring families experiences of support when they have a young child with a learning delay

At every stage in the research I will share all my notes and interview scripts with you so that we you can decide on anything that should be added, amended or deleted.

At our first meeting I will ask you to sign a consent form which outlines your rights and my responsibility to you. We will also decide how every effort can be made to maintain your anonymity. This means that we will agree on an alternative name for you (a pseudonym) and other personal details that would be changed to help to disguise your identity. All written information will be kept in a locked filing cabinet and any on my computer will be password protected. None of your identifying details will ever be used in anything I write or present.

Although all attempts will be made to protect the identity of you and the family I cannot guarantee that those who read my work will not put two and two together and identify you as a participant. However if your name is suggested to me I will not confirm that you helped me to carry out my research.

In the light of the personal nature of this study you are free to withdraw from my research at any time. This will not have any effect on the support you currently receive. To do this you can contact me to let me know that you do not wish to meet me again or you can withdraw through speaking to your family support worker or another member of staff at the Children's Centre. In either case I will not contact you again on the subject of the research and any previous information I have gathered will be destroyed.

If you are unhappy with any aspect of our contact or the research at any point, I encourage you to discuss your concerns with the Children's Centre Manager by arranging an appointment or telephoning her on 01329 841097. You may also contact Melanie Nind who is chair of the Research Ethics Committee at the University of Southampton on 02380 595813. In both cases your concerns will be considered seriously and appropriate action taken.

Further details about research standards can be found on the University of Southampton website in the School of Education by selecting research. A paper summarising the information found there is also available from me.

My final report will be submitted to the University of Southampton to be marked by examiners. A copy will be kept in the university library which will allow other students to read it. A summary of my findings will be circulated to anyone who is interested including your family. The research may also be presented at conferences and in research journals.

As I am not receiving any funding to carry out this research I am sorry that I will not be able to pay you for the time you spend helping me to gather information for this study. However I will endeavour to make the experience of working together a positive one which is of mutual benefit to us both. I also hope to present my findings in a way that persuades professionals to provide support, based on what is most useful to you.

**CONSENT TO INTERVIEW AND RECORD INFORMATION**

**For the research project: 'Exploring families' experiences of support when they have a young child with a learning delay '**

I consent to Gina Sherwood interviewing me for the purposes of her research for the degree of MPhil/PhD and to her audio recording part of our conversations, she has given me an outline of her research.

Initials

Interview

Audio recording some of the interview

Visual representation of my support network

I understand that when an interview has been recorded I will be shown the transcript. I will also agree the representation of my support network and on request view any further notes taken. I will have a chance to comment on all of them.

During the interview, I have a right to ask to suspend the discussion at any point. At the first interview I understand that we will draw up a representation of the support network that I have access to. I understand that when complete, with my permission, it may be used in the final report.

I recognise that I can refer to the Children's Centre to provide me with additional guidance and support if I am unhappy with any part of this experience. I have nominated ..... to help me if I feel I need to talk, in confidence, to someone about being a participant in this research.

Appendix 1

I understand that Gina may use material from our meetings in writing her research report (thesis), which following examination will be available in the university library and online, and also in any conference presentations she may give. The information may also appear in future publications. She may also describe her findings when teaching families and child care professionals. I realise that this means what I say could be in the public domain, but understand that my name will not be included and that all possible efforts to conceal my identity will be taken including personal details of where I live and work.

The audio recording, transcript, notes and visual representation of my support may be heard or seen by Gina's supervisors, but will not be divulged in detail to anyone else. Recordings and transcripts will need to be kept after the thesis is written to verify the authenticity of the work but will not be kept in an identifiable fashion.

I have a right to withdraw from the interview and research at any time without the need to give a reason, and I can request that certain aspects of what I say or Gina writes are not used by her in future writing. This would not affect my rights to receive any of the services offered at the Children's Centre.

This consent is limited to the first 3 meetings I will have with Gina and will be reviewed at the beginning of each interview. Further consent forms will be used as the research progresses.

Signed

Printed name

Date

Signed

Gina Sherwood

Date

Appendix 1  
School of Education  
University of Southampton  
University Road  
Highfield  
Southampton  
SO17 1BJ

9<sup>th</sup> July 2010

Dear Melanie

**Project Title: Exploring Families Experiences of Support when they have a Young Child with a Learning Difficulty (RGO Ref: 6404)**

Following confirmation of approval to conduct research for this project agreed on 1<sup>st</sup> April 2009 by Dr Lindy Dalen, Research Governance Manager, and agreement to carry out a pilot study for the second phase of this project. I am writing to request permission to carry out additional research with four parents who have agreed to help me in the final phase of data collection.

To undertake this research I intend to carry out two observations, the first with a mother and her son receiving support from their Portage worker. The second of a professional nominated by Alfred and Andrea. In each case the observations will take place in the participant's home which is the location used in the first phase of the field work. Following the observation I will stay in the house for a further thirty minutes to write notes of any impact arising from the support received.

In addition to this I will request that the four parents record their own reflections following the receipt of support on a selected occasion. The method of recording will be discussed and agreed with the participant. At their convenience we will agree a final meeting where each will present their reflections and I will audio record our conversations.

Finally I will arrange to visit each family to carry out a recorded interview which provides me with an insight into their experiences of receiving support during the year since we last met.

The purpose of the research is to gain more in-depth information about the impact of support on the family and to define with the parent elements that seem helpful and any areas that could be improved. By asking the parents to make an independent record of responses to support I hope to gain insights that limit my influence and embrace the participatory approach that is a feature of my study. Please see the attached letter of consent for the participant to sign in advance of this phase of my field work. The final interview will provide evidence of a longitudinal element to how families' experiences alter and where experiences match or change over time.

Appendix 1

With your permission it is my intention, with your permission to carry out this research over August and September 2010.

Yours sincerely

Georgina Sherwood

**CONSENT TO OBSERVE, GATHER DATA GENERATED BY PARTICIPANT AND AUDIO RECORD A FINAL MEETING**

**For the research project: 'Exploring Parents' experiences of support when they have a young child with a learning disability'**

I consent to Gina Sherwood observing me for the purposes of her research for the degree of MPhil/PhD and to recording my own reflections of the impact of an experience of support I receive; she has given me an outline of her research.

Initials

-	
Observation of me receiving support	<input type="text"/>
Observation following support	<input type="text"/>
Records of my reflections of receiving support	<input type="text"/>
Audio record of final meeting	<input type="text"/>

I understand that Gina Sherwood will take notes when observing the professional in my home. I will discuss my reflections of this support with Gina so that she can gain an impression of the impact of this visit. I will have the opportunity to read the notes that have been taken. I will have a chance to comment on all of them and request that sections be omitted in the final report. She will transcribe the audio recording arising from our final meeting and I will have the opportunity to read and comment on this.

On an occasion I select, I agree to record my reflections of the impact of one or more experiences of receiving support as soon after the event as is practicable selecting a method which is suitable to me.

I recognise that I can continue to refer to the Children's Centre to provide me with additional guidance and support if I am unhappy with any part of this experience. I have nominated ..... to help me if I feel I need to talk, in confidence, to someone about being a participant in this research.

Appendix 1

I understand that Gina may use material from her observations, transcripts and my reflections in writing her research report (thesis), which following examination will be available in the university library and online, and also in any conference presentations she may give. The information may also appear in future publications. She may also describe her findings when teaching families and child care professionals. I realise that this means what I say could be in the public domain, but understand that my name will not be included and that all possible efforts to conceal my identity will be taken including personal details of where I live and work.

The observations, notes, transcripts and my personal reflections of my support may be heard or seen by Gina's supervisors, but will not be divulged in detail to anyone else. All records will need to be kept after the thesis is written to verify the authenticity of the work but will not be kept in an identifiable fashion.

I have a right to withdraw from any part of this research at any time without the need to give a reason, and I can request that certain aspects of what I say or Gina writes are not used by her in future writing. This would not affect my rights to receive any of the services offered at the Children's Centre.

This consent is limited to the observation and a further meeting where I will present my reflections, consent will be reviewed at the beginning of each meeting. Should Gina need to have further contact a separate consent form will be used.

Signed

Printed name

Date

Signed

Gina Sherwood

Date

## CONSENT TO OBSERVE

### **For the research project: 'Exploring parents' experiences of support when they have a young child with a learning disability'**

I consent to Gina Sherwood observing me for the purposes of her research for the degree of MPhil/PhD I have received details of her research from my manager and the participant.

Initials

Observation of me providing support

I understand that Gina Sherwood will take notes during the support I will provide in my professional role. I recognise that Gina may use material from this observation in writing her research report (thesis), which following examination will be available in the university library and online, and also in any conference presentations she may give. The information may also appear in future publications. She may also describe her findings when teaching families and child care professionals. I realise that this means what I say could be in the public domain, but understand that my name will not be included and that all possible efforts to conceal my identity will be taken including personal details of where I live and work.

The observation notes may be seen by Gina's supervisors, but will not be divulged in detail to anyone else. All records will need to be kept after the thesis is written to verify the authenticity of the work but will not be kept in an identifiable fashion.

This consent is limited to one observation.

