

***Living with the spark: Recognising ordinariness in the
lives of disabled children and their families***

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Abstract

Over recent decades, while substantial advancements have been made in the understanding of living with impairment in a disabling world, the family experience of disablement has been less widely recognised. This thesis is primarily a comparative exploration of literature around disabled family experience, augmented by a small amount of fieldwork to test out a developing theoretical framework through which to develop support systems enabling disabled children and their families to live ordinary lives. Data collection involved 18 months of in-depth and serial qualitative interviewing with 6 families. Disabled children/young people, their non-disabled brothers and sisters and their parents were engaged in the process through interviews, conversations, artwork, 'spending time with', and 'going out with'. Visits to a range of family support services took place and the views of service providers were included through interviews, networking, meetings, conversations and collaborative working. Placing the data firmly within the context of a disabling world, it is evident that all family members suffer from disablement. It is equally evident that this understanding is not reflected in the theoretical perspectives informing support services. The thesis identifies key features of a theoretical framework to underlie the provision of support services that might allow families to lead ordinary lives. Central to this framework is the position of paradox in the lives of families living with impairment and disablement; the recognition of the family experience of disablement; the need for family support services to be based firmly within an understanding of our interdependent nature; and finally, the need for support services to prioritise respectful relationships.

Chapter One

Setting the Scene

Introduction

The starting point for this thesis lies in my own family experience of living with and learning about cognitive impairment and disability. The experience of parenting both a disabled and a non-disabled child led me to the discovery that family life is radically changed as the result of both impairment and disability. The fact that impairment itself is perceived as being 'extraordinary' and 'unfortunate' rather than 'ordinary' and 'just one of those things' meant that our family was largely viewed as extraordinary, whilst our experience was that our circumstances were unusual but ordinary. Contrary to the messages I had grown up with and was given by a disabling world, my relationship with my son taught me that he had much to offer and was fun to be with, thus challenging the widespread cultural belief I had internalised of cognitive impairment rendering individuals 'sub-human'. In addition, because of the nature of his impairments, he led me to think deeply about impairment and physical health, life and death – issues of importance and relevance to all but which, reflecting the culture around me, I had successfully ignored prior to his birth. Whilst my parental role forced me into a position of contemplating such issues, it was evident that his exclusion from the mainstream denied others the same opportunity to discover that his impairments did not make him 'less' of a human being and indeed, that he had much to teach us all through his presence in the world. Knowing other families living through exactly the same experience, I set out to explore

possibilities of ways in which disabled children and their families could be supported to live ordinary lives.

The work began as a conventional piece of research with fieldwork as primary. However, in the early days of doing the fieldwork I found myself confronted by a wide range of theory level questions about the way in which family support is currently constructed that creates disabled families. This discovery led to a shift in direction as I realised that actually the work I needed to do was around explaining and developing theory about the family experience that did not further pathologise that experience. For these reasons I found – to my surprise – that I was primarily engaged in a comparative exploration of literature around disabled family experience, augmented by a small amount of fieldwork to explore alternative family support provision.

In searching for a context within which to place this work I have moved far beyond the writings of the social model to the realms of philosophy, cosmology and quantum physics. My rationale for such a wide exploration is that it is only by addressing the problem of exclusion in the largest possible context that lasting change can be found. To this end, I argue that the root cause of discrimination, with people with cognitive impairments as with other marginalized groups, lies within our failure to fully embrace the paradoxical nature of the relationship between self and other – recognising the differences between us whilst acknowledging we are all of equal value (Taylor, 1992; Phillips, 1999; Tregaskis, 2004). At present the widespread belief underpinning

all relationships is that there is an essential difference lying between self and other that allows for the positioning of individuals as superior or inferior (Shakespeare, 1994). Acknowledging the commonality underlying superficial differences (Thakar, 2001) changes the perspective to the extent that we can recognise that although we have different physical attributes and a large variety of experiences, we are part of the same human experience. Adherence to a perspective embracing paradox allows for *all* to be acknowledged as having a valuable part to play within our common human experience.

Establishing a relationship of mutual reciprocity between the micro and the macro in this way allows for the individual experience to merge with the greater universal experience:

In an acceptable cultural context, we would recognise that the unique properties of each reality determine its value both for the individual and for the community. These are fulfilled in each other. Violation of the individual is an assault on the community.