Signed

Printed name

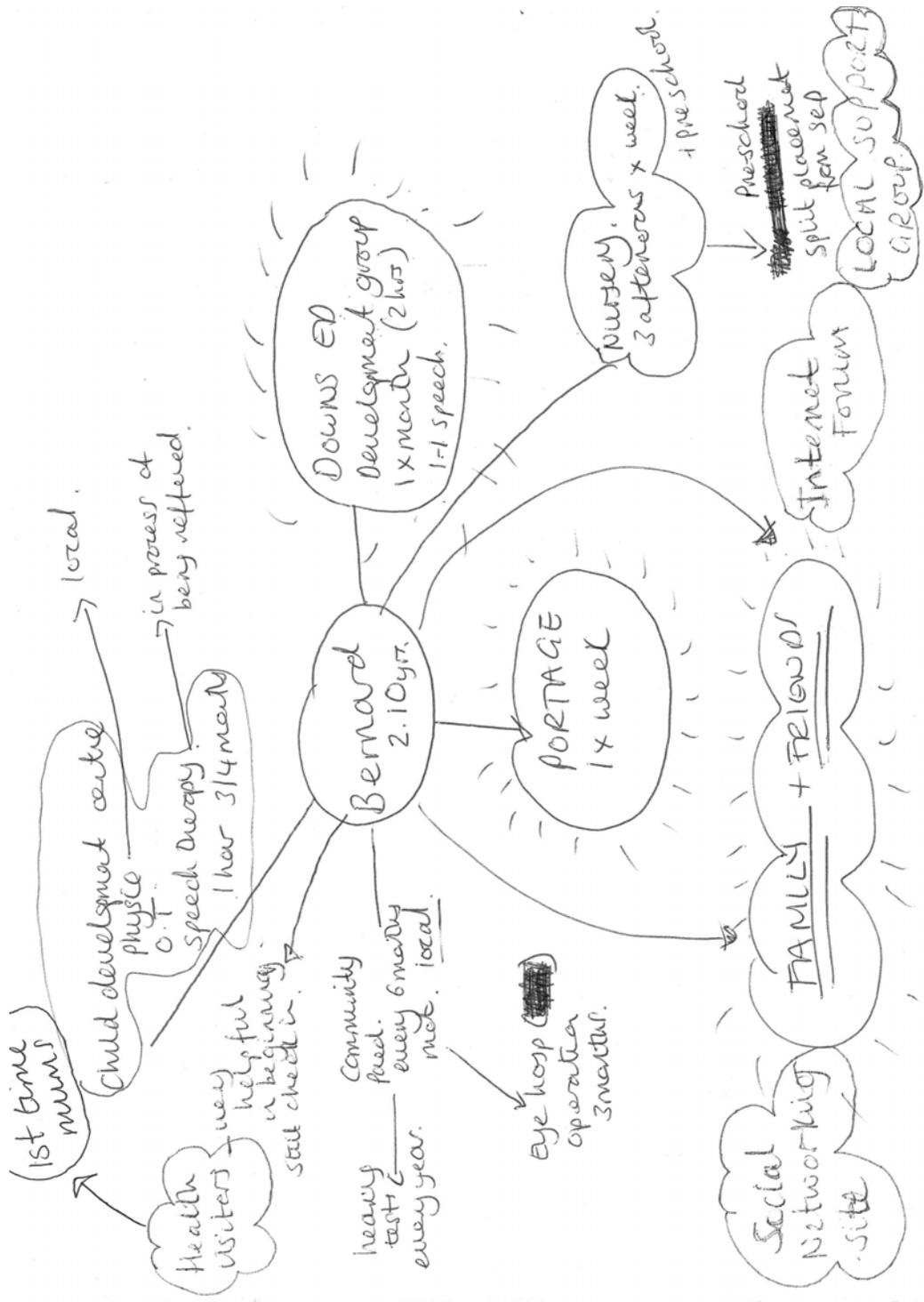
Date

Signed

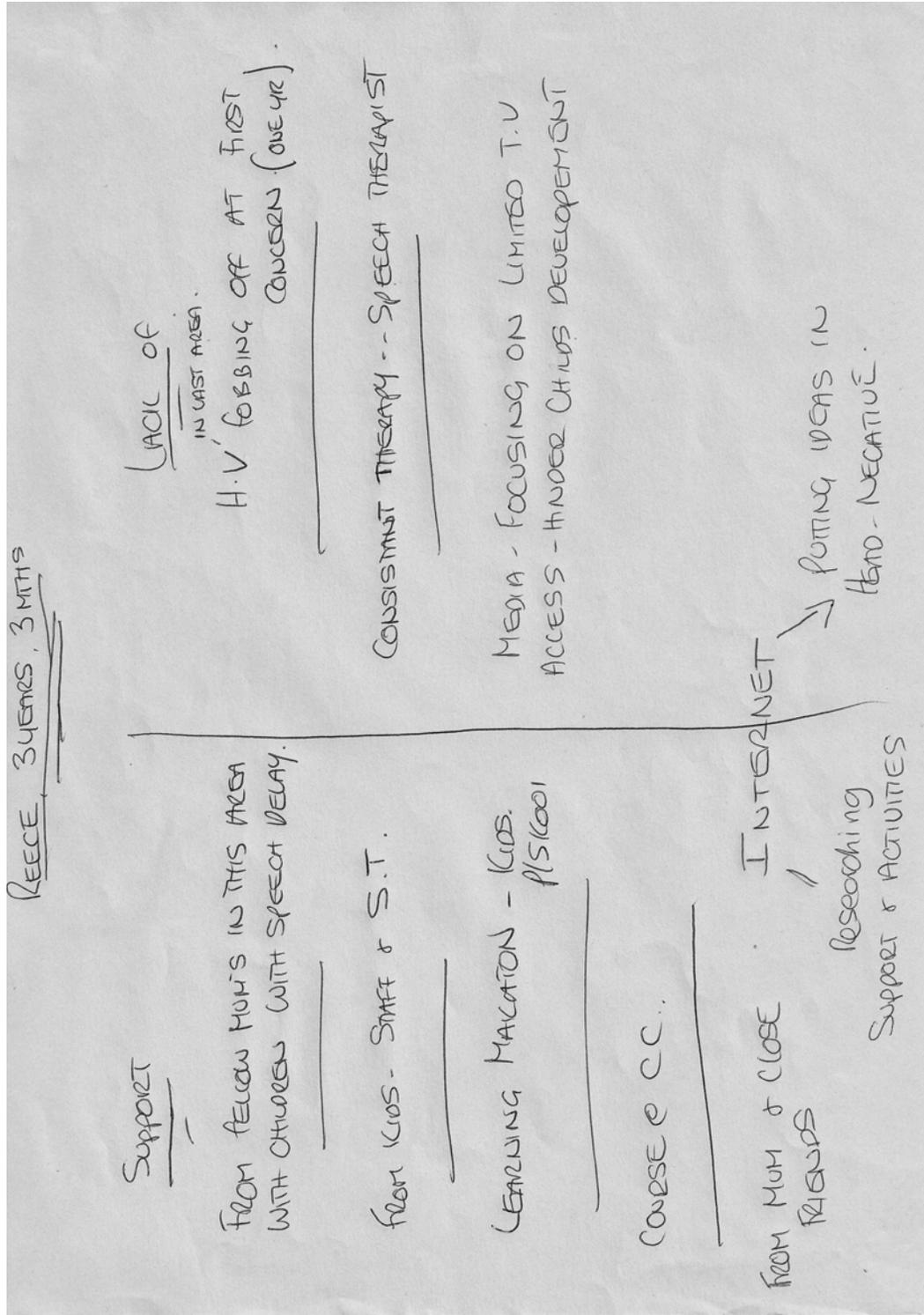
Gina Sherwood

Date

Appendix 2: Barbara's visual representation of support

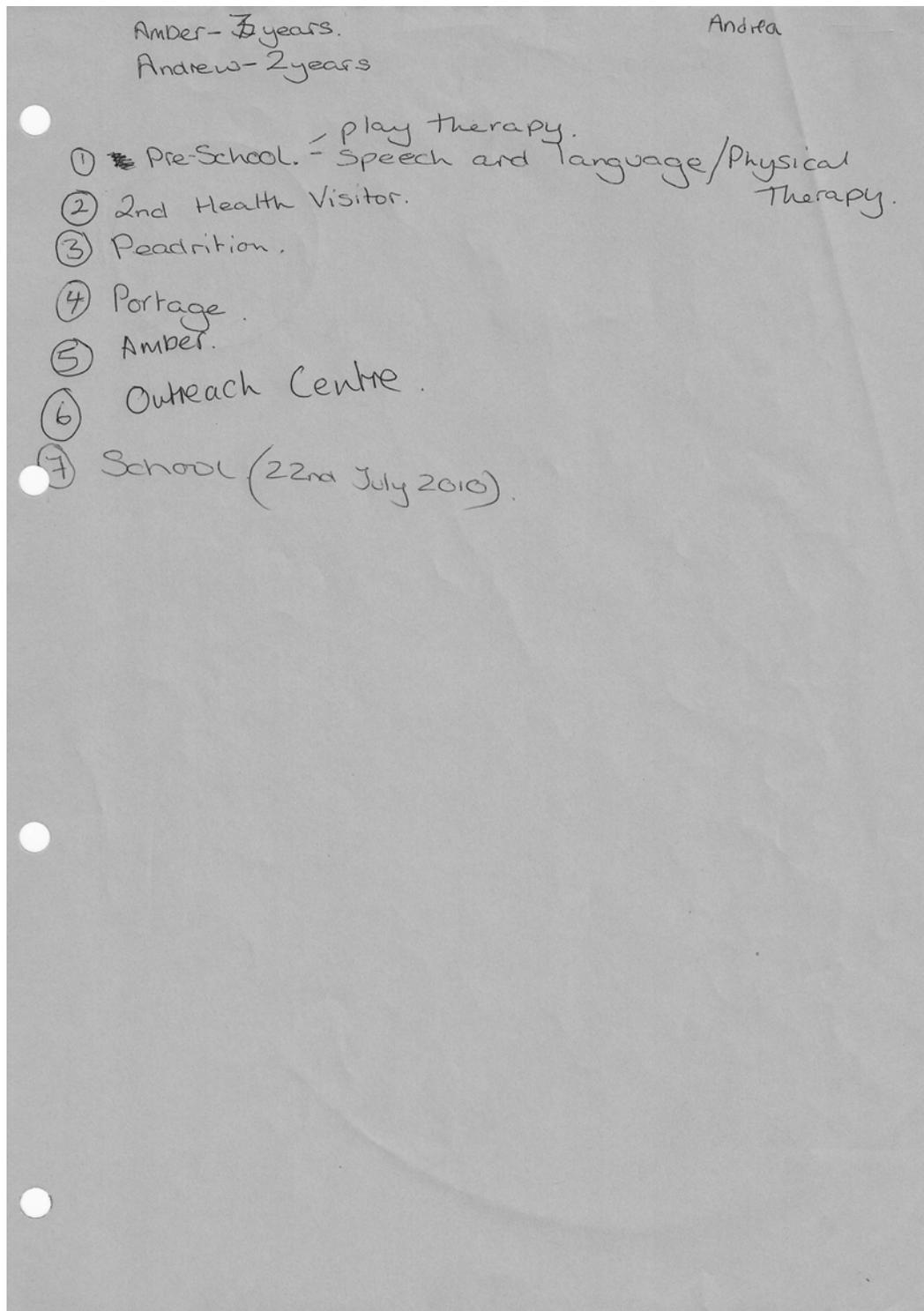


Appendix 2: Ruby's visual representation of support

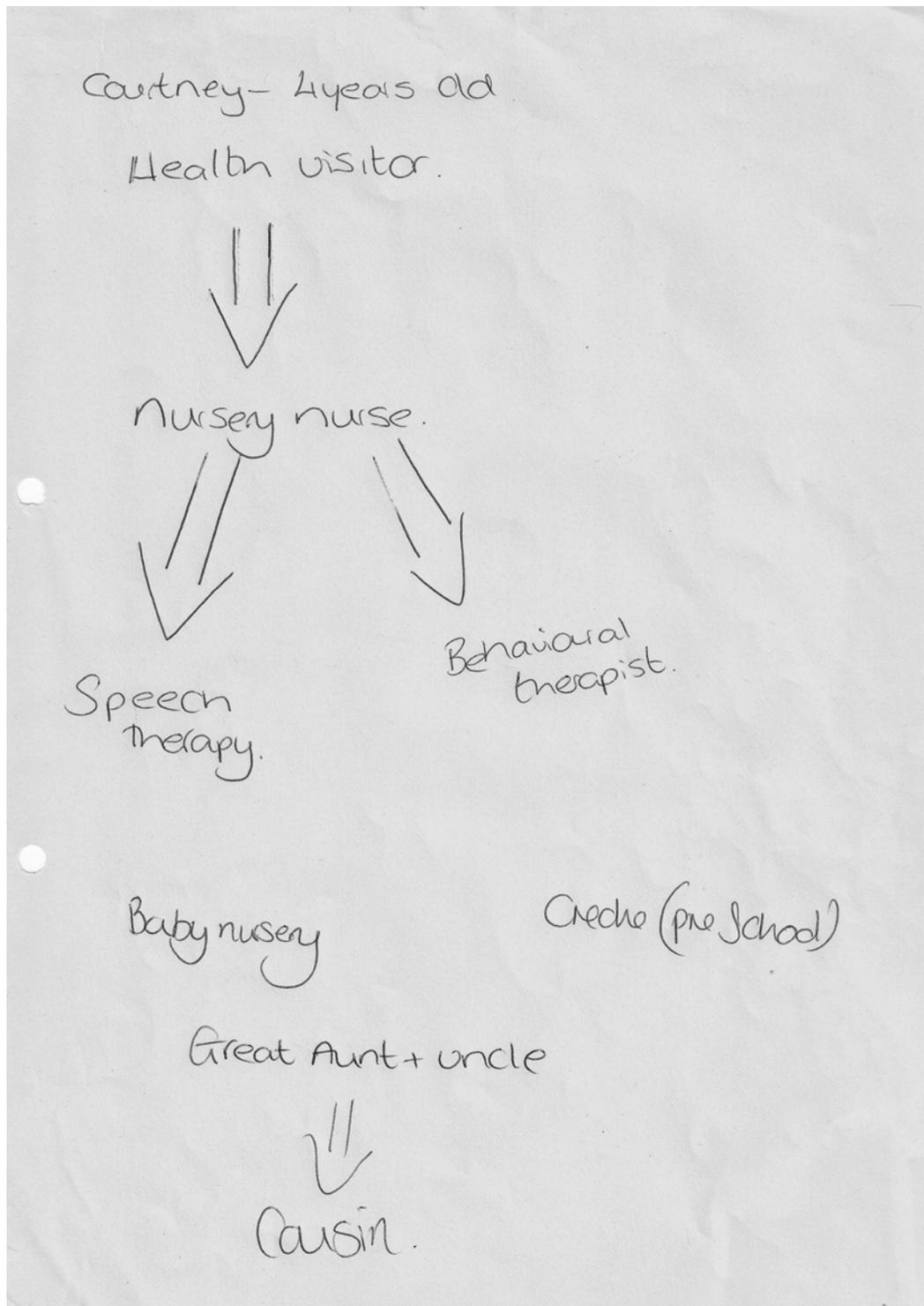




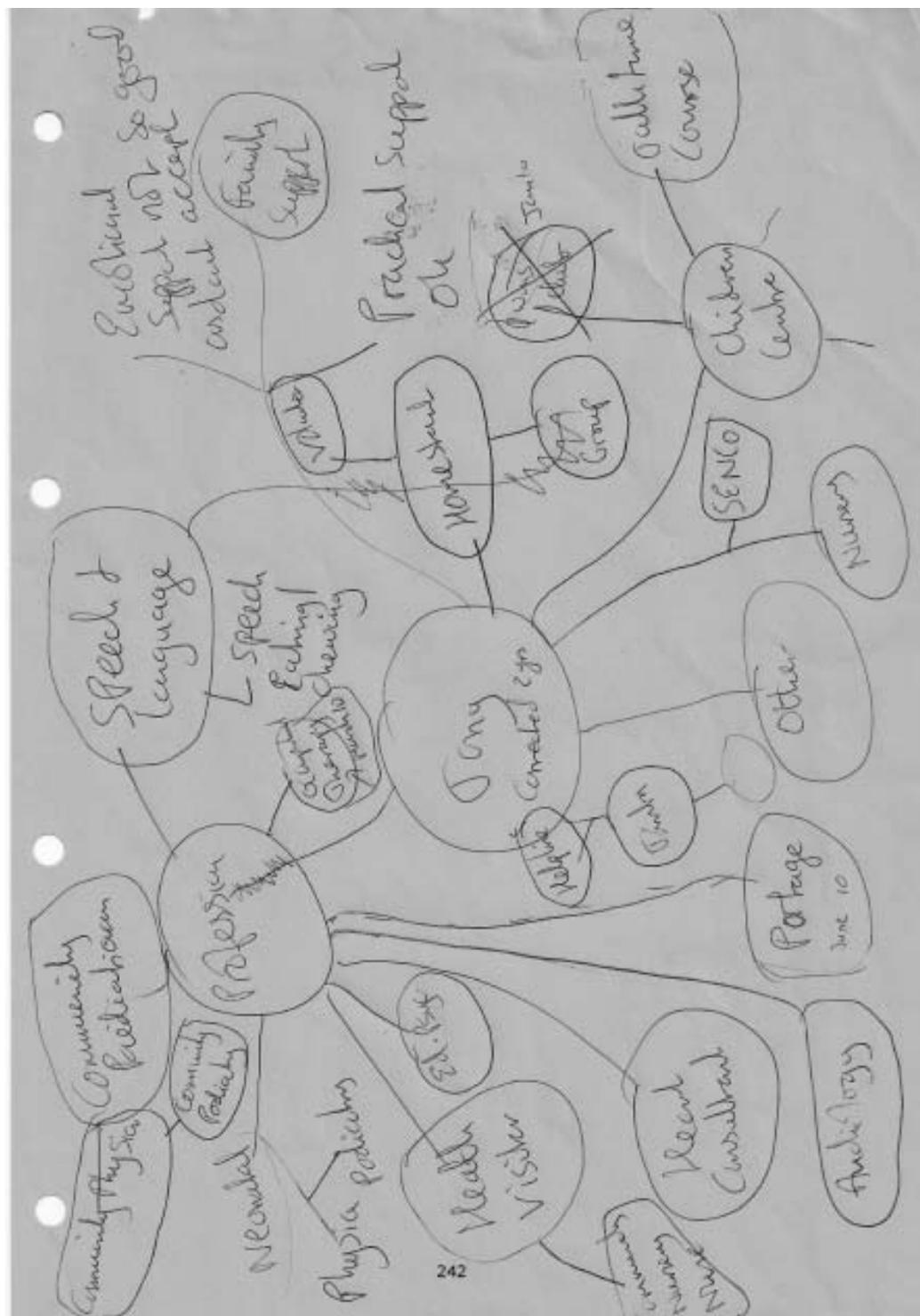
Appendix 2: Andrea's visual representation of support



Appendix 2: Catherine's visual representation of support



Appendix 2: Tasmin's visual representation of support



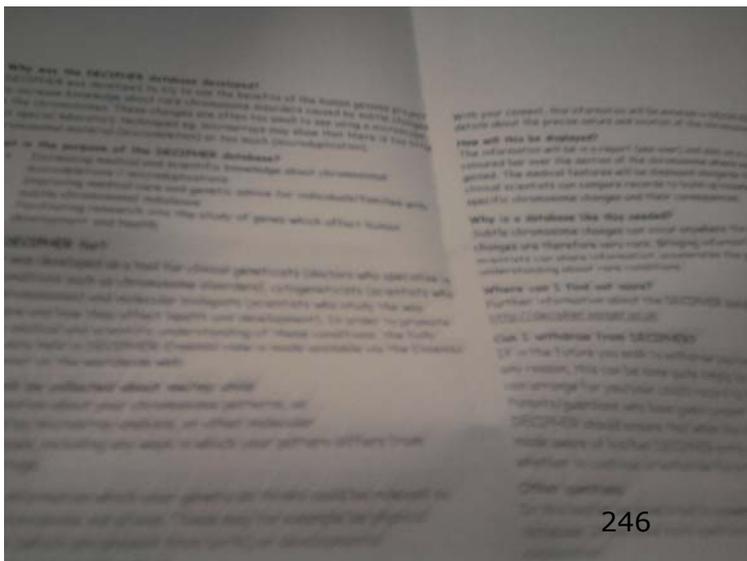
Alfred and Andrea's Evaluation of Support



This is what we were shown after a very short appointment. This exit sign represents the amount of help/info we received from the hospital.



The size of the hospital is horrible. We had to traipse around the whole of the bottom of the hospital. As the reception for the children was shut. This represents the huge hospital that we have to go to every time and how little info we got.



This is the info we got for Amber condition. Which really was confusing and useless.

## Appendix 3

### Wednesday July 2009 Home visit – meeting a new Speech Therapist (approx 1 hour)

Present: Barbara, Bernard and ST

#### My thoughts the evening/morning before the appointment

In no particular order (or with no particular time allocated to the thoughts – some were fleeting, others spent more time popping in and out!)

- **Will I like the new ST?** Important to feel comfortable and at ease, especially as she will be Bernard's ST in his new pre-school for a year. Will we be on each others 'wavelength'? Can I be honest with her? Will she be honest with me?
- **Will Bernard like the new ST?** Will he feel comfortable with her? Will he want to play with her? Again, important as she will spend some time each week with him for the next year.
- **Will Bernard show the ST what he can do?** Will she get a true reflection of his strengths/weaknesses? Will I have to say 'he can usually do this activity' ....? Will he be distracted by other things? Will he be 'well behaved'?
- **Are Bernard's Speech and language resources easy to find if the ST wants to use them?** Have we used them recently? Are they chewed? (!) Are they in one piece?
- **Is the house tidy?** Is there enough space for all of us to sit, chat and play? Have I hoovered the carpet?? What would she think if the house was a mess? Will she find the house ok and will she be able to park the car??

I will try to describe how I felt in the session, how it progressed over the hour and try to link back to any answers I have to my questions before the visit.

I had spoken to Bernard beforehand about the ST coming to play – he was keen to meet her. He could say her name which he was pleased about. She came (on time – important!) with a big bag similar to the one the Portage worker has, so he was instantly excited to find out what was in it.

The ST also had familiar resources with her, so Bernard knew what was expected from those resources, Although I appreciate that different resources can test children in different ways, I felt it was good for a first visit as it put Bernard at ease because it was something he could achieve with. It also put me at ease as I knew it would be something that Bernard would be able to do and be more able to show his skills to the ST.

I was really pleased to find that the ST had talked with Bernard's Portage worker before the visit and shared their ideas. I have the upmost confidence that the PW can report about Bernard in an accurate and honest way, so I felt that activities and discussions were relevant to the NOW, and the ST wouldn't have to waste time going through activities that were too easy/too hard.

The ST seemed friendly, approachable and patient, and instantly sat on the carpet with Bernard to get to his level. I knew that he would respond to this – he loves to play with other people and is getting more used to 1-1 adult play. He also loves praise and seems to relate doing the activities with this. I think I feel he is more ‘reliable’ with any therapists now – of course he is older and has an understanding of what is expected of him, but I’m not sure if any mum can say they know exactly what their 3 year old will do...I also feel more confident that I can describe what he can/can’t do, even if he doesn’t demonstrate this. I felt the ST asked me relevant questions, and all of them were based on things either Bernard had done, could do, or was working on. Nothing came as a surprise or seemed irrelevant. (This links to earlier times when there would sometimes seem like too much information from therapists, some with conflicting or confusing information/advice).

The hour continued with the ST mainly working with Bernard on the floor and chatting to me at the same time. I felt fairly relaxed and I’m sure there have been times when I haven’t been relaxed during appointments and Bernard has been able to pick up on this, therefore creating a vicious circle of stress – the more stressed I got the more he gets too!

We discussed reading flash cards and I got them out for Bernard to read to the ST. I wouldn’t have been able to do that if we weren’t in our home or if I wasn’t feeling relaxed about it. I am proud of Bernard and I wanted to show the ST what he could do, even though she hadn’t brought the subject up. In sessions that aren’t at home I feel like things are run more to the agenda of the therapist, so tend not to join in or contribute unless I’m asked to. I’m aware I always join in more when I’m at home. Whether this is wrong or right, it just seems to be something I prefer, and feel more relaxed in doing so.

Linking back to the thought I had about is the house tidy, may seem not as important as the other thoughts (and it isn’t really) but is probably the only downside (in my view) of a home visit. I think that having let many people (like therapists etc) into our life, I have at times felt like my parenting skills were looked at, especially if Bernard hasn’t managed to understand something even after a lot of work. Questions of, ‘are you doing this? (And me thinking ‘No I’m not, should I be? Or ‘yes, I do that all the time and it doesn’t seem to be making any difference’). I’m sure this is due to not being confident, rather than actual concerns about my parenting skills, but I have come away from quite a few appointments (especially in the early days) feeling like a bad parent. So, when we have had home visits I have thought, I wonder if they will make assumptions about my home life? If the washing up isn’t done, will they think I’m a slack mother? Does it look like a place that a child could live happily in? I feel this less and less now, and the fact the ST had spoken to the PW about Bernard beforehand (and we have had portage sessions when the washing up and hovering definitely has not been done!!).

Overall, it was a good, positive session. The ST gave good feedback and asked me what help I would like. Bernard enjoyed her visit and seemed to enjoy himself. She had ideas that were specific to Bernard based on what she had been told, what she had seen and what I had told her. I feel positive that she will be able to help Bernard at his new pre-school and that he will like working with her.

### **Appendix 3**

Even though I feel more confident about sessions like this one, it doesn't stop the same thoughts popping in my head, but I am more likely to feel positive and proud, (rather than negative and upset) and that is a lovely feeling to have.

Tasmin's Observations of receiving support

**Occupational Therapy Early August 2010**

We finally had this appointment after 3 cancellations (once by me, twice by them – lack of rooms). These appointments are at ....which is a fair distance from home. In the end I had to accept an appointment at an inconvenient time (12.00) in order to avoid a significant delay. I also find it incredibly frustrating trying to arrange these appointments. I have to speak directly to O.T, they do not appear to have admin support who can access their diary. As she is obviously out a lot and I am working we constantly miss returned calls. I have asked for email address and been told they do not give these out to patients (I was told the same by SALT). Why not? I give my email out to customers why do they not, at least I could then send dates/times that we are free and they could respond with appointment. This should be changed.

On the actual day we are in a very small room – barely large enough for 3, never mind 4. Room is effectively an office with a small desk for Tony to work on. Unfortunately he is much more interested in the computer and the sink and taps. Tammy is also interested in these things. I spend the whole appointment jumping up and down to stop them doing things, Tony is too distracted to sit still and listen to OT requests and I am too distracted to talk to her properly, The whole thing is a nightmare and takes approx 2 hours door to door, Car parking at the centre is also problematic – very narrow spaces, no parent and toddler and often no spaces, I am very relieved future OT and SALT appointments will be at the nursery.

**Community Paediatrician mid August 2010**

What a difference to the OT appointment. We see the paediatrician in a very local hospital. I am not able to arrange this for a non-working day, however I can choose a sensible time. I take Tony and Tammy to pre-school as normal and work at home. I leave home 20 mins before appointment and arrive at local hospital in good time, lots of easy parking, including parent and child (more than at ....which is about 7 times bigger and a maternity hospital!). The health care assistant comes to collect us. She remains in the room with us and plays with Tony so I can talk properly to the doctor. The H.A. then incorporates things into play so Dr can see various things (e.g. pencil grip, jigsaws). After the appointment the H.A. walks us out, I drop Tony back to pre-school. He is happy and relaxed and so am I. The whole thing takes only about an hour.

When I reflect on the appointment I appreciate it was partially less stressful because Tammy was not there and also the ease of the location, however the biggest difference was the presence of the H.A, who by occupying Tony allowed me to talk sensibly to Dr. without losing my train of thought.

## Appendix 4: Example of Interview data

Interview two with Barbara 21<sup>st</sup> May 2009 4.20-5.00p.m.

### Barbara:

1. Okay... well yeah I was saying I thought there was some extra
2. things and it was interesting umm that they sort of popped into
3. my head as soon as you left uhmm and I thought why didn't I
4. say them I think they are not as instantly obvious but actually
5. a couple of things I actually do every day umm in terms of
6. support and that kind of thing umm so I thought why why didn't I
7. mention them? Two of them come from the internet one is umm
8. a support forum for parents or anything to do with Down's syndrome
9. but specifically for parents umm which I joined when Bernard was
10. about I guess probably just coming up to a year umm and its just
11. I pop on there every day, I usually don't write much on there but
12. you get to sort of um you get to know people randomly through
13. their children through their posts err that they post on the forum
14. um so its just nice to know there are other people out there that
15. have the same problems or we we celebrate mile stones on there
16. all sorts there's stuff for chat there's all sorts of sections you can
17. go into, its nice just to lurk actually and have a read of things but
18. I realise that I do pop on there every day just to have little read
19. and sometimes post things or respond to other people if you think
20. ohh I, I know about that or I can help you there so that sort of
21. didn't pop in my head actually has been really helpful so...

**Comment [GS1]:** Relating to adding to the picture of support

**Comment [GS2]:** Sound of me saying "oh lovely" in the background as I am interested in this channel of support and its significance to Barbara

### Gina:

22. Can you tell me how you were signposted to that in the first place?

**Comment [GS3]:** Thinking about how people would find out about it as it has obviously helped Barbara and others may not have thought about accessing this type of support

### Barbara:

23. Umm I think I randomly found it on the internet when I was umm just
24. searching for anything I think to do with Down's I think I found it, had a
25. lurk about there before I joined and cause you can read certain parts of
26. it before you become a member umm and then thought actually
27. no this seems quite nice umm so you know you can...I think
28. I think that's how I found it I just randomly found it um
29. which is um yeah

### Gina:

30. Right and do lots of people um use the sight do you think? I mean
31. would you have any idea?

### Barbara:

32. I guess probably a couple of hundred members and people come and
33. go people are very people seem to go through phases of always being
34. on there and then I guess depending on what happens in your life you
35. you move back but I've always just sort of been keeping my eye
36. on there (laughs) and you get to you think you know people and you
37. remember people's children and people can post photos of you know

**Comment [GS4]:** Interesting point to think about why people might "move back" and Barbara states that she goes on this website every day, I wonder if her commitment to it has been consistent? Also whether people continue to use it but do not post any comments about their lives. In other words I'm thinking about the role that this plays in people's lives e.g contact with others (perhaps reaching out to someone who they have something in common with) or more for information?

38. birthday parties and that sort...it's quite a it's a very positive things
39. because everyone knows what you know you what you can
40. go through, so it's actually
41. really nice umm so I'm going to pop that down with family and friends
42. cause its something that I found rather than was put upon
43. me see what I mean? So I guess it was not something that
44. was given to me but I've actually found it um quite useful, so I'll call it
45. internet forum there....

**Comment [GS5]:** Slower speech seems to increase emphasis of its significance

**Comment [GS6]:** Almost implies that other things were an imposition rather than taken up independently through choice? I acknowledge this with the word right.

**Comment [GS7]:** I say right yes I see what you mean which on reflection I don't completely see comment below.

**Comment [GS8]:** Draws round it to denote significance but does not give it any symbols of sun

**Gina:**

46. And I presume you you hear from people all round the country?...

**Barbara:**

47. Absolutely, yeah and occasionally, I mean I haven't been
48. involved in any but people do meet up umm there's been
49. a couple of people locallyish err in the South I've umm
50. recommended a few things to and you sort of you realise they
51. are in the same hospital area and that kind of thing so there's
52. you know always bits, bits like that, you get to know people
53. because they are they become local you "Ohh did you pop
54. to that hospital, oh well that's not far from me" its its
55. quite nice so umm and as I say you can dip in or out as
56. much as you want to and that sort of thing but I sort of
57. realise yes I suppose I pop on every day just to check
58. whose posted or if there's anything so that's that is
59. helpful...

**Comment [GS9]:** Voice is raised in tone suggesting a personal connection with the person on the forum

**Gina:**

60. With that, sorry, I just wanted to ask you a question about it
61. umm would that be the sort of place, would you ask questions
62. on there or do you post mainly information about Bernard...

**Barbara:**

63. Yes it's really questions, you ask questions "has anyone had this
64. problem?" or "does anyone know where I could find x y and
65. z?" I think you have to make sure it's not a medical opinion, its
66. not a professional opinion its just people, just families who might have
67. been through or understand what you what your going through. ..
68. Just trying to think of some lists that there is, there is a
69. medical advice section there's all sorts of lovely things like ur just
70. general experiences um milestones, occasions coming up all sorts
71. things, you can talk about appointments, "has anyone been to this,
72. seen this doctor or this
73. appointment?" and someone can go "oh no but..." you know
74. or if they have had trouble with something someone else might
75. recommend something else um, behaviour, any behaviour issues I
76. mean as I say you have to remember it's just parents advice
77. and opinion and um umm but all sorts of things you can possibly
78. imagine I think are probably there and you either you can write to
79. help somebody or can post your own questions or your own thoughts

**Comment [GS10]:** Calm, level voice used here

**Comment [GS11]:** Uses a concerned voice here and then quickly shifts back to description

**Comment [GS12]:** Suggests again the limitation of the parents expertise

80. or something it's just nice to say "Hi (laughs) haven't been on for a  
81. while how's everyone doing" or something like that ...

**Comment [GS13]:** Suggests that sometimes she acts as a listener (lurking) rather than a contributor which may of course apply to others too

**Gina:**

82. Right, thank you that's really interesting. It's not something  
83. I have a lot of experience of which is why I was asking you.

**Comment [GS14]:** Suggesting that we move onto something else

**Barbara:**

84. To be honest me neither I would I'm not, you know I'm not  
85. usually that sort of person but I just thought actually its probably  
86. more helpful than I think it is umm I think and I would go on there  
87. if I did have a problem, it wouldn't be my only route the only thing  
88. do but I'd perhaps put the feelers out if there was something I was  
89. stuck with or something so umm so yeah and then on the same  
90. as the internet which I think again is possibly more help than I  
91. think it is is umm social networking site umm face book because  
92. I'm on there just for me not for any particular issues to find things with  
93. Down's syndrome its just a little kind of a friendship thing but I am  
94. friends people that are A on that internet forum and have come  
95. over umm and I've realised that quite a few of my friends are parents  
96. of children with Down's cause you you kind of have realise you've got  
97. friends in common I don't know them, I've never met them you say  
98. "ooh yeah that's..." and you have a bond that pops up somewhere  
99. else so that's more casual its not as I say Down's syndrome focused  
100. but because you know face book is a place you can put photos  
101. you can write lovely things and again there's that  
102. little understanding because "I don't really know you but I know  
103. of you and I know your son is my  
104. son's age and "ooh that's a lovely picture, what a lovely picture  
105. you've posted" and that's again that's a lot more positive  
106. because its not a place where I would discuss it, it's not a place I  
107. would ask for advice although one time I, I did ask if anyone  
108. knew the Makaton sign for zoo (laughs quietly), I thought  
109. I'll just ask it out there and see if anyone... and then people  
110. come back and say "Oh I think its this or this is the link" so  
111. that's quite nice because its all very friendly and very positive  
112. and as I say I don't do a lot to do with Down's on there because  
113. it's my time its my little but I do have the friends that have got  
114. children with Down's and its just nice to again have have that  
115. contact ummm so I'm on that every day as well (laughs)  
116. not all the time, but I, you pop on for other things as well  
117. so umm I just thought yeah that's a really positive part because  
118. its its not serious its not.... you know horrible in any way  
119. (laughs) its all fun that's the nice part to celebrate you  
120. know...

**Comment [GS15]:** Drops her voice slightly here, I'm aware of the range of opinions about this area and my own inner concerns about privacy, trying not to look as if I judge this negatively

**Comment [GS16]:** Background sign of me saying right

**Comment [GS17]:** Sounds slightly embarrassed as if I may be judging this as wasting time (which is not in my mind) and perhaps feels she should justify this behaviour?

**Comment [GS18]:** I add no in the background

**Gina:**

121. Yes yes, we did mention that a little bit last time, didn't we about  
122. celebrating um as well

**Barbara:**

123. Yeah but I've put these all down as family and friends because it  
124. is all to do you know like I posted a video actually when Bernard  
125. took his first steps and I popped it on there and the amount of  
126. response you get from all sorts of people "that's brilliant that's  
127. fantastic" and you just think yeah it is actually "thanks very  
128. much!" (laughs) "thanks" (laughs again) you know its its  
129. yeah its all very positive but yeah absolutely so they  
130. were the two two I think more unusual I think that I hadn't  
131. thought about but I would probably have as I say more support  
132. than I think, the other one was umm a Down syndrome a local  
133. Down syndrome support group that umm was intro introduced  
134. to us when um Bernard was born as part of the pack we get  
135. from the hospital and the lady actually came to visit me with  
136. Bernard in the hospital umm and was brilliant absolutely  
137. fantastic in fact was the only thing I wanted to do with all the pile  
138. of leaflets that you get given to read that was the only thing  
139. that popped out that I actually wanted to have just to  
140. to investigate to see what it was  
141. umm its basically local parents umm and support group  
142. you meet up every month although unfortunately I haven't been  
143. for a while because I work but at the time didn't, used go every  
144. month and you meet, have a cup of coffee and just have a  
145. chat umm but although I don't go now I know that that person  
146. would be there if I had a problem or had "don't know where  
147. to go to here?" local knowledge of support that she's got is  
148. really good and she's also good at things like filling in forms  
149. and fighting for things (laughs) that sort of thing so that's, that's  
150. a connection although I used it a lot in the early times I haven't  
151. so much now but I know where she is she's always, you know  
152. on the end of a phone and that sort of a thing but very helpful in  
153. the beginning so um

**Comment [GS19]:** I say and encouraging and in the background to show that I recognise the significance of this

**Comment [GS20]:** Perhaps resonates with previous indicators that personal contact with someone else who had Down's in common was particularly significant

**Gina:**

154. and is the person who is your main contact is she somebody  
155. who actually sort of runs the support?

**Barbara:**

156. Yes so she runs it , she two errm children with Down's and I  
157. think, felt, probably felt there wasn't anything for her at that  
158. time wasn't anything local so kind of started to build it up umm  
159. and probably realised there is a need for help really in the early  
160. days to go and visit people in hospital cause that that was  
161. absolutely brilliant umm so I think probably from her own needs  
162. and from her own awareness of how things were going in that  
163. sort of direction so that's what she offers and then come  
164. together with other parents and because you're local localish  
165. (laughs) ummm  
166. that's what kind of brings you together and you would bump  
167. into people and you can start friendships and that sort of thing

168. umm as I say at the early days that was absolutely fab, to have  
169. someone just normal that had been through it was just  
170. listening to me just waffle on urr and wasn't judgmental or  
171. anything and was absolutely fab umm so that's yeah... that's

**Gina:**

172. Do you know how many people are in that group?

**Barbara:**

173. I don't know probably more than I think now we sort of  
174. there's always an email circulating umm and there's  
175. always "new baby being born, joining the group"  
176. that kind of thing so I don't know and I wouldn't  
177. umm probably, I guess probably 20, 30 families  
178. but not all at once, probably a few have moved  
179. away or left or come back and there's new ones  
180. coming but I don't really know, not all those people  
181. would come at once to a support group but they'd  
182. be on the sort of emailing list

**Gina:**

183. So when you did go along to the meetings what sort of  
184. size group were you meeting with at that time?

**Barbara:**

185. Umm I say a maximum of 10, 10 families again it would  
186. depend on what people could manage some people  
187. would come all the time, so I guess a maximum of  
188. ten, sometimes there'd only be 3 of us and that would  
189. be it but its nice just to have that meeting point umm  
190. and to touch base really. As I say I haven't been for a  
191. while because I can't do the days which she does but  
192. she doesn't forget and she's (laughing in her voice)  
193. always, you get emails and any information she's found she  
194. passes it on and that sort of thing...

**Gina:**

195. That's really interesting and positive as well. So do you meet  
196. would that be meeting in somebody's home or is it...

**Barbara:**

197. It used to be in someone's home but she's now managed  
198. to get a bigger room um for free which is nice though um it  
199. was actually nicer meeting in people's homes (laughs)  
200. I felt bit more personal and "oh come to my house"  
201. and people seemed to make the effort, um I quite liked that  
202. (laughs)

**Comment [GS21]:** Leaves me reminded to the impact of 'personal' for Barbara and feeling particularly comfortable in a home environment

**Gina:**

203. Yes it has a different atmosphere doesn't it?

**Barbara:**

204. Absolutely but its space if you have a lot of people  
205. had it here once and err we were crammed (laughs)  
206. really it was lovely but you were kind of crammed in you've  
207. got toddlers haring around and things err and so no  
208. what shall I call **that**?

**Comment [GS22]:** Begins to write it on her diagram and draws a line round it to give it shape but does not add sun lines

**Gina:**

209. Local support group?

**Barbara:**

210. I'm not massively, I don't, it's you know, it's there  
211. if I want it now but in the beginning it was brilliant  
212. so it's squashed down in the corner **there**

**Comment [GS23]:** Point

**Gina:**

213. And that's quite interesting because one of my  
214. sub-questions is how does um, how does your  
215. support requirements, how do they change  
216. over time? Um and you're given me a hint  
217. about how that works that you know, things do  
218. change slightly your life changes as you said  
219. you are back at work now so things are very  
220. different to how they were you know almost  
221. 3 years ago

**Barbara:**

222. Oh yeah, they've definitely err, absolutely definitely  
223. change as you as you change as you grow and  
224. as your child grows. Um and you have different  
225. **needs** definitely and I'm sure that pretty  
226. individual for different people um depends how you kind  
227. of not cope with but how you... I don't know as you  
228. learn about the disability or learning difficulty as **you**  
229. become more accepting of it **perhaps?** or more  
230. understanding of it that kind that changes as **well**  
231. so and the last one which I feel really bad for missing  
232. out (laughs) is the health visitors because and I forgot  
233. because I... but in the early days the health visitors were  
234. fab and came over all the time (laughs) came  
235. to visit the house and were brilliant, absolutely fab and  
236. even now and I used to go every week any way to get  
237. Bernard weighed and that kind of thing umm and they  
238. were lovely because they knew instantly who I **was**  
239. obviously (laughs) different child err which was nice um and  
240. even now I don't go to see them I never ring them but about  
241. every sort of six months I get a phone call from them saying  
242. "you **alright?**" can we come they come over have a  
243. little chat just check everything's fine which I think is really

**Comment [GS24]:** The word 'needs' has not been applied to support very often?

**Comment [GS25]:** Clearly enthused here!

**Comment [GS26]:** Suggests the need for adjustment, coming to terms with the difference? There are hints here of this without the details

**Comment [GS27]:** Me in the background saying "yes absolutely"

**Comment [GS28]:** Personal recognition is raised as a quality statement here?

**Comment [GS29]:** Uses bright and familiar tone here.

244. sweet because I don't I don't know if what they could offer  
245. me I'm not doing already but they are just checking up to  
246. make sure that you know may be Pre-school's happening  
247. or may be you know I'm feeling okay or you know umm I'm  
248. trying to think what they, just checking that Bernard's sort of  
249. healthy and nice, just that little bit of sort of extraneous is nice  
250. and I don't think as I say that they couldn't, probably couldn't  
251. recommend anything I'm not already doing but it's just really  
252. nice to say to have them to pop round so I feel sorry "health  
253. visitors for forgetting you cause you were very nice" (laughs) um  
254. I'll put you over **here**.