...As a second imperative derived from the cosmological process, we find that each individual is not only different from every other being in the universe but also has its own inner articulation, its unique spontaneities. Each being in its subjective depths carries a numinous mystery whence the universe emerges into being. This we might identify as the sacred depth of the individual.

...The third cosmological imperative indicates that the entire universe is bonded together in such a way that the presence of each individual is felt throughout its entire spatial and temporal range. This capacity for bonding the components of the universe with one another enables the vast variety of beings to come into existence in that gorgeous profusion and yet comprehensive unity we observe about us (Berry, 1999 p. 163).

In this way, a concentration on the particular experience of cognitive impairment leads to an exploration of issues relevant to all human relationship, and therefore to our social organisation. For example, the issue of interdependence (Morris, 1993; Shakespeare, 2000; Lloyd, 2003; Stalker, 2003), of such crucial importance in the lives of disabled people with cognitive impairment can be viewed in cosmological terms as a universal truth – though one which as members of an individualising society we are loath to admit to. In exploring such universalities, I was able to move towards a scientific basis for diversity rooted in commonality that reflected and ‘made sense’ of the experience of participating families. The problem at hand was that of ‘making the jump’ from such writings to the daily experience of living with impairment and disablement. Within this thesis, I do not claim to have completed such a huge task – rather my aim has been to open up questions relating to the family experience of living with cognitive impairment in a way that allows all of us to feel safe to explore the issues.

Defining definitions

Prior to writing up the exploration, I had naively imagined that this part of the process would hold no surprises – I had after all done the background reading, carried out the work and the writing was simply to report what I had found. Contrary to these expectations, the actual process of writing provided the invaluable opportunity to explore new ideas and so to place the family experience of living with impairment in a disabling world in the context of the whole human experience. Within this process I struggled to make sense of the

language – a common issue in disability studies. At the beginning I was happy to use the phrase ‘disabled people with learning difficulties’ as this is the stated preference of ‘People First’. As the writing progressed, however, the phrase became problematic and confusing due to the way in which, as I describe in Chapter 4, the term ‘learning difficulties’, is widely used to describe an impairment whilst also being a social construct. In acknowledgement of this, I tried out the term ‘disabled child *perceived* as having learning difficulties’. Whilst this is perhaps a more accurate description, it denies the actual impairment, is clumsy, and does not bear repeating too many times in any one paragraph. In addition to this, I became aware that the term ‘learning difficulties’ does not always make sense. For example, several of the participants perceived as having learning difficulties are highly intelligent and articulate. Whatever the ‘technical’ understanding of the phrase ‘learning difficulties’, our ‘common understanding’ (Williams, 1967) is that of someone who has difficulties in learning and is therefore, ‘not very clever’. Such a definition makes no sense when applied to Owen or several other participants whereas the term ‘cognitive impairment’ allows for ‘being clever’ *and* ‘not being clever’. As I grew more comfortable with the term ‘cognitive impairment’ I began to see that, in addition to giving a more accurate description of a particular impairment, it also placed the experience on a level with physical and sensory impairment, rather than being ‘something different’ (i.e. ‘learning difficulties’) and therefore easy to keep at arms length. This move in turn carries the advantage of bringing people with a range of cognitive impairments (for example, Alzheimer’s disease, autism, and ‘learning difficulties’) under one umbrella. For these reasons I have chosen to

use 'cognitive impairment' as the main term but have also used the terms 'learning difficulties' and 'perceived learning difficulties' in order to give fluidity to the text.

Relationship and service provision

The history of the lives of people with cognitive impairment has been dominated by service provision denying their humanity and thus acting as a barrier to the building of relationships. Today, in spite of the rhetoric of inclusion and human rights within both legislation and policy initiatives, research carried out by Morris (2001) has found that people with complex impairments and high support needs are largely absent from their communities. It is this absence that makes their lives (and those of their families) 'extraordinary'. It is, for example, extraordinary that one participant should have his first friendly chat with a stranger at the age of 21. Such isolation and segregation serves to feed the fear of cognitive impairment, giving greater strength to the barriers already in existence. Within this work, I argue that the primary factor in providing support that might facilitate ordinariness in the lives of disabled children/young people with cognitive impairments and their families, lies within the building of respectful, mutually reciprocated relationship (Lloyd, 2003). As a result, we are all implicated in the process of change as respectful relationship is possible on the bus and in the classroom; in our own communities and in the wider community; and in the role of professional, family member, friend, acquaintance or stranger. This imperative of responsible relationship with people with cognitive impairments is no different from that within all relationships if we are to live well together.

The social model

The social model of disability, which makes clear the distinction between impairment and disablement, is an explicit challenge to the dominant, implicit medical model. With this crucial distinction out in the open, the whole picture changes. Although I argue in Chapter 4 that the social model fails to fully embrace the experience of cognitive impairment, the claim made by social model theorists that impairment is an ordinary part of the human experience (Hunt, 1966; Morris, 1991) underlies the entire thesis. As a parent, I recall the relief of the early days of learning about the social model of disability and the way in which it allowed me to make sense of the tension I felt between the (ordinary) love I had for my son and the contradictory messages coming from a disabling world that he was not as valuable as my non-disabled daughter. As time went on, however, I became aware that not only was my son's experience invisible within social model writings or at conferences I attended, but also the divide within the social model of disabled/non-disabled marginalized the role I had in my son's life and rendered his sister completely invisible. In this way, just as the effects of my son's impairment went unacknowledged, neither were the relationships most important to his well-being part of the picture. I had escaped from the role of 'carer' ascribed to me by the medical model only to find myself given the role of 'ally' within the social model, when what I claimed was the ordinary role of parent. This background, mirrored in the experience of other parents, provided the starting point from which to explore the limitations of the social model with regard to cognitive impairment (Chappell, 1998). In the early stages I imagined that all that was required was for social model theory to expand through an

incorporation of the experience of cognitive impairment. As the work developed however, and I explored the positioning of the family within the social model, I became acutely aware of the inherent limitations within a binary model (Corker, 1999). Suddenly, the social model appeared too small and I found myself engaging with texts exploring a move from the dichotomy to the plural (for example, hooks, 2000; Zohar and Marshall, 1994; Young, 1990).

Figure 1: Distinctions between the binary and the plural

Binary	Plural
Disabled/non-disabled	Everybody
Mind/body	All human experience
Either/or	Both/and

As the above diagram shows, the advantage gained from engagement with a pluralistic view lies in the fact that it allows *all* of us to be included just as we are rather than having to adjust ourselves to fit in to the norm. Within this view, the division between ordinary/extraordinary dissolves as everything and everyone belongs. Continuing an exploration of 'ordinariness' led to the writings of Raymond Williams who moves from the binary to the plural as he argues that true democracy depends upon diversity without creating separation (Williams, 1967, p. 334). Such a democracy is based on the recognition of 'equality of

being' and it is in turn equality of being that leads to the acceptance of common experience being valued:

An inequality in other than personal property – that is to say an inequality in ownership of the means of life and production – may be found intolerable because in practice it may deny the basic processes of equality of being. Inequality in a particular faculty, however, or unequal developments of knowledge, skill and effort, may not deny essential equality: a physicist will be glad to learn from a better physicist, and will not, because he is a good physicist, think himself a better man than a good composer, a good chess-player, a good carpenter, a good runner. Nor, in a common culture, will he think himself a better human being than a child, an old woman, or a cripple, who may lack the criterion (in itself inadequate) of useful service. The kind of respect for oneself and one's work, which is necessary to continue at all, is a different matter from a claim to inequality of being, such as would entitle one to deny or dominated the being of another. The inequalities which are intolerable are those which lead to such denial or domination (Williams, 1967, p. 318).

This definition of 'equality of being' resonates with the definition of human rights given by a disability activist as 'an intrinsic dignity which lies deeply embedded in the human condition' (Fitzgerald, 1994) echoing the experience of participants who referred to 'the spark within' being the signifier of valued inclusion in relationship.

Embracing the paradox: towards the equal valuing of difference

Moving beyond the binary meant that apparent contradictions relating to the family experience of living with cognitive impairment could be embraced rather than denied. Whilst there is open questioning of the culture of 'body beautiful' in relationship to physical impairment (Wendell, 1996; Bartlett and Masefield, 2002), there is a significant silence surrounding comparative issues related to cognitive impairment. For example, how does confusion, memory loss, and

difficulty in understanding language (common consequences of cognitive impairment) fit into a culture placing such a high value on social and intellectual competence? How can unpredictable behaviour go alongside (often necessary and desirable) socially accepted ways of behaving? Within an educational system emphasising intellectual and social achievement how do we welcome people with cognitive impairments who cannot progress and might even show regression? How do we encourage some to excel intellectually, whilst at the same time valuing those who do not? These questions are extremely challenging and although I lay no claim to approach solutions, I argue that it is only through openly exploring such issues that we will be in a position to move from the status quo automatically devaluing people with cognitive impairments towards a society valuing all its members.