**Comment [GS30]:** As Barbara writes them on the diagram she puts a border around them and qualifies our discussion by writing 'very helpful in beginning - still check in

**Gina:**

255. It sounds when you said that as in the plural so its not a  
256. particular...

**Barbara:**

257. I've had quite a lot yeah (laughing) because they change in the  
258. three or so years they change and so a couple have **moved**  
259. away and things but its very nice because I say they all knew  
260. who I was I think there was may be a team of 5 started off with  
261. one but she moved away the other one would go "Oh I know  
262. you!" and come and you'd still feel that they did know you, you  
263. didn't have to retell your story which is very annoying you know  
264. to someone who didn't know who you were umm so they you  
265. know they all you know I know all of them by their first name  
266. "**hello**" so um they were fab in the beginning, absolutely

**Comment [GS31]:** I sound surprised here because I know that my health visitor still works in the same surgery 20 years after my eldest son was born!

**Gina:**

267. And they sort of prompt the visit themselves and come to...  
268. your home?

**Barbara:**

269. Yeah they ring up and go "oh just checking up on you...you  
270. alright?" and I go "Yeah, come on" (laughs) "Come on round"  
271. so **I don't know how many times they came round in**  
272. the beginning numerous occasions .....

**Comment [GS32]:** Raises some important issues in this bit, again raising the importance of the personal touch, also highlights communication between the team of professionals, is clearly pleased not to have to retell the story and likes the fact that their communication is friendly, she is pleased to know them by their first name and they communicate in a way which suggests to Barbara that they are pleased they know her

**Comment [GS33]:** I say brilliant

**Gina:**

273. Were they kind of um did they make that quite organised?  
274. Did they sort of say "Right I'm coming on a Wednesday and I'll  
275. be back again next Wednesday?" Or was it a bit more ad  
276. hoc than that?

**Barbara:**

277. Umm, I think that and ad hoc as well to be honest, yes I think so  
278. yeah I had a regular slot which was weekly for a  
279. little while and um and one if I'd wanted one of them  
280. one of them would have popped round I think ad hocly  
281. probably, probably did I expect to be honest (laughs)

282. so that was nice so I would feel I could ring them, I  
283. don't know why I would because I'd probably go  
284. somewhere else that's nothing to do with them not  
285. being able to help me but I think I've got more  
286. direct channels in place umm.. possibly um and  
287. because they they're not experts at Down's  
288. syndrome they are experts with babies which is  
289. essentially what Bernard is (laughs), you know but umm if I  
290. had anything specifically I don't I'd go there first but um  
291. didn't want to miss them out (laughs)

**Comment [GS34]:** Keen to label the area of expertise as in the first interview implying that the categories count when looking for particular advice and support

**Comment [GS35]:** I say absolutely in the background - it will be a useful area for me to check when interviewing other parents

**Gina:**

292. From what you've just said to me it almost  
293. sounds as if it was not just about Bernard it was actually  
294. meeting a need within yourself, so it wasn't just  
295. Down's syndrome it was, it was to do with how  
296. you were and they were meeting that need does that  
297. sound...

**Comment [GS36]:** I sound quite tentative here could have rephrased 'need' for looking for personal support. In the background Barbara quietly says "absolutely"

**Barbara:**

298. Yes, they were definitely, they were listening they were just  
299. yeah they obviously, I mean I had a bit of a difficult labour  
300. and obviously the shock of having something unexpected at  
301. the end umm they were fab they just came and listened to me  
302. rant as well as yeah helping out with the actual looking after a  
303. baby which had kind of gone out the window a little bit cause  
304. "woo yes I have a baby as well" (laughs) as well as all these  
305. extra things that had sort of appeared they were brilliant  
306. actually, yeah. So I think that's, when you go  
307. I'll probably think of more things but I don't think so  
308. cause I've had a week to mull on it (laughs)

**Gina:**

309. Well I'm happy to bring this back every time  
310. we meet actually and I know we've only got one more  
311. meeting and then we need to look at something else  
312. as well but um I'm very glad that that you've actually  
313. added to it because err its nice to hear your reflections  
314. on what you've done there in relation to the other things  
315. you've added so that's super so... describing yourself, if I was  
316. to describe you what would I say

**Comment [GS37]:** Pointing to the areas defined by the sun. This section acts as a marker to remind both of us of the time we have left.

**Barbara:**

317. (Clarifies whether I mean as a family which I confirm)  
318. Well my immediate family are a little family of 3 umm  
319. I come from a family of 4 who are local and been local  
320. (laughs) all my life um although I did go away to university  
321. lived in the north for 7 years umm but I missed here (laughs)  
322. and came back umm yeah.

**Gina:**

323. How long before you had Bernard did you return to this  
324. area?

**Barbara:**

325. Lets think about 3 years, I returned then um got a job teaching  
326. down here and met my husband and yeah... got pregnant  
327. just after we got married (laughs) so yeah so urr yeah been  
328. here about 3 3 years I think just about yeah .

**Comment [GS38]:** A little hesitant here, I felt Barbara was not sure of the information I needed and I could have explained more clearly as I just want to be able to paint a picture of who she is as part of her story using her words rather than my own.

**Gina:**

329. And did you move into this house just after you got married or  
330. had you been?

**Barbara:**

331. Umm, I had a flat which I'd sort of managed to buy myself when  
332. came back being single, then met my husband and he moved in  
333. urr and we realised a one bedroomed flat was just not big  
334. enough umm and we planned to move anyway but because  
335. I got pregnant quite quickly after we got married it kind of made  
336. it (laughs) quick we have to look somewhere so we moved here  
337. I think I was 36 weeks pregnant when we finally moved in here  
338. err which was a relief to say the least um yeah

**Gina:**

339. So it was quite a close um thing between moving in here sort of  
340. and actually giving birth to Bernard so two big changes going on  
341. at the same time...

**Barbara:**

342. Yeah, it was all very exciting at the time, absolutely umm but  
343. yeah I guess there were a couple of big things going on you, you  
344. realise afterwards they are probably quite big aren't they  
345. but its all exciting yeah

**Gina:**

346. And if you were to describe this area that you live in, how  
347. would you..

**Barbara:**

348. Err in what, in what sort of way?

**Gina:**

349. In terms of the sort of housing structure the kind of near  
350. to this place or that place without using any names of the  
351. places?

**Barbara:**

352. Urr, I guess you'd call it a housing estate umm I'm

353. not entirely sure what you **mean**

**Comment [GS39]:** I can feel myself getting uncomfortable as I pick up that Barbara is hesitant about what I am asking perhaps due to the lack of clarity and also wanting to provide the information she thinks I am looking for.

**Break in the tape to have a brief discussion to clarify the information**

**Barbara:**

354. Yeah, umm it is a housing estate I would imagine  
355. mostly privately owned um  
356. it is bang slap in the middle to two cities  
357. which is very good (laughs) um easy access  
358. to motorways umm lots of facilities around, umm  
359. we're not sort of leisure centres and um  
360. community centres, a wide range of shops  
361. urr

**Gina:**

362. Yup that's lovely thank you, thank you for that and um  
363. I hope you are happy if I was to describe your ethnicity  
364. as white British, **would** you describe yourself? Lovely  
365. thank you very much. If you, as you look back over your  
366. life umm in terms of just sort of growing up and making  
367. decisions and things like that about where you are now.  
368. What do you think might have been the main influences?

**Comment [GS40]:** Barbara says yes in the background

**Barbara:**

369. It is really difficult but I think influences in how I feel now about  
370. my **situation** .....I think I always was brought up in quite  
371. I'd say caring family, my mum always her role in her occupation  
372. was primarily, I think, to be quite a people person to look after  
373. people to care for them to guide them and that sort of **thing**  
374. and I think from early on I always knew I wanted to work  
375. with children umm so and yeah I've always wanted to be a  
376. teacher umm and I think I just generally urr, possibly not  
377. following in my Mum's footsteps, she used to be a teacher  
378. as well but I just, that was just where my head was at all  
379. the time (laughs) um so ....mmm it's difficult to think of  
380. influences but I just think that naturally as a child and has I  
381. grew up I think I say had a caring nature, I don't mean it  
382. big **headedly** I always wanted to help people and I  
383. wanted to in a way always be quite upset if it didn't, if  
384. people weren't the same as me, I'm quite like that as an  
385. adult **actually** (laughs) um so I trained to be a teacher  
386. and I just thought that I always wanted to go that ...  
387. I wanted to go that extra mile and I really felt and children  
388. in my class I would really look at individually ...and really  
389. try and see them as a child not just trying to get results you  
390. know trying to work with the parents so I think that's what  
391. I've expected cause **now** I'm on the side if you like so I don't  
392. expect it but I know that I get upset if it doesn't happen  
393. because I think that's not how I how I work if you like, does  
394. that make any **sense**? I think yeah I've always wanted to

**Comment [GS41]:** I say yes in the background

**Comment [GS42]:** Uses a measured tone as if thinking carefully as she speaks

**Comment [GS43]:** Suggests that caring is an important quality? Perhaps an important criteria when receiving support?

**Comment [GS44]:** This may have a link to expectations although it is interesting that looking back over what Barbara has said she is not inclined to criticise people who have provided support for her

**Comment [GS45]:** I wonder if she shares her disappointment with the professional would they know if she was upset?

**Comment [GS46]:** I say it does make sense to me yes definitely I can I can hear what you are saying there, perhaps should have asked for an example here?

395. to sort of help and support people and now I'm definitely  
396. on the other side err where I need that help and support  
397. I do, I want it to be ...I want it to be helpful (laughs) and I  
398. want it to be individual and I want it to be with an element  
399. of umm definite caring as if its just me as if the only  
400. person actually you know umm rather than just a list  
401. or or just an appointment I think that's, that's really important  
402. to me umm and that is based on how I am as a person I think  
403. ....I'm trying to think of other influences what sort of, can  
404. you give me an example

**Comment [GS47]:** Strong emphasis here in the tone of voice

**Comment [GS48]:** These wants seem very important to reflect on in relation to her experiences

**Gina:**

405. Umm I'd rather just hear what you think how you'd interpret it  
406. because obviously I don't want to put words into your mouth  
407. umm about it...umm do you think there have been influences  
408. from Brian in all of this..as well does he influence what, what  
409. your expectations are or how you regard things?

**Barbara:**

410. Yes he does and he's actually umm he's very different to me  
411. in that respect actually umm I would I would come back  
412. say I came back from an appointment that didn't go well  
413. for whatever reason I'd be upset by it, Brian would be very  
414. very gung ho with "go back and make sure you say this and  
415. why didn't you say that or you know I'll come with you next  
416. time and we'll sort it out" You know we we're very good  
417. together actually because we have the middle version of me  
418. being the, I don't know wanting everything to be just beautiful  
419. and rosy and him being the very direct person and usually you  
420. manage to sort of meet in the middle umm so yes he has  
421. influenced me cause I think he's maybe slightly stronger in  
422. terms of making sure I say what I want to say when I go to  
423. places umm, you know make sure I come away with all my  
424. questions answered rather than just saying "yes okay  
425. thank you very much" and leaving um that kind of thing and  
426. yeah making sure that I yeah achieve my goals in terms of what  
427. we want from that appointment or sometimes doesn't work  
428. but um he's definitely influenced definitely in a good way I think  
429. we are quite err um a good team in that respect cause we  
430. are very, I would say we are quite ends of that sort of spectrum  
431. but um meeting in the middle we usually come away fairly  
432. satisfied knowing you've been nice (laughs) and  
433. appreciative and um friendly and also knowing you've got what  
434. you wanted without perhaps sounding mean or kind of...

**Comment [GS49]:** Uses a slow strong voice as if he is confident in what he is saying

**Comment [GS50]:** An example of this not working would be useful to have a contrast with things that do work linked to the helpful/unhelpful theme

**Comment [GS51]:** This sounds important to Barbara this is qualified as she goes on with this point

**Gina:**

435. And that would worry you if you felt you had?

**Barbara:**

436. If I felt I had to be mean, yes it would just because

437. that's not in my nature but umm I'm getting a lot  
438. better because at the end of the day its  
439. about Bernard isn't it? its about getting what you  
440. want umm for your child but it's also about being  
441. reasonable and also from being a teacher I know  
442. its sometimes really hard job really you know and I make  
443. sure that if something's gone really well I've  
444. make sure that I tell those people and say  
445. "wow that's fantastic" because if I'd worked really  
446. hard at something in school and a parent comes  
447. back and says "that was brilliant, my child loved  
448. that" that that feels fantastic, if you worked hard on  
449. something and come back and say that was  
450. awful (laughs) and you've then you've got to terrible  
451. so it's the meeting of those two ways of thinking  
452. I think yeah definitely....

Comment [GS52]: Implying it is a weakness

**Gina:**

453. Thank you yes that's really helpful um and if you now  
454. looking at the subject support which is obviously  
455. the centre of what I'm looking at. How, could you  
456. define, in your own, could you put it into your  
457. own words as to exactly what it means for you?

**Barbara:**

458. Umm, I mean good support in whatever that comes  
459. under which is huge looking at my um picture  
460. is the umbrella is huge but good support is actually  
461. the difference between having a good and  
462. a bad day. It's the difference between feeling included  
463. and accepted and actually feeling isolated and  
464. abnormal, (small laugh) its that, its that  
465. important that one appointment or one visit if it goes  
466. wrong or isn't good for again for what ever reason  
467. because it is so huge can  
468. actually leave you feeling kind of awful again for  
469. whatever reason and a good appointment can make  
470. you feel on top of the world and feel you can achieve  
471. anything so support for me is so and it has changed  
472. through the three or so nearly three years but support  
473. for me is about feeling positive about your situation  
474. and feeling that you are entitled to and can achieve  
475. anything that you want and if there if that's underpinning the  
476. support then I'm, I'm a happy lady (laughs) yeah

Comment [GS53]: Uses a measured and considered tone throughout this definition key words seem to be individual, caring and positive which leads to her feeling empowered

**Gina:**

477. Thank you. Just as a matter of interest do you think  
478. Brian would have, would have described it  
479. very differently to that or do think he would have  
480. probably ...

**Barbara:**

481. He would definitely describe it differently, absolutely  
482. without a doubt, a lot of it because um just cause our  
483. circumstances, he still, he works full time is a lot of  
484. it I do on my own umm and I, I am quite happy to  
485. do that and that's the way our sort of our family  
486. situation is but I think he wouldn't um probably pin so  
487. much of his feelings about how he feels on how  
488. things have gone but I think as I'm the prime sort of  
489. the primary carer of Bernard it does affect me cause  
490. it's a large percentage of of my life and of how I go about  
491. my life and so (laughs) so umm yeah err  
492. he wouldn't describe it like that at all err he would just say  
493. I'm sure he would probably say, yeah if it's good its great for  
494. Bernard if it's not just ignore it! Probably (laughs very  
495. enthusiastically) and he'd probably be more black and white  
496. I think (laughs)

**Comment [GS54]:** Attributes feelings to the amount of time spent in receiving support rather than her personality?

**Comment [GS55]:** Uses a very matter of fact tone here

**Gina:**

497. Right, that's helpful thank you

**Break in the tape to allow a short space before moving on to the next subject**

**Barbara:**

498. Um Brian comes from err large and slightly unusual family  
499. he umm was originally err born in South Africa and  
500. now his family live in Scotland um he has quite a lot of  
501. half sisters kind of scattered about but he does have  
502. he does his sisters are in fact half sisters but they  
503. are not they are his sisters um and they live with his mum  
504. umm up in Scotland but um we keep in regular contact  
505. with them they absolutely adore Bernard think he's  
506. amazing which he is umm so they are very much urr good  
507. support network as well. They are almost fun fun side  
508. support because they don't see any other bits they don't  
509. they don't see the day to day bits that are maybe not  
510. so great they see fun (laughs) you know so umm

**Comment [GS56]:** Implies challenges without details

**Gina:**

511. Do you have contact with them very regularly, I suppose being  
512. where they are? Do you get to go on holiday or do  
513. they come to you?

**Barbara:**

514. I'd say twice a year we go up umm we've actually  
515. got a couple of visits coming up, they're coming down  
516. to see when they can umm we alternate Christmases  
517. down here down there that sort of thing so its all

518. and probably weekly we'd keep in contact at some  
519. at some point um phone, text keep them updated send  
520. pictures that kind of thing, again linking back  
521. to the sort of networking sites all the family are on  
522. there, so that's how they get to see pictures and that  
523. that kind of thing as well more instantly than perhaps  
524. sort of posting them up (laughs) or that sort of thing  
525. so yeah

**Gina:**

526. Thank you a question that's just occurred to me is  
527. um is Bernard an only grandson to either side  
528. of the family? Oh right.

**Comment [GS57]:** Barbara says yes both sides which is cool

**Barbara:**

529. Absolutely yeah

**Gina:**

530. It just occurred to me because sometimes that makes a  
531. difference in a family a bit doesn't it?

**Barbara:**

532. Like a family or eight not like (laughs) no no he's the  
533. first one

**Gina:**

534. Okay thank you for that. So um Barbara what I wanted  
535. to do is just was just ask you the question about  
536. if you could give me the history really of how things  
537. have evolved through support um since Bernard was born?  
538. I don't know exactly where you want to start but I want  
539. to give that to you really.

**Barbara:**

540. In terms of what what we first had?

**Gina:**

541. From the beginning of the story if that's okay with you?

**Comment [GS58]:** My tone is tentative with the aim of giving the decision to Barbara

**Barbara:**

542. I think I'm going to need to use this really umm  
543. so the very beginning well the very beginning to be  
544. honest was in hospital and was with the way we were  
545. I say treated, sounds slightly harsh but um the way  
546. that the doctors were with us and what support they  
547. gave us because I think, I think how you leave the  
548. hospital your frame of mind depends how you were  
549. in the hospital umm so we actually had some really  
550. lovely um doctors and the one in particular that was  
551. looking after Bernard very sensitive and very positive

**Comment [GS59]:** Points to her picture of support

552. actually nothing that particularly scared me or that he  
553. implied that we needed to do or anything like that  
554. and they were actually very positive saying how  
555. lovely parents we'd be and that's fine you know (laughs)  
556. we were given lots of leaflets to look through as I think  
557. I've previously said um but that is that was probably  
558. the first bit of support cause that does shape how you  
559. then leave the hospital (laughs) um and how you  
560. feel

**Comment [GS60]:** Listening to this I wonder what Barbara meant here?

**Gina:**

561. Could you tell me if, if you would, how did they actually  
562. talk to you about the diagnosis initially?

**Comment [GS61]:** I'm looking for clues about the attitude that professionals showed to DS

**Barbara:**

563. Um when Bernard was born they suspected it but  
564. in a very fifty fifty kind of way because, there were things  
565. about Bernard that didn't really add up in terms of  
566. Down's and things that didn't add up in terms of not  
567. having Down's umm so they were kind of he may or  
568. may not have so (laughs) we were stuck in limbo for  
569. a little bit and I think he was born on a Thursday  
570. and then over the weekend blood tests don't get done  
571. or something so we didn't really know for sure for  
572. four days which ..that was the worst part because  
573. I think people didn't want to talk to us about it in case  
574. it wasn't an issue so for about four days no one really  
575. spoke to us err about it, it was a bit of the elephant in the  
576. room if you like um which I found quite upsetting and I  
577. think umm Brian and I had had a discussion and said  
578. come on what's your gut reaction about this what do  
579. you feel does Bernard have Down's syndrome and we  
580. both he does ....

**The interview was suspended for a few minutes because Barbara became emotional and needed some time before moving on. Before doing so I checked this she was happy to continue and she explained that she was.**

**Barbara:**

581. Yes we had a bit of a wait but um my husband and  
582. I said that our gut reaction was that err Bernard  
583. did have Down's so we started that process before  
584. anyone really umm anyone really um anyone wanted to  
585. acknowledge it which I found quite upsetting because  
586. over the weekend I was having all the big thoughts of  
587. everything that comes in your head about Down's syndrome  
588. umm and nobody was there to talk to or umm that kind  
589. of thing however when I mean um I remember we had to  
590. take Bernard for a heart scan, I think of the Monday when

591. we came back our room was suddenly filled with people  
 592. (laughs) we thought hmmm, wonder what they're going  
 593. to tell us you know, midwife, couple of doctors, a nurse  
 594. just thought yeah you're going to tell us now because  
 595. you've got the results now we were you know ready  
 596. we knew what they were going to say umm and at that  
 597. point it was still upsetting and that was reality because  
 598. we were being told by a consultant who was very lovely,  
 599. very softly spoken let me have a cry and just sort of...  
 600. I don't remember him saying anything negative  
 601. or anything at all so I was pleased, very glad about that  
 602. umm and then once that happened everyone came in  
 603. it was lovely and was just you know just fantastic  
 604. treated us completely normally umm having had that sort of  
 605. three days of no one saying anything and having a private  
 606. room and being ushered away I think nobody really knew what  
 607. to say and to be honest looking back I don't really know what  
 608. they could have said, I'm not sure what I would do its very  
 609. difficult because umm not sure what I wanted in those  
 610. sort of three days to be honest I think I wanted someone to  
 611. say no he hasn't got Down's probably looking back (pause)  
 612. I don't know what I wanted, how I wanted to be treated but  
 613. we just felt that nobody really spoke to us beyond the  
 614. niceties of coming in to check I was alright and things (laughs)  
 615. like that umm and I didn't have Bernard with me either because  
 616. he was in special um special care so it was all very weird  
 617. umm so that that going back that was the first kind of support  
 618. having and then off they pootle leaving you with lots of  
 619. leaflets to look at and umm and sort of sift through . I guess  
 620. I knew a bit about Down's syndrome before, being a teacher  
 621. I'd had a girl with Down's in my class urr for two years actually  
 622. so I knew I knew umm, I guess the bear minimums and I'm  
 623. quite embarrassed to say, really I didn't know enough didn't  
 624. know enough at all ummm even though I'd had a girl in my  
 625. class with Down's but that also links back to how times are  
 626. changing umm we're talking mind you only tenish years ago but  
 627. when she was in my class we hadn't got a clue, nobody  
 628. had a clue she had none of this I would say if you  
 629. asked her to write down a pictorial representation of  
 630. support it would have been pitiful it would have been  
 631. awful and um we we struggled you know with  
 632. the school umm to get support for her and that sort of thing  
 633. and umm, I yeah, I didn't know enough, I should (low laugh)  
 634. have known lots more but I didn't, it wasn't available and  
 635. it wasn't there .....yeah but then you don't know until it  
 636. properly happens to you do you so umm so yeah  
 637. so knew a bit about it knew it knew it wasn't as awful  
 638. as some people kind of I guess make out make it  
 639. some hideous thing but at the same time you are  
 640. struggling with the fact that it is not supposed to happen

**Comment [GS62]:** Changes her tone here to suggest they knew very well what they were going to say

**Comment [GS63]:** Barbara's tone sounds celebratory here

**Comment [GS64]:** I say "right" gently in the background

**Comment [GS65]:** I wonder if they would treat everyone the same as for some people leaflets may not be the best way to be introduced to support?

**Comment [GS66]:** Sounds disappointed in herself here

**Comment [GS67]:** Pointing to her picture of support

**Comment [GS68]:** Says this with emphasis

**Comment [GS69]:** Sounds as if she is pondering on this and then changes her tone back to a more confident and measured level

641. to you that's not what you planned umm your nine  
 642. months of picturing what your child is going to look  
 643. like what they're going to be like what their  
 644. personality is going to be like how brainy they're  
 645. going to be all those sorts of things that you enjoy  
 646. for nine months chatting with your partner is suddenly  
 647. absolutely gone. In that ten minute conversation  
 648. and um and that's that's..that's the biggest thing that's the  
 649. biggest thing of all umm to get your head round, now  
 650. Bernard couldn't have been anyone else (laughs) he  
 651. that's who is was supposed to be and that's who we  
 652. were supposed to have you know...

**Comment [GS70]:** Sounds as if she is reading off a light hearted list that represents normal behaviour

**Comment [GS71]:** Sounds very final and definite here

**We pause here again as Barbara is a little emotional and needs a few minutes to collect herself. Again I try to support her gently here and aim to make sure that she is in control of whether we continue at this point**

**Barbara:**

653. That is an example of how how your support  
 654. changes and how you change because now  
 655. Bernard is my son he couldn't be anything else um and  
 656. that's that there is no more but at the time  
 657. he wasn't really who I was expecting to give birth to  
 658. at the end (laughs) of nine months and that was  
 659. odd very odd.

**Comment [GS72]:** The tone is quite matter of fact at this point

**Gina:**

660. How long did you stay in hospital for?

**Barbara:**

661. I guess in total (laughs) probably about  
 662. a week err quite a long labour I had an  
 663. emergency C section in the end and then  
 664. Bernard was in special care for I think  
 665. two or three nights I think probably about  
 666. a week in total which in a way worked out  
 667. quite nicely cause you had that breathing  
 668. time you had that time, not home haven't got  
 669. to start my life yet (laughs) umm Bernard  
 670. wasn't with me for a while which was awful at  
 671. the time but again gave us time to just to umm  
 672. talk a lot and um and um sort of get our heads  
 673. as much round it as we possibly could so  
 674. when we got home we'd kind of done all the  
 675. not all of it but um kind of this is, this is our life now  
 676. now we are home

**Comment [GS73]:** Exhales a breath here

**Gina:**

677. And you'd presumably Bernard was  
 678. whilst he was in special care was having

Appendix 4: Example of Interview showing my additional notes for Barbara to comment on

679. all the all the sort of regular, not regular  
680. but the extra checks you've said about  
681. the his heart and...

**Barbara:**

682. Yes, they immediately went into sort of Down's  
683. syndrome over drive but um and luckily for  
684. us he was is was as fit as an ox...he was only  
685. in intensive, in special care because I think  
686. I think his oxygen levels were slightly low  
687. umm I think mainly due to the stress of the birth  
688. to be honest um but it did give them a good chance  
689. to sort of check him out cause there are health  
690. issues linked to Down's um but um he was um and  
691. remains really healthy which we is an absolute blessing  
692. because I'm sure um that can be such a massive  
693. thing on top of that especially the little babies that  
694. have massive heart surgery and things like that  
695. can be can make a massive difference, I think um  
696. so yeah really blessed about that cause err cause he's very  
697. healthy (laughs) umm so that was yeah that was  
698. the first support um then off you go home (laughs).

**Comment [GS74]:** There seems to be some ambiguity over the time Bernard was away from Barbara, when she talks about being separated this seems significant to her but here she infers that the medical side of things was without too much concern

## Appendix 4

### Interview extracts that show examples of positive experiences of support

Int 1: Alfred - 17<sup>th</sup> June 2009 9.45 – 10.45

1. Well with my wife and all the family around me
2. I've got them to support me when my wife goes
3. away on holiday. So when Andrea is away it's a
4. lot easier for me to to um correspond with all the
5. family as well.

77. Well she's [Portage worker] helped our daughter out, well they've helped  
78. our daughter out and our son, basically with everything that  
79. they need to do and that well apart from that I can't  
80. fault anyone else...

Int 2: Tasmin 19<sup>th</sup> August 2009 12.15 – 12.48

103. actually um Tony's key worker is also the woman who  
104. kind of leads the toddler unit so it's quite good um  
105. and she's very you know he's, he's established quite a  
106. good relationship with her actually um and I feel  
107. quite confident that you know they'll kind of give him the support  
108. that he needs,

329. so I went to the twins club primarily cause my health visitor  
330. suggested it and what I liked particularly about the twins  
331. club is um obviously everybody's got two children, not  
332. everybody's got children as badly behaved as Tony  
333. but at least they kind of appreciate that you know while  
334. you're doing something with one of them the other one  
335. might be running riot and nobody kind of flickers really

Int 3: Ruby 10<sup>th</sup> August 2009 8.00 – 8.30p.m.

179. Err I think I mean as soon as I went in there (KIDS) I  
180. felt a sense of warmth, being welcomed, um cause  
181. obviously we went to look around umm and as  
182. soon as I walked in, you know the staff were so  
183. friendly I liked how everything was set out

281. Yeah coz err Reece's pre-school are always asking

282. you know an update from KIDS you know what the speech  
283. therapist has been doing with him so they can you know  
284. do a few bits I mean I know that um as you know  
285. with Reece they've diagnosed the muscles so um  
286. I told the pre-school that they're you know sort of blowing  
287. bubbles like through a straw or kissing you know a bit of  
288. paper or something like that so ... the following week  
289. the pre-school got all the children to you know get  
290. straws out and start blowing bubbles into water so  
291. obviously Reece didn't feel excluded you know so it seems  
292. even though they haven't met you know obviously  
293. everyone's working, working all together.

Int 4: Andrea 22<sup>nd</sup> July 2010 10.30 – 11.30a.m.

9. Um, the support has got a lot better actually  
10. um, we've got a lot more support now err  
11. we have all different things in place for her  
12. um like there's, she's in a special class for  
13. um her school and she gets a lot of support  
14. there she's got her physical therapy carrying on  
15. through school and her speech therapy all the way  
16. through school so ..school's been very supportive

195. The physio-therapist has told me what to do anyway  
196. so I do that every day for her (right) so we jump on  
197. the trampoline (she laughs) all that sort of stuff  
198. so its quite easy but you know when she gets cramps  
199. and all that and she gets quite bad cramps I have to  
200. sit there massaging they taught us how to do that  
201. so the physio-therapist she's very good but we haven't  
202. seen her for ...about nine months now, so its been  
203. a long, long time.

### **Interview extracts that show examples of negative experiences of support**

Int 1: Tasmin 12<sup>th</sup> August 2009 12.15 – 12.45p.m.

38. so I can get some support, practical  
39. support but not very much emotional support I I  
40. suppose so I'll put that on here I'll put practical is  
41. support as okay .....um but emotional support  
42. may be a bit lacking um ....because they don't  
43. understand

358. seeing quite a few people um and the only additional  
359. people he'd be seeing there would be the community  
360. physio and a um OT, an occupational therapist and  
361. so what she did cause I did say to her I was happy to do it but it's  
362. a real pain in the neck to go to that city for me and obviously  
363. I've got the two of them and I haven't got anyone I can  
364. um leave his sister with in the day so they'd both  
365. have to go trekking of to wherever we go um and um

Int 2: Catherine 4<sup>th</sup> August 2009 12.30 – 1.00p.m.

270. Probably just having more of a conversation with me  
271. than sort of trying to pre-empt what I was going to say and  
271. sort of trying to pre-empt my needs by  
272. saying "right" you know "I've bought these for you, I've brought  
273. this leaflet for you and this is what you need to do and  
274. go to this group and I've arranged transport for you" and  
275. its like I can actually drive you know (laughs) and nobody  
276. asked any sort of remotely sensible questions really in  
277. my in my opinion anyway...

Int 3: Alfred 15<sup>th</sup> July 2009 10.00-10.30a.m.

17. In the school of education board they don't  
18. seem to want to know anything about  
19. um dyslexia, autism or anything else. I can't  
20. see them um getting um that sort of education  
21. until everyone realises and puts themselves  
22. together and everyone gets their finger out of  
23. their bottom (I say "right") to err do something  
24. about it basically...

99. Well in the past I would say that the board don't  
100. realise and don't understand what is going  
101. on with people with learning difficulties  
102. they just think that everyone's all normal  
103. to them and if there was someone in that  
104. board who had autism or who couldn't understand  
105. and got to read lips or whose deaf and got

106. to use sign language why can't they put  
107. them forward to translate every word what's  
108. going on sign language, Makaton or just  
109. someone um who knows what's going on instead  
110. of um just...

Int 4: Barbara 2<sup>nd</sup> August 2010 2.10 – 3.00 p.m.

79. um coz then obviously we had to go  
80. and apply for a statement ...err for Bernard umm which was kind  
81. of bewildering cause although my background (she laughs)  
82. when its your own child, umm I've never done anything like  
83. that before, didn't know the process and a bit of me felt that  
84. some people thought that I did? (right), which I didn't, I know what  
85. they are and I know what they are used for

524. you're the professional glasses, fitter people.  
525. And um I was there for two hours and I knew in my mind  
526. I needed to kind of say "hang on a minute you're not giving  
527. me any advice on fit here" but I didn't and went home and  
528. went "this is awful" but by the time I'd kind of got to that  
529. point Bernard had been in the push chair for two hours  
530. and was getting grumpy

541. it depends on your mood and it depends how you're, that actually  
542. annoyed more than at the moment to something like therapy or  
543. something big, something small, where you think I'm just a parent  
544. that wants to get glasses for their child and I can't that's  
545. more annoying to me at the moment than, than something  
546. large (yes) linked to Down syndrome, you know something  
547. big, it's just the little things where you think that shouldn't be that  
548. tricky just to get a pair of glasses that fit

569. and sometimes the Facebook thing has attracted not with  
570. me personally but I know it has attracted sort of unwanted umm  
571. comments (right).

**Observation of the Andrea and Alfred receiving support from their Lead Professional on 19<sup>th</sup> August 2010 3.00-3.40p.m.**

When I arrived the family support worker was in the living room and greeted me wondering whether she should have met me outside of the home first. I reassured her. I noticed an atmosphere of tension, which seemed to stem from uncertainty about what everyone should be doing. The lead professional (L.P) 'broke the ice' by talking to Andrea and Alfred about the changes to the living room. I noticed that she asked how long ago they made the changes and instead of answering this Alfred told her how long it had taken him to re-plaster the wall.