Due to the nature of cognitive impairment, it is unlikely that many people with cognitive impairment will engage in an exposure of the disabling factors in their lives through the same channels or in the same manner open to people with physical and sensory impairments. Although it is impossible to imagine what the full engagement of people with cognitive impairments within the mainstream might look like, it is useful to consider for a moment the success people with physical impairments are having within the realm of community dance (Bartlett and Masefield, 2002). Initial consideration of the idea of people with physical impairments taking part in professional dance performance presents a challenge to conventional ideas about physical beauty and grace. The success and

popularity of groups such as CandoCo¹ in the last few years have challenged mainstream ideas to the extent that dancers with physical impairments have been included in the advertising of the BBC summer programme (BBC 1, 2002). The move towards the appreciation of the physical grace and beauty of people with physical impairments is akin to that required for the recognition that people with cognitive impairments have something uniquely valuable to offer our social organisation.

As I explore in Chapter 8, whether it is due to the direct effects of impairment or the consequence of being thought by the majority to be 'incompetent', the full engagement of people with cognitive impairments within the mainstream is largely dependent on being in valued relationship with others who can articulate their experience in a conventional way at the same time as breaking the boundaries of convention by encouraging the recognition of 'different ways of engaging' and different ways of being. In this way, the presence of people with cognitive impairments leads inescapably to a focus on relationship.

Focus on relationship

It is in the area of establishing respectful relationships that the valued presence of people with cognitive impairments has so much to offer to all of us. In the words of Raymond Williams:

The primary human obligation is towards responsible relationships, and relationship for which one is responsible for in society (Williams, in McIlroy and Westwood, 1993, p. 91).

¹ CandoCo is an internationally renowned contemporary dance company made up of disabled and non-disabled dancers.

The issues of human relationship arising between people with and without cognitive impairment serve to highlight issues pertinent to all relationships. For example, establishing a respectful relationship with someone with 'severe' cognitive impairment demands serious engagement with issues of power as there is no denying that the balance of power lies firmly within the hands of the person without cognitive impairment. Acknowledgement of this, whilst fully valuing the individual with cognitive impairment, leads automatically to an exploration of creative as opposed to dominative power (Arendt, 1958). Such an exploration in a world being destroyed by dominative, abusive power holds valuable lessons for social organisation generally. Similarly, the level of support required by many people with cognitive impairments highlights the way in which, as human beings, we *need* each other to survive – that we are not in fact independent but rather, we are first and foremost members of a collective (Berry, 1999; Williams, 1961). In this way, our relationships and social organisation take on a primary importance as the collective is seen to be of greater importance than the individual.

The experience of participating families (described in Chapter 8) is that of 'coming closer together' and 'looking out for one another' as the result of having a family member with cognitive impairment. This 'looking out for one another' takes on a wider dimension when placed alongside the evidence that many brothers and sisters of people with cognitive impairment go into the 'caring professions' as they grow up (NCH, Action for Children, 1994). This transfer of lessons learned through one relationship, to 'wanting to make a difference' in

the wider sphere serves as an example of the way in which relationship with people with cognitive impairments hold the potential to positively affect the whole community.

Chapter Two

Legacy of the Past

Introduction

Patricia Williams (1997) argues that the persistence and tenacity of racism is sustained by habit, deflective rhetoric and hidden license – all of which find their roots in a past dominated by slavery. The ultimate solution, she suggests, is that of breaking the sense of division between self and other:

For better or for worse, our customs and laws, our culture and society are sustained by the myths we embrace, the stories we recirculate to explain what we behold. ...What a world it would be if we could all wake up and see all of ourselves reflected in the world, not merely in a territorial sense, but with a kind of non-exclusive entitlement that grants not so much possession as investment. A peculiarly anachronistic notion of investment, I suppose, at once both ancient and futuristic. An investment that envisions each of us in each other. (Williams, 1997 p14).

Taking a similar approach to looking at the history of the relationship between the non-disabled majority and disabled people with cognitive impairments, it is my aim in this chapter to explore the past in order to seek out the tenacious ideas we have adapted, disguised and re-interpreted to fit into the modern world in order to preserve the sense that disabled people with cognitive impairments are 'less than human'.