*The response helped me to see how easy it is to mishear a question and begin to give different information to that which has been requested. The LP listened to what was being said and included gestures that implied she was impressed. I was interested to see that she did not ask the question again and wondered if she was aware of what had happened and was using the conversational style as an icebreaker.*

The LP followed this by pointing out that the dog was a new addition to the home. As she moved and asked where she could sit I gave her the consent form to read and sign. This gave me an opportunity to view the room and its inhabitants. The LP sat on one settee at the far end with her body turned towards Andrea. Andrea sat at a distance from her on the same settee with Andrew on her lap and Amber next to her. Alfred stood throughout the visit and occasionally left the room to smoke outside. The television was on which I commented on asking if we were interrupting a good film. Andrea said that it was fine it was a rubbish programme and moved to turn the sound off. It remained on throughout the visit.

*Alfred's behaviour reminded me of my first visit to their home with another LP when he chose to stand and moved around under the pretext of checking to see when his son was being dropped off. I wondered whether he had selected this position for a purpose, perhaps because it gave him an air of authority and enabled him to feel free to move around as was comfortable to him. When I visited on my own, I noticed that he often sat down to talk and chose to sit for the interviews, yet part of his character seems to involve moving as he showed during this visit and when I met him on courses at the Children's Centre, offering to get drinks or leave the room to answer his phone. There seemed to be a pattern of remaining standing when he felt less sure of himself.*

*I watched Andrea hold her children close and I wondered whether she was trying to convey a message of care for them. At the same time her body language reminded me of a protective mother gathering her children near and looking out as if to say "these are mine do not try to take them away". In this way she communicated tension and concern, on guard. While this appeared powerful to me I was aware of the background information that Andrea had given me about the threats to having her children taken away and realised that I may have been reading too much into the scene as a result. Another*

*explanation would be that she felt more secure in having her children close to her, something I could relate to as I remember holding my children if I was in a situation where I felt nervous. In either event this behaviour reflected the idea that the relationship between Andrea and her children was significant and important to her. Whether consciously or unconsciously presented and I wondered whether when the LP commented that Andrea seemed more settled she was acknowledging a difference in her behaviour from a previous visit.*

Once the LP had sat down she took out a pad of paper and a pen ready to record the key issues. She introduced the subject of TAC meetings explaining that one had been cancelled and that another one needed to be set up. Andrea and Alfred remained passive. When the LP asked about the school Alfred sprang to life forcefully saying that they were not happy and explaining what had happened on sports day when he had to “step in and help our daughter”. He pointed out that they had been told she would have support on the day and he thought that this should have been offered. To reinforce the point he told her that she had developed cramp.

*This challenge seemed to come out of nowhere and was directed towards the LP although it was a situation for which she had no responsibility. I wondered if this reflected his desire to exert a role in the situation rather than present himself as a passive victim of the situation where the LP had come to take charge in ‘his home’.*

I noticed that the LP managed a mixture of writing and showing that she was listening. She clarified Amber’s age as six and was corrected to five with Alfred jokingly saying “don’t wish that on us”. She talked about their actions on the day and the names of the teachers involved, asking whether the problem had been raised at the time. The questions were direct beginning with when, what who?

*I noted the reaction of the Andrea and Alfred. Andrea remained quiet and did not add anything and Alfred gradually became calm. It appeared that his joke with the LP helped him to make a connection with her and lightened the situation.*

They concluded this interchange with Andrea saying that the school had agreed to sort it out next year. The LP said that it was strange because they normally offer good support which Andrea agreed with. She said that she would raise it at the next TAC meeting.

*I wondered how Andrea felt about Alfred raising this subject as they did not seem to be in harmony over it which suggested that they had not agreed what they would raise with the LP prior to the meeting. I noted the fact that the LP was showing her support by telling them what she intended to do.*

The subject moved on as the LP asked about how Andrea was coping. At this point Andrea and Alfred were keen to share the good news that Alfred had secured a permanent job which led to a discussion during which they talked

about the pay and the LP confirmed that it was lorry driving which is something he had experience of.

*Although Andrea introduced the subject I noticed that this provided a lead in for Alfred who immediately continued by telling the LP his weekly wage. His body language noted his pride in being able to pass on the information. I found myself wondering how these details may impact on the benefits they currently receive and whether this was something the LP was also thinking about.*

The LP talked about how she had observed that Andrea copes well when Alfred is away. [I later found out that she had visited when Alfred and Andrea split up for a month in March]. Andrea agreed that she could, looking pleased that this had been acknowledged.

*I was surprised by this as it communicated Andrea's ability to manage without support, something she has previously told me she struggles with. This left me wondering whether there was a contradiction in the way that Andrea presents herself so that on some occasions she seems confident and on others in need of help and that because of the inconsistency she is not taken seriously when she does cry for help. I made a link between this and the manic depression she described on my visit for the final interview realising that she presents herself according to how she is feeling on the day which may have a significant impact on the support she receives.*

As the LP then asked who could give her some additional support when she needed it I thought that perhaps she realised what I had been thinking. She asked about whether her mother or mother in law could help but she said no due to poor health and in her mother's case the fact that she does not have a car. Andrea then spoke enthusiastically about another mum, older than herself who lives locally and has 5 children. The LP looked pleased and asked her where she lived saying it was good to make a connection with another parent who she had something in common with. She moved on to ask about how they were coping with the children on holiday. Alfred answered drawing the conversation back to his job saying it had been "hectic". Andrea took a different position talking about the things they had done. She said that they had been black berry picking and cooking, housework, finding "local things to do". The LP said "getting the children involved, brilliant, brilliant".

*I realised that making a new friend felt really positive as Andrea smiled and looked pleased. I also noted that this links to the value I place upon having friends to share things with. I noticed that Andrea appeared very pleased with the feedback and that this encouraged her to talk further about Amber's role in polishing explaining that she had to avoid giving her the polish when dusting, laughing at the likely consequences.*

The LP said "you seem a lot happier, did you make use of the play schemes?". Andrea said she hadn't needed to because she was fine, saying she had done cake baking with Amber on the day that it had been arranged.

*I was interested to reflect on this subject because they had raised it as an issue the previous year, expressing disappointment that they had missed the chance for Amber to go along. This time she seemed proud that she had not needed it suggesting that it was a place of last resort and she had avoided that. I wondered whether the example of cake making was presented to reinforce a picture of being a 'good' mum. I also considered the implications of not taking up the place that was booked for her. Perhaps another family could have used that instead?*

As the LP asked if there was anything else they could say in front of the children I became aware of her being conscious that some subjects were best left to another time and that she was showing sensitivity towards Andrea and Alfred.

This prompted a detailed conversation about their concerns about Amanda not eating. This was represented as a recurring problem and involved the health visitor. They were trying scare tactics showing her a film of someone under weight. The health visitor had told Amanda she would have to go to hospital for 6 weeks.

The LP made no comment on this method and asked if this had worked. Alfred cited examples of where food was still being hidden, put in the bin or put under the mattress. Andrea said that she was giving her cereals instead. The LP asked if they knew why she was doing this and they explained that she had been called fat at school. She asked if the school had helped and Andrea said they had on a previous occasion but not now because of the holidays.

As the LP introduced the subject of involving the GP Alfred became strident in his voice and body language citing examples of delayed appointments for both Andrea and Amber. He described getting an appointment as trying to "get blood out of a stone". The LP suggested changing surgeries or asking for another doctor. She also suggested school health become involved.

*I had the impression that the LP was concerned about what she was hearing but wondered if she was making too many suggestions to them. She appeared to assume an expert role at this point where it had been more family centred earlier in the visit. This presented the difficulty that arises when parents tell a professional about their problems and they (and I) instinctively go into 'fix it' mode.*

Amber interrupted the proceedings to announce pointing to each parent "this is my mum, this is my dad". Alfred joked and said that it was the other way around to tease her. She smiled suggesting that she understood the humour.

The LP asked if there were any other concerns and Andrea explained the problem with Amber being rough and trying to strangle, her, the dog and her brother. The LP asked if the person was in the room because she missed the pointing hand gesture and Andrea confirmed that she was. They then go

through the length of time it had been happening for and links to past episodes of violence which led to bruising.

*I found myself wondering what the LP may be concluding from this as she asked about whether Amber had got the idea from a film. Alfred said no because the children are not allowed to watch anything violent. I realised that if I was her I would be thinking about whether she had learned this behaviour through someone she knew being rough with her. I also considered the fact that Alfred had been clear about Amber's chronological delay and that she was operating as a two year old which would mean that she is likely to get excited and due to her size be unaware of the consequences of her actions. Looking at the LP I had no idea of how she may be interpreting the information.*

The conclusion of the discussion was that the LP offered to refer them for family therapy.

*This was interesting as I noticed that she did not ask them what they thought would help but instead offered them an option. This seemed to imply that she thought they could not manage to solve their problems without intervention.*

She gave them time to consider whether this was an option they would be happy with. The LP was clear that if she referred them they would hear in a couple of weeks. She checked looking at Alfred and he said that Andrea should take the decision as he may not be there due to his work commitments. Andrea agreed. She then said that she thought that Amber thinks she is just playing and is unaware of the consequences. She told the LP that she can't joke and so the LP suggested that they try being more literal with her to help her to understand.

*Having noted Alfred's tendency to joke I realised that this may be a difficult thing to achieve.*

Alfred then raised the issue of problems with the neighbours, saying that the children are making nasty remarks and "should know better". The LP agreed and asked if they have thought about what they can do? Alfred said there are many things he would like to do. He pointed out that it is difficult because the adults are also a problem when the children were laughing and making a noise in the garden they threatened to contact social services. The LP asked if they know about the 'Safer neighbourhood team' and explained how to contact them and that a police officer would come round.

*This part of the conversation was sad to hear as I recalled the first visit with the FSW including problems with receiving nuisance calls on the mobile. I also remembered that in the interviews last year they talked about how good the neighbours were compared to those in the previous home.*

The LP summarised this by saying that there are lots of positives and a few problems which led the subject on to Andrea and Alfred asking about getting a grant for carpets in the lounge and bedroom. They explained that this came

through Portage last time who arranged to get the money from the social fund grant. The LP said that she could apply to the local welfare trust and asked how much money they will need. They said about £250 for each carpet.

*I found myself surprised that they were asking for this sum of money as they told me that the carpet they bought with their lottery win for £300 had not lasted well because it had no underlay which made me think that they would ask for more. I wondered whether they had answered this way because they were put on the spot. I realised that this can happen very easily and that between them it would have been better to delay saying an amount until they had got prices.*

When Alfred said that he may not be able to attend the TAC meetings, the LP said it was fine and that they would send him the minutes to read.

*I realised that this may not be meeting his needs as he had said that he is not a confident reader due to having dyslexia. I wondered if asking him how he would like to be kept informed would be better and if they suggested audio recording the meeting this would help.*

I had the impression that the LP was attempting to draw the meeting to a close as she began to talk about the next TAC meeting asking about times they cannot do. Andrea explained when she needs to take Andrew to pre-school and collect him so the LP suggested that they will stick to the same times as before to fit in with school. She then summed up what she would do in the way of referrals and recommended that they contact the police about the problem with the neighbours. Alfred said that the previous occupants of their house had the same problems and the LP said that there may be a connection.

*I was left with the impression that the Andrews family would not contact the police but perhaps need advice about managing the situation so that they do not feel so intimidated by it.*

Andrea said that some neighbours are supportive and Alfred said that the council had been round and are pleased with all the improvements in the house saying that they are better tenants than the previous family. The LP said that the work they have undertaken means that they are seen as good tenants.

Before the LP left Andrea raised the subject of family therapy saying that they have been offered this before and that it came to nothing. The LP asked how long ago this was and she said 2 years. She explained that they are more efficient now. As the LP was leaving they discussed birthday celebrations including a bouncy castle and where it would be located. Andrea talked about Alfred babysitting so that she could go out with friends on Saturday night and stay out. The LP said that it was nice to catch up and asked if they were ready for the children to go back to school. Andrea said no because she had to buy new shoes for Amber and they would be expensive.

*The LP seemed to be trying hard to leave the Andrew's home on a happy note but found that they were more focussed on negative points.*

*As I looked back over the interactions they reflected elements of the roller coaster often associated with manic depression. On the one hand things were good on the other they are terrible. There was information that seemed to reflect extremes today and was consistent with the way they had conveyed their experience of support during interviews. I noted that in the early stages of the visit they were attempting to portray themselves as good parents who were capable. Alfred did this by challenging showing he understood his rights and Andrea by being compliant and giving examples to show how well she was doing. As they relaxed the problems began to emerge, revealing the things they were finding difficult. I wondered if this represented the reality more clearly or that it was simply a case that both sit closely together in their everyday lives.*

*I felt a mixture of concern and confusion about how this could be tackled. It seemed that the LP had knowledge of this family and was attempting to use the negotiating model to help them to take ownership of their issues. I realised that the progress this family makes is not just in relation to what they receive but in the decisions they take to move forward. I wondered whether the family therapy would enable them to do this or whether it may reinforce the idea that they are 'inadequate parents'.*

Following the departure of the LP I asked Alfred and Andrea for their impressions. Andrea described her as a "lovely lady". She likes her chatty, friendly personality. She is better than the others (names the health visitor as a comparison) because she "is not judging she is helpful". Andrea has met her on 4 occasions since January and Alfred knew her due to meeting her in his youth. Andrea thinks that she takes a genuine interest in all areas of their life. She is also confident that she will follow things through as she helped when their boiler broke down and she got some assistance in ten minutes. Based on this experience they expect her to follow up with a phone call. She is a person who they see as straightforward and direct because she tells them if she is unhappy about something rather than leaving it for them to read it in a report.

They return to talking about other professionals who they see as cold hearted, disinterested and lack understanding because they do not have children. In discussion they describe their disappointment in the GP who has ignored the letter from the hospital telling them that Amber is a priority if they phone up for an appointment.

I asked about how they felt in advance of the meeting and they said that they had to quickly tidy up and get rid of the grass, although they also said it is usually tidy.

I was interested to try to glean some information to help me to fill in the gaps after transcribing Andrea's final interview. So I asked about the additional help that they had received following her 'exploding'. She said that social services

became involved and created a working agreement. This meant that she had to attend a parenting course at the school. After this which helped her to manage Amber and Andrew's behaviour she felt that they were satisfied that she could keep the children. They also provided the opportunity to review all the benefits that they were receiving and helped them to work out what they could claim. They thought that a lot of families were left in the dark about this and that a website which explained entitlements would be helpful. They were very happy with the additional money they could claim this had been helpful as a way to support them. They also received information about how to help Amber with her problems of hyper mobility.

As Andrea is Amber's main carer she can claim money so that they can have a short break together. They have not used this grant but are planning a family holiday next year and will use the money to pay towards this. They also talked about respite saying that they would not be entitled to this until Amber is 7 which they thought was poor as parents need help when the child is younger.

*I thought that this was an important observation and linked to Tasmin's struggles with exhaustion. However when Andrea told me a story about a child who had been in the newspaper following being given respite care I realised that some parents may be put off using it. In this case the child had been lifted incorrectly and was paralysed as a consequence. They told me that this had made them think twice about the benefits of respite. This reminded me, along with Andrea deciding not to use the play scheme of the complexity of offering a service to parents who may or may not choose to take up the opportunity it offered.*

Andrea briefly returned to her early memories of being unable to leave her maisonette when the children were young and that the health visitor had organised a volunteer to take Amber for an hour a week. I asked her if this was through Home Start and she said that she thought it was. She explained that this had been a great help to her. She reminded me of her condition saying that being a manic depressive was hard.

Andrea completed her reflections of the recent experience of support by annotating the photographs. She began by apologising for her handwriting which I pointed out was better than mine. She explained that she finds it difficult to write because she has arthritis in her hands following having to write 10,000 words for her law degree.

*I was surprised that she had chosen to hand write this but did not question her further. I asked her if she was in pain now, explaining that I would be happy to write for her if she would like me to. She said that she was fine.*

She told me that she was happy with the content of the narrative because she thought it said what their experiences were like then but that they have changed since.

## Appendix 5

As I was leaving she talked about the fact that she felt different now and was ready to face challenges now. She gave me the example of negotiating a discount for Amber to go to the after school club two days a week and said that she liked the system of an older child (from year 6) being appointed as a 'key person' for Amber to refer to. Finally she told me that she would be attending the 'managing your stress' course in the autumn.

*As I left I thanked both Alfred and Andrea for their time and noticed that they smiled looking relaxed and genuinely pleased that they had been able to help me.*

## **Appendix 6: Extracts from fieldnotes which show additional observations and my comments on what the parent shares**

### **Barbara**

1.05.2009

During the discussion she mentioned that although there was a lot of information in the PIS she liked to have everything set out for her so there were no hidden surprises later.

*I wondered if this would be the same for other families and thought that it would be interesting to compare their reactions. Information is offered as part of support, so the level at which this is communicated may impact on the value that families place on what they receive?*

7.05.2009

She said that she had seen a Mum with a very young baby and noticed that it had 'Down's' and said that she looked really shattered, really drained. She wanted to say something, ask her to look at her son and say it would be alright but then she thought when I first found out I would have probably hit someone like her. So she just circled around her without making a direct approach.

*This made me think about that making connections with others is important to Barbara. I wondered how isolated she felt as she had talked about her friends and family not really understanding the condition of Down Syndrome and wishing she had a close friend to share the experience with.*

### **Ruby**

23.06.2009

She talked about the need to plan ahead and take qualifications while she can. She explained that she had considered becoming a driving instructor as several members of her family had been but did not like the idea of becoming isolated. Prior to having children she worked in an office and in a call centre. She also talked about wanting to train to be a midwife. At this point she said she would have to do an access course.

*These things helped me to form a clearer picture of her background and character in that she likes being with people and enjoys planning for the future and thinking ahead. Her need to do an access course made me think that she probably completed her education to GCSE level only.*

14.07.2009

*Entering the house this time I was struck by the more relaxed atmosphere as Ruby had been cooking and Robbie had been left on the floor to lie on the changing mat and look at the T.V. I noticed my own reaction to this as I find it really difficult when there is a television flickering in the background and I felt myself wishing she would turn it off. Later during the interview the subject of television was raised by Ruby who suggested that when her son was diagnosed*

*with the speech delay she felt that she may be responsible due to having the telly on and that others had reassured her that this was normal behaviour. I noted that the advice from the professionals would have been to turn it off but that she had been reassured by her family and friends to such an extent that this had once more crept into her daily routine as 'normal'.*

10.08.2009

*This conversation made me think that it is important to Ruby to feel valued for what she does and that although at times she may come across as confident and on top of things underneath she really does need to feel reassured that she is a good mum. She has offered a lot to this study and although I may have made the mistake of over directing her at times I believe that she has revealed some authentic messages about how support can be delivered in a way that has a positive impact on her.*

**Andrea**

8.06.2011

We discussed whether or not it would be a good idea to interview both of them together and the Mum was very clear that we should because she sees herself as the main one to deal with the support such as Portage. She said that she understood why I wanted the Dad's opinion and that as he attended with her it would be fine to find out what he thought too.

1.07.2009

Andrea talked about an experience of having a meeting at the nurture unit this week and how disappointed she had felt when it became apparent that the interviewer had not read through Amber's notes before they arrived. She pointed out that she had made a special effort to go there and it sounded as though she thought the professional was not doing her job properly due to having not prepared.

*This left me wondering about expectations from parents and the difficulty that professionals face when meeting with the family as they may find that their work schedule does not leave space for preparation. I also wondered if Alfred and Andrea had prepared for the meeting in any way. I did not ask that question. I did get the impression that going out requires a big effort for Andrea. I wonder if this is connected to her school experiences of being bullied which she disclosed later in the meeting today. She also talked about violence in the home which meant that she was not comfortable describing her childhood experiences. During the recording I heard about her defensive reactions to being told what to do by professionals I wonder if she identifies this behaviour with the bullying she has experienced in her life.*

15.07.2009

I began by asking if they had any amendments to make to the first interview and they apologised saying "the children got hold of it", it had marks on it and seemed a little screwed up. Andrea said that she had tried to correct a bit regarding the change over from the speech therapist through the NHS to the pre-school. This was recorded on line 117 and she added some more information explaining that

an appointment had been cancelled because the speech and language therapist was ill and that they had not been able to attend the next one, six months later because it had been snowing heavily that day. After that the pre-school (KIDS) provided Amber's speech and language and physiotherapy.

*Discussing this with me seemed to help them both to relax although they showed in their body language that they had more to share. Both were looking at me very intently and they continued by sharing with me a series of things that had happened which had left them feeling very disappointed. I was struck by the difference in their demeanour when comparing it with the other visits. On this occasion there were signs of them having discussed what they were going to tell me in advance of my arrival.*

She feels that someone should let them know about benefits but that people simply signpost them to leaflets and there are so many they do not know which ones to look at.

*This experience seems to link to the sub-question regarding how parents access support. Listening to them I was interested and pondered as to why this had happened as Andrea. As she has taken a degree with the Open University the implication is that she does not have difficulties in reading. However she has described a lack in confidence especially when she is outside of her home. Andrea has confided in me and described her fear when out especially of men and that on some days she finds it hard to go out. I wonder if this is affecting her ability to process the information in places where the leaflets are on display. During the interviews she has also talked about the quantity of information and how overwhelming this can be. I can relate to the feeling of having so much information in front of me I am unsure about where to begin and wonder if she is feeling the same way.*

22.07.2010

*I feel that I am witnessing Andrea on a good day, on a day when she is in control of her depression rather than the other way around. I am aware of encouraging her, prompting her comment that she is very proud of her progress. I also find myself hoping that she can maintain this attitude for at least some of the time.*

### **Alfred**

17.06.2009

Alfred's body language suggested that he was feeling nervous, he was quite tense and red. He seemed concerned about getting things right and was worried about his spelling. I did my best to reassure him and carefully kept to the twenty minutes I had so that I could split the time equally between Alfred and Andrea. He referred to his wife who used her fingers to show him how long things had been happening for. As he raised the subject of the GP and struggled with some of the words for the medical experts I was conscious of neither correcting him, or using the correct terms as I did not want to undermine his confidence. So in place of physiotherapist I described it more generally in terms of support with physical development. When I explained that we could go back to the picture next time so

that he could add for example KIDS, he wanted to say something straight away and did so.

*I felt that Alfred was able to articulate the value of particular support in terms of where it fitted on the dart board but found it more difficult to put his experiences into words which inferred that the picture was a useful vehicle to communication. I was concerned that I needed to do quite a lot of prompting which meant that I may have influenced what he said more than I wanted to.*

When Alfred got up he began stretching his back and I apologised for asking him to sit somewhere uncomfortable. He said that he was fine and continued to stretch saying that he didn't want to have any more injections.

1.07.2009

When I arrived Alfred had the door open and was smoking a cigarette, he welcomed me in and said that they were expecting me and when I checked that it was still convenient he said that it was fine. I noticed that he seemed more relaxed than at our first meeting and was smiling as if he was pleased to see me. As I parked my bike inside my eyes were drawn to a large pile of dirty washing on the floor and then within seconds to the newly ironed clothing hanging in the doorway. I commented on the ironing to Andrea who said that Alfred had done it.

*This made me think about what we as professionals choose to look at and about the assumption that the ironing must have been done by the Mum. This out of date thinking creeps as a natural habit. I am aware of challenging it in the context of the classroom but have to revisit this in myself when it becomes an instinctive thought!*

In explaining their experiences of people not listening to them, Alfred said that he thought the FSW and myself came in wanting to get their point of view whilst the 'real professionals' did not.

*I was interested by his definition of this and the difference in relationship he felt between myself and the FSW. I wondered if because he felt more comfortable with us we did not come across as the professionals?*

15.07.2009

*I was very conscious of Alfred's mood during the interview as he was still showing signs of feeling pushed to one side and his tone of voice was more determined and emphatic than in the past. I noticed that the positive experiences of support seemed to have faded into the background.*

15.07.2010

As the television was on I suggested that I audio record the interview with Alfred in the hall. This meant that the dynamics of the conversation were different because Andrea was not in the background giving hand signals to guide him. He seemed relaxed and made a joke about Andrea only holding a licence "to drive

people up the wall" (Int4:281-282) saying "don't let her know I said that" (Int4:282-283).

### **Catherine**

9.06.2009

Meeting in the home with family support worker, the house is situated in a housing estate in what is known as a 'rough' area. Leading to the family home all the housing is mainly owned by the local authority and in their road evidence of poorly maintained gardens with rubbish in the front.

Approaching the house the frontage is simple grass with a drive very like the houses either side of the property. The freshly wood stained gate opens into an oasis of play and children's entertainment with decking for the adults and an assortment of children's play equipment including as a full size trampoline. This suggests a stark contrast to the gardens I had passed to get to this house although others may hold the same secret.

Entering the living room the FSW was sitting with the baby on her lap, the room appears freshly decorated and in a good state of repair with laminate flooring, there is a play pen in the corner and two mats for the baby to lie on. The pictures on the wall are mainly of prints, flowers stood out for me perhaps from Ikea. A vase of fresh lilies is in the corner and the seating is an L shaped leather settee with throws over it. This home speaks of limited income with a financial prop in the background. This is the same design as the seating for Andrea and Alfred and yet speaks of a different standard as the material peeping out from the latter is worn and dirty while in this home it is shiny and clean.

30.06.2009

At the end of our conversation she asked me if she had been okay and been helpful and apologised for saying so much. I reassured her that what she had said was important and interesting and wondered if she had prepared for the interview as she was very coherent. She explained that she had been thinking about it prior to my arrival so that she could express herself clearly. I explained that I may ask her to go back on something to check out her perception of an experience on more than one occasion. We also talked about the fact that Clive would use a different communication style to describe his experiences and she said that she would like to question him and tell me what he thinks.

*This gave me a clue about her expectations of herself which I wondered like Barbara would have a knock on effect in terms of the standards of support she would want. I was also interested in her descriptions of Clive which involved explaining that I may be disappointed if I talked to him because he would have much less to say. It has been interesting to think about Alfred who says less but reveals some very important information for me to consider.*

12.08.2009

*I was aware of how difficult it is for some mum's to express their needs and how important it is to try to tune in to their communication style so that the professional can read when the person is concerned. Catherine suggests that she is difficult to read and that she thinks she is misunderstood as a result so this seems particularly significant. I wonder if there is something in the mind of the professional with their 'expert' hat on that makes them think they should be able to read the needs of the parent without checking this out with them.*

*The other issue is the fact that the parent may not like to correct the professional when they read something wrong because they see them as being more important than they are.*

### **Tasmin**

12.08.2009

As she talked about the time in hospital again and in particular the experience of expressing breast milk she used the word 'horrendous' and I felt a huge amount of emotion in the whole experience. I noticed that when I reassured her that using a word such as 'horrendous' probably only went a small way to describing what that time was like for her, she looked visibly relieved to have permission to express it in that way.

*Listening to Tasmin left me feeling that the experience had provoked emotional issues that perhaps she had yet to completely resolve. There seemed to be scars that were still livid and I wondered if this was because of all the families her son is the youngest so she has had the least time to come to terms with the experience or whether it was a case of not having had the opportunity to talk this through and make some sense of the what had happened to her.*

*I was grateful that I could talk about the feelings of expressing milk as I had found that difficult when my boys were babies.*

*I wondered if the relief arose because other people had suggested that it was not so bad after all and was transported back to her own words when she described having premature babies as being so much better than it could have been. During this part of our conversation she talked about another mum in the unit with her who had given birth to twins at 25 weeks and one of them had died and the other had cerebral palsy with many medical complications. She seemed to use this example to try to moderate her own anguish regarding her experience as if to apologise for her feelings because what had happened to her was less traumatic. She also said that this could have been her as she went into labour at 25 weeks but they were able to stop it and gave her steroid drugs to stimulate the growth of the lungs which helped the twins after they were born.*

*Today's meeting has left me thinking that there may be a lot more emotion to be explored with Tasmin over the next two meetings and possibly beyond. In some ways I am pleased that she is the last Mum for me to see as the experience of*

*the others has given me more confidence. I also found myself aware of giving her space to explore rather than bombard her with questions.*

As I went to leave she explained how exhausting her life was as Tony still wakes once or twice a night and that this means that she feels tired.

*This had a connection with Ruby who had said the same about her two boys and once again I was thrown back in time to when my children were young realising, now even as I did then how fortunate I had been that they were good sleepers.*

*So many parents talk to me about disturbed nights and I wondered if the problem was compounded by the additional concerns about these children given their history of complications in their health. Reading later I find that there are questions about expectations that parents have in these situations, which means that they accept difficulties as being part of the package instead of trying to alter them (Woolfson, 2004). It left me considering the connection between physical exhaustion and psychological stress if indeed there is one? It seems likely that there is but I wondered how much or little one contributed to the other and decided that it would be very difficult to build a case for either without knowing the situation in depth.*

19.08.2009

*I notice that in conversation Tasmin often moves quickly from making a positive point to a negative one and wonder if this reflects her overall view of the world. Sometimes I think she is aware of it as she tries to correct it and when using negative examples she moderates them with "quite" and "sort of" but her tone of voice lacks enthusiasm and energy.*

23.09.2010

When I arrived today, the house was clean and tidy and Tasmin was wearing a skirt for the first time. I noticed the contrast in her appearance to when we had met last year as she looked more relaxed and less tired, a subject we discussed just before I left as she explained that she had tried the controlled crying last year and it had only taken 4 nights before Tony had slept through. She has had mainly uninterrupted nights since then. We agreed that this had improved her quality of life.

To establish a rapport I talked with Tasmin about her job which had been hectic before going on holiday. She said that there was some doubt about whether or not she would be able to continue her role part time and we discussed the possible implications of this.

When I turned off the audio recorder I thanked her for being so honest about her experiences and pointed out that although it portrayed some failings in the support it was useful for professionals to recognise how it felt to be a mum in her position. She returned to the subject of diagnosis and said that it was difficult as professionals wanted to avoid putting a label on Tony until he was five. He had been assessed for autism but they did not think he had this because they were

looking for areas of strength and then an obvious discrepancy in the pattern which was not the case for Tony because he was delayed in most areas.

*In this I caught the combination of frustration at not really knowing and the understanding that they did not want to make a mistake. This resonated with her idea that the professionals seemed to think that she was exaggerating which left me wondering whether this was linked to other parents wanting a diagnosis. Although professionals may interpret it this way, having met with Tasmin I realised how desperate it feels to have concerns put to one side.*

## **Appendix 7: A list of codes which were applied when using Atlas ti.**

The numbers next to each show how the number of examples in the parent's interviews, fieldnotes and observations

	<u><b>Selected codes for analysis</b></u>
Adjustment to diagnosis	<b>32</b>
Analysis pictures	<b>26</b>
Apathy	<b>3</b>
Attitude to support	<b>8</b>
Being judged	<b>25</b>
Benefits of participating	<b>2</b>
Changes over time	<b>68</b>
Comparing	<b>193</b>
Connection with other families	<b>86</b>
Consistency	<b>65</b>
Contradictions	<b>45</b>
Delays	<b>10</b>
Empowerment	<b>40</b>
Examples of unhelpful support	<b>80</b>
Expectations	<b>54</b>
Explicit support	<b>12</b>
Improvements that could be made	<b>41</b>
Isolation	<b>26</b>
Judging other people	<b>41</b>
Judging professionals	<b>130</b>
Judging themselves	<b>59</b>
Labels	<b>16</b>
Lack of power	<b>43</b>
Making a connection	<b>32</b>
Managing the child	<b>46</b>
May exclude some families	<b>45</b>
Mixed reactions	<b>30</b>
Models of partnership	<b>43</b>
My concerns	<b>32</b>
My role as researcher	<b>90</b>
Neighbourhood	<b>4</b>
Parent knowledge	<b>33</b>
Parent preference	<b>74</b>
Parent concerns	<b>130</b>
Partnership	<b>47</b>
Personal descriptions	<b>134</b>
Personal feelings	<b>250</b>
Personal influences	<b>28</b>
Personal values	<b>201</b>
Political influences	<b>39</b>
Pressure to get it right	<b>59</b>
Professionals concerns	<b>23</b>
Progress	<b>6</b>
Reactions to disabilities	<b>76</b>
Research on the children	<b>2</b>
Restrictions	<b>42</b>
Sharing information	<b>29</b>
Sign posting advice	<b>33</b>
Specific problems	<b>15</b>
Stress	<b>38</b>
Support options	<b>27</b>
Things that are missing	<b>57</b>
Value of support	<b>134</b>

001 Interview 2 with Andrew's family  
 002  
 003 1<sup>st</sup> July 2009 9.30 - 10.30  
 004  
 005 **Gina:**  
 006 1. Okay, um Alfred now I noticed the first  
 007 thing  
 008 2. you said you wanted to write down  
 009 CPCK  
 010 3. um on your support um dia, um  
 011 picture can you  
 012 4. tell me something about what that  
 013 was like for  
 014 5. you as a dad?

012 **Alfred:**  
 013 6. Well being on on the course of CPCK  
 014 its brilliant  
 015 7. good exercise it was good  
 016 communication and um  
 017 8. basically its helped me a lot coz I  
 018 used to be  
 019 9. shouting, screaming at my kids and  
 020 they  
 021 10. wouldn't listen so going on the  
 022 course was  
 023 11. absolutely one hundred percent  
 024 brilliant it  
 025 12. really was (I say "right") it was

Judging Professionals (a)~  
 Value of support (a)~  
 Explicit support (b)~  
 Changes of time (a)~

Value of support (a)~

021 **Gina:**  
 022 13. Right, thank you and you feel that its  
 023 changed  
 024 14. your behaviour towards ....

025 **Alfred:**  
 026 15. Yeah it has changed my behaviour  
 027 towards  
 028 16. the kids but I do still shout a little bit  
 029 but not  
 030 17. as much as I used to so.. its has  
 031 helped  
 032 18. me a hell of a lot

Changes of time (a)~ Value of si  
 Comparing (a)~

031 **Gina:**  
 032 19. And obviously the the course is all  
 about confidence

033 20. for you and also confidence for the children as well

034 21. umm so in what way do you think you feel more confident

035 22. as a parent?

036

037 **Alfred:**

038 23. Well we've done more as a family we always

039 24. have done and always will do now umm I do

040 25. more things with the children and its like

041 26. if um my wife um wants to stay indoors I'll go out

042 27. and play err with my kids its helped me a lot

043 28. actually really has

044

045 **Gina:**

046 29. Great, thank you very much that's really

047 30. interesting and helpful to hear umm as

048 31. you look round your support um picture

049 32. that you drew up last time is there another

050 33. area that you that that sort of jumps out for you

051 34. as having had a personal impact?

052

053 **Alfred:**

054 35. Um well me wife she's helped me out a lot

055 36. as well so its gonna keep jumping out

056 37. every time when I see it because my wife's

057 38. been there, supported me through whatever

058 39. I've done and she's helped me out by saying

059 40. things that I should be able to do myself basically.

060

061 **Gina:**

Personal values (b) Empowermei

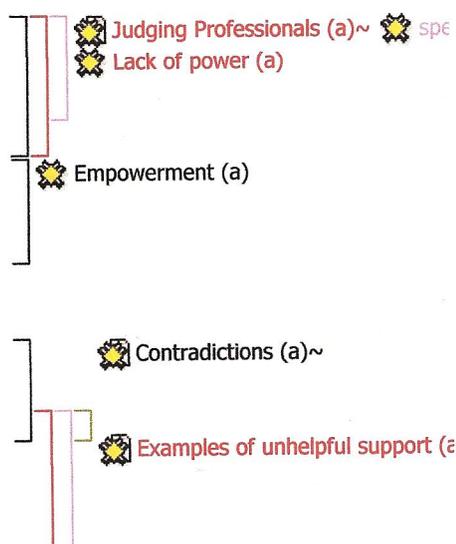
Personal descriptions (a) Empowerment (a)

Consistency (b)~ Partnership (a)~ Contradi  
Being judged (a)~ Value of support (a)~

- 062 41. Right, right so she's always going to be the number one
- 063 42. support (Alfred says "yes always"), that's that's good
- 064 43. do you think the professionals are aware of that
- 065 44. when you go to see them? (Alfred "no") what makes
- 066 45. you say that?

067  
068 **Alfred:**

- 069 46. Well some professionals think of their selves and don't
- 070 47. ask questions and also um they're not willing to listen
- 071 48. um but with my wife and I'm an ex-paramedic so I can
- 072 49. do things myself but more um not like some of the
- 073 50. professionals who do it all the time now so...I can't
- 074 51. say nothing about them (I say "no") so but they don't listen
- 075 52. (I say "right") never have done and they don't want to
- 076 53. listen...

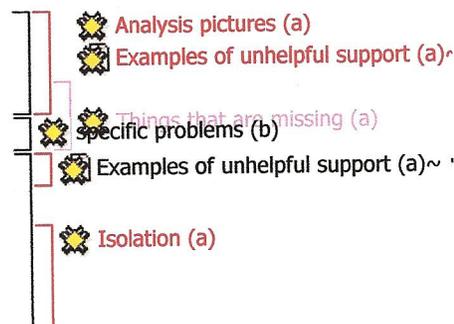


077  
078 **Gina:**

- 079 54. Do you have any thoughts about why they don't listen?

080  
081 **Alfred:**

- 082 55. Umm its very hard to say, it is very hard to say
- 083 56. but nine times out of ten it could be "yes, we'd
- 084 57. listen to you" and then they they tend to curl up
- 085 58. in their selves within themselves and won't ask you any questions
- 086 59. and then you get frustrated coz they are not asking
- 087 60. any questions and you've got to do all the asking
- 088 61. and answering as well...



089  
090 **Gina:**

091 62. Right, right, so from what you've just  
said can

092 63. you describe how you feel when  
you've come

093 64. away from a meeting like that?

094

095 **Alfred:**

096 65. Very disappointed, it is very hard and  
err

097 66. present yourself as the parent and  
then

098 67. like they are parents themselves and  
then

099 68. it does tend to err make you feel well  
why

100 69. bother...

101

102 **Gina:**

103 70. Right, right and when that happens

104 71. do you, is there anything you feel  
you can

105 72. do about that, anything you've tried  
to do

106 73. about that?

107

108 **Alfred:**

109 74. Um there's a couple of things we  
could do

110 75. we could all sit down together all the  
professionals

111 76. in one room and we could all talk,  
have one talker

112 77. for the parents and have a talker for  
the professionals

113 78. (I say "right") and they should read  
up on the reports

114 79. and everything else but apart from  
that ....no

115

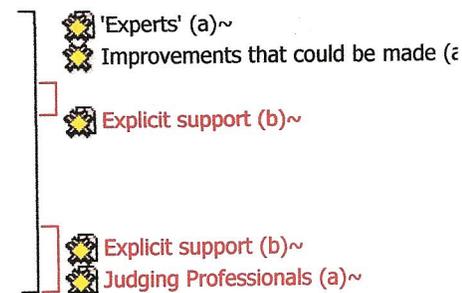
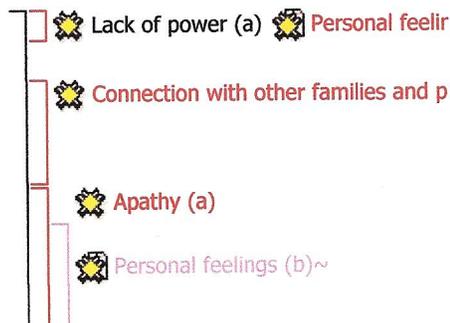
116 **Gina:**

117 80. Right, okay yeah so it's something  
you've sort of come

118 81. back and talked to Andrea about?  
(he says "yep")

119 82. is how this could be improved for  
you, and yet there

120 83. are other people who've really made



149 we could do and  
150 106. how we could help each other out

Partnership (a)~ ac/wor  
Sharing information (a)~  
Value of support (a)~

151 **Gina:**  
152 107. Can you give me just one example  
of where you've  
153 108. you've done that because that's  
that's useful I think...

154  
155 **Alfred:**  
156 109. Um, yes I can we've had leaflets on  
how to help

157 110. Amber walk on her tiptoes and  
everything else  
158 111. and stand on one feet ...um I've  
also passed the

Empowerment (a)  
Partnership (a)~  
Sharing information (a)~  
ac/work

159 112. leaflets over to the key worker and  
she's helped  
160 113. her at pre-school to help her out  
before she gets  
161 114. into err to mainstream school

Political influences (a)~

162  
163 **Gina:**  
164 115. Right, right, that was good actually  
where did you get  
165 116. the leaflets from?

166  
167 **Alfred:**  
168 117. From the NHS trust  
169

170 **Gina:**  
171 118. Oh right right so that was something  
you gathered in the way  
172 119. of information and then you were  
sharing that with her key

173 120. worker so you were doing the same  
working on the same

Consistency (b)~ ac/work  
ac/work

174 121. thing together. You mentioned last  
time too that you think  
175 122. that some things Amber finds easier  
than others I think you

176 123. know some things that she picks up  
quite quickly and other

177 124. things she finds more difficult why  
do you think it is that she

178 125. finds some things easier than  
others?

179

180 **Alfred**

181 126. The easiest things she finds is a lot  
umm more for her because

182 127. she interacts with animals more  
than she does with people coz

183 128. in crowded places she tends to curl  
up in herself and start

184 129. panicking but with um animals she  
can interconnect with

185 130. others um with animals more easily  
so....

☀ Analysis pictures (a)

☀ Explicit support (b)~

186

187 **Gina:**

188 131. So is that something else that  
you've passed on to

189 132. her key worker?

☀ ac/work

190

191 **Alfred:**

192 133. It is, it is and the key worker they've  
got a little area

193 134. and it's a little farm area which has  
got more

194 135. teddies than um we have in the  
household

195 136. basically and if they can't find our  
daughter then

196 137. they look in the farm area and she's  
there interacting

197 138. with all the animals cuddling up to  
um so she she does

198 139. that but then she won't watch, well  
she'll watch people

199 140. play but she won't join in coz its very  
hard for her to

200 141. join in to the play and to interact with  
other people

☀ Partnership (a)~ ☀ ac/work

☀ Personal descriptions (a)

☀ Parent's knowledge of the child (b)

201

202 **Gina:**

203 142. Right, right and you understand that  
is a particular aspect

204 143. of her really isn't it? of her  
personality (he says "it is yeah")

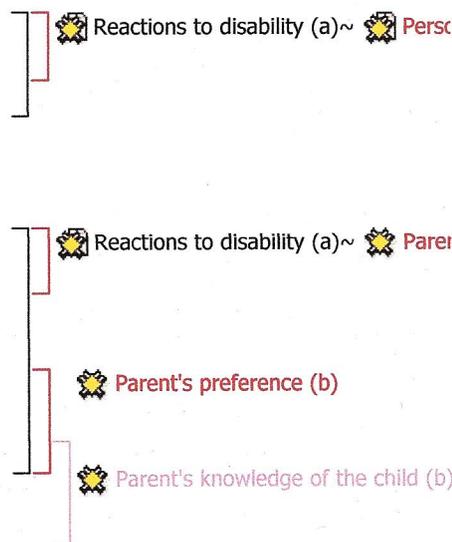
205 144. where she is...does, how does that  
that make you feel when you

206 145. think about that?

207

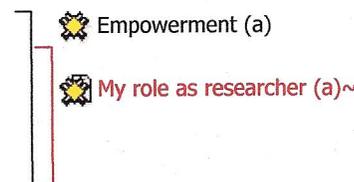
208 **Alfred:**

209 146. It makes me feel really confident  
and proud of my own  
210 147. daughter (I say "right") yeah I know  
its hard for us when  
211 148. we go out places and that she can't  
interact with other  
212 149. people um but its what she knows  
best (I say "yes")  
213 150. err she knows herself more than  
what we do so its  
214 151. how she wants to do it and its how  
we prefer her to  
215 152. do it as well, if she don't want to do  
it then she won't do  
216 153. nothing..



217  
218 **Gina:**

219 154. Right, right yeah coz we are all  
different at the end of  
220 155. the day aren't we? (he says "we  
are") And yes and its lovely that  
221 156. you feel proud of of that because I  
think that's  
222 157. that's important for her and for for  
you. No that's  
223 158. good thank you.



224  
225 There is a break in the recording at this  
point so that I can flag up the subjects  
that I would like to cover with Alfred for  
the last part of the interview.

226

227 **Gina:**

228 159. Um, Alfred, that's been really useful  
thank you now  
229 160. one of the things I'm interested to  
know is if you  
230 161. look back over your life and you  
think about, you  
231 162. know your opinions about support  
and things like  
232 163. that, can you describe how those  
might have been  
233 164. influenced from your past?

234

235 **Alfred:**

236 165. There is I'd like to go back to school  
 237 166. (I say "right") literally because things  
 that I've  
 238 167. learnt now I could have done at err  
 239 168. at school, and ....I'd rather do  
 school  
 240 169. work than go out umm at work at the  
 241 170. moment coz I wanna learn more  
 and  
 242 171. get more A'levels, GCSEs  
 everything

- Comparing (a)~
- Empowerment (a)
- Expectations (a)~
- Personal descriptions (a) ac/w

243  
 244 **Gina:**  
 245 172. Right, right, how do you think that's  
 influenced  
 246 173. what what you expect in the way of  
 support now  
 247 174. how do you think.....

248  
 249 **Alfred:**  
 250 175. Well...I can't read properly um  
 because I'm dyslexic  
 251 176. (I say "yes") so with the support that  
 if I had the  
 252 177. support when I was at um senior  
 school then  
 253 178. I could have done more and helped  
 myself out  
 254 179. by doing the reading. I was only um  
 found  
 255 180. out in the umm last year of school,  
 pretty much  
 256 181. before I was leaving that I had  
 dyslexia which  
 257 182. weren't very helpful to me but if I  
 had that help  
 258 183. before hand I could have done  
 something about  
 259 184. it basically

- Personal descriptions (a) Things
- specific problems (b)

- Restrictions (a)~
- Examples of unhelpful support (a)~
- specific problems (b)
- Explicit support (b)~

260  
 261 **Gina:**  
 262 185. Yeah, so what it sounds as if you  
 are saying is  
 263 186. that you recognise that things have  
 really moved  
 264 187. on in education from when you were  
 at school

265 188. (he says "yep") and that actually if  
 you had those  
 266 189. opportunities now it would have  
 made a difference

Restrictions (a)~

267  
 268

269 **Alfred:**

270 190. It would have made a lot of  
 difference, because I've got  
 271 191. my oldest daughter whose coming  
 on seven and she  
 272 192. sits down, she helps me read and  
 well with her maths  
 273 193. I'm good at sums so I help her with  
 her maths work and  
 274 194. everything else but with the  
 education now it should have  
 275 195. been a lot more improved when I  
 was at school...

Parent's knowledge of the child (b)  
 ac/work  
 Personal values (b)

276

277 **Gina:**

278 196. Yeah and does that make a  
 difference to what, how  
 279 197. you feel about what will happen to  
 Amber as she goes  
 280 198. through education? (he says "yes")  
 in what way?

281

282 **Alfred:**

283 199. Well now the education has got all  
 these information  
 284 200. on um autism, dyslexia um anything  
 basically to do  
 285 201. with school and out of school they  
 could um get that  
 286 202. support in before anyone starts  
 school now to say  
 287 203. right you're going to need one to  
 one or um a couple  
 288 204. of people to help you out

Comparing (a)~  
 Expectations (a)~  
 May exclude some parents? (a)  
 Political influences (a)~  
 Support options (a)  
 Explicit support (b)~  
 Political influences (a)~  
 Explicit support (b)~

289

290 **Gina:**

291 205. Right, yeah, thank you that's  
 interesting and that's  
 292 206. that's different (he says "yes it is") to  
 your experiences when you  
 293 207. were at school yourself. Thank you

Changes of time (a)~

294 that's really helpful. If you  
 208. were to define, what support means  
 for you, if you had to say  
 295 209. somebody came along and asked  
 you "what do you mean by  
 296 210. support?" what, could you put that  
 into words?

297

298 **Alfred:**

299 211. Not in so many words, um my wife  
 she could do  
 300 212. everything like that um I can't do  
 nothing like it.

☀ Lack of power (a)  
 ☀ Personal feelings (b)~

301

302 **Gina:**

303 213. No that's absolutely fine, um I think  
 you've given  
 304 214. me quite a lot of information about  
 the things  
 305 215. that are helpful and the things that  
 aren't helpful um  
 306 216. so I'm happy to kind of draw that  
 out, that's fine.  
 307 217. The last thing I wanted to ask you  
 Alfred is if you  
 308 218. um had to describe to me your  
 home and your  
 309 219. the area you live in could you, could  
 you do that?

310

311 **Alfred:**

312 220. Well it's a detached house, four, um  
 three bedroomed house  
 313 221. neighbours are brilliant, um they are  
 all friendly they'd  
 314 222. help us out if we need it and they  
 are so friendly we  
 315 223. can't fault them. (Andrea says  
 "they've given us the dining  
 316 224. room table and chairs and the shed  
 out there")

☀ Personal descriptions (a)  
 ☀ Personal values (b)  
 ☀ Judging other people (b)

317

318 **Gina:**

319 225. Oh that's really nice isn't it. Have  
 you been, how long  
 320 226. have you lived here?

321

322 **Alfred:**  
 323 227. Um a year now, a year and three  
 weeks

324  
 325 **Gina:**  
 326 228. Right and is this different to the  
 place you lived in  
 327 229. before?

328  
 329 **Alfred:**  
 330 230. Yes it is because we only lived,  
 used to live in a  
 331 231. maisonette, flat, top floor two  
 bedrooms (I say "right")  
 332 232. so it was a lot difference

☀ Comparing (a)~  
 ☀ Personal descriptions (a)

333  
 334 **Gina:**  
 335 233. Right and how did you come to live  
 here?

336  
 337 **Alfred:**  
 338 234. Um from the council umm Amber  
 and she's  
 339 235. got autism so ...

☀ Changes of time (a)~

340  
 341 **Gina:**  
 342 236. Yes so they recognised that Amber  
 had some would  
 343 237. benefit from (he says "yeah")  
 having a a different space  
 344 238. and things? So you moved here and  
 met different people?

345  
 346 **Alfred:**  
 347 239. Met different people and um when I  
 used  
 348 240. to drive lorries and everything else  
 someone  
 349 241. said to me I'd never get a lorry down  
 here  
 350 242. and I done it

☀ Personal descriptions (a) ☀ Empow  
 ☀ Personal feelings (b)~

351  
 352 **Gina:**  
 353 243. (laughs) right, oh right, excellent so  
 it kind of  
 354 244. fitted in with work as well as your  
 personal life so

☀ ac/work

- 355 245. you feel quite settled here (he says  
"we do") good
- 356 246. and you're actually quite close to the  
Children's
- 357 247. centre as well and quite close to the  
local town and
- 358 248. all the rest of it so happy? (he says  
"we are"), excellent
- 359 249. thank you very much.

360

361 At this point we take a short break for the  
two of them to swop (see field notes for the  
report of the discussion regarding Andrea's  
childhood)

362  
363

364 **Gina:**

- 365 1. Hi Andrea so we had got as far as  
number five
- 366 2. well number four actually last time  
and we are
- 367 3. now onto number five and err you  
wanted to put down
- 368 4. Amber?

369

370 **Andrea:**

- 371 5. Amber as herself... because with all  
this we wouldn't
- 372 6. have had any sort of contact with err  
any of these
- 373 7. professionals if she didn't do any of  
the work then yeah
- 374 8. she wouldn't be getting any better so  
um I'm really
- 375 9. pleased...

376

377 **Gina:**

- 378 10. Good, what do you notice about the  
way that she's
- 379 11. developed in relation to this?

380

381 **Andrea:**

- 382 12. Um we've before we had all this stuff  
um
- 383 13. she wasn't really speaking or  
anything like that
- 384 14. and now she's had the confidence to