In order to do this, rather than focus on the well-documented evidence of the incarceration of disabled people with learning difficulties in long stay institutions (Morris, 1969; Atkinson, Jackson and Walmsley, 1997; Oswin, 1978, 1998;

Wright and Digby, 1996) I look at the underlying ideology of this experience (the ways in which the majority justified such inhumane treatment) identifying the traces left on the practice of today.

Throughout the last century, the provision of services has been driven by the ideology that disabled people with learning difficulties and communication impairments are an unnecessary drain on society (Morris, 1969; Dyer, 1996). Whilst there is evidence of inhumane incarceration and segregation during the greater part of the century (Atkinson, Jackson and Walmsley, 1997; Oswin, 1978; Smith, 2000; Barron, 1996), this belief is demonstrated in the present in a more subtle fashion by the fact that disabled children and their families inhabit a 'different world', present but invisible in the world of the majority. Kliever and Drake (1998) argue that not only are segregated services for disabled people infused with the logic of the eugenic movement, but also that general discriminatory attitudes towards the behaviour and means of communication of people perceived as having learning difficulties bear traces of that same logic. In other words, they argue that although the eugenics programmes of the past are no longer socially acceptable, the logic that created those programmes lies within present service provision and attitudes. The two main ideological thrusts supporting such practice lie within the realms of eugenics and normalization (Felce and Grant, 1998). In 1999, Disability Now ran a news story about a father who had unsuccessfully attempted to kill both himself and his 22-year old son. When the case went to court, the father was discharged on the grounds that he was under considerable stress at home due to the fact that his son was

'autistic'. The article failed to question why the outcome would have been so different had the young man been non-disabled. Similarly, the fact that the young man in question required support at the age of 22 (i.e. was perceived as having failed to reach 'normal' developmental, social and/or behavioural milestones), was perceived to be the reason the father was under such dire stress. Due to the unquestioned acceptance of eugenicist ideas running alongside the multi-faceted goals of normalization, both the father's attempted suicide and the attempted murder of his son were legitimised.

Whilst there were undoubtedly positive motives behind both the practice of eugenics (See Whitney and Schick (1931) for a discussion on the possibilities of reducing human suffering) and normalization (based as it was on human rights (Nirje, 1980) the practice of both eugenics (questioning the right to life), and normalization (that has developed in such a way that it questions the right to belong), has resulted in an oppressive model of service provision (Hughes, 2000; Ward, 2001; Atkinson, Jackson and Walmsley, 1997; Dowse, 2001; Williams and Nind, 1999) maintaining the dichotomous relationship between self and other; the family and the community; the micro and the macro.

Early years of the 20th century

The dominating force of ideology lying behind service provision in the early years of the 20th century was rooted in the practice of eugenics. Although the original motives of the eugenics movement were in part motivated by a desire to eradicate physical suffering, as eugenic practice developed this aim was quickly

overtaken by the advantages seen in eugenics as a tool to control the population by encouraging the upper classes to breed (positive eugenics) whilst simultaneously discouraging/ preventing the procreation of 'undesirables' (negative eugenics). The Mental Deficiency Act of 1913, informed by a paper written for the Eugenics Review (Tredgold, 1909), argued that disabled people were at worst a danger, at best a burden, to society and proposed government measures to limit the number of 'undesirables' coming from 'bad stock'. Two approaches were adopted to further this aim - birth control through contraception and sterilisation (Kevles, 1997) alongside mass segregation (Tredgold, 1909; Davis, 1997; Kevles, 1997).

Although knowledge of the widespread killing of disabled people in concentration camps as part of the Nazi programme of ethnic cleansing was less well known than the equally brutal extermination of both Gypsies and Jewish people, the Nazi atrocities resulted in a heightened awareness of the dangers of eugenic cleansing. The civil rights movement in America and the spreading recognition that discrimination based on race was a human rights issue, led to changes in general attitudes, policy, and practice surrounding eugenics (Whitehead, 1992). At the same time, the feminist movement was campaigning for a woman's right to have control, autonomy, and to make choices over her body (Phillips, 1979). As a consequence of this heightened awareness, there was a move away from eugenics towards the 'new genetics'.

Moving towards the 'new genetics'

In contrast to the wide reaching aims of population control through eugenics, new genetics aimed to prevent physical suffering and allow for 'informed choice' (Ward, 2001). Shakespeare (1998) argues that although there is a clear difference between eugenic practice and the 'new genetics', there are nevertheless links to be made between the two. Clarifying these links, he suggests the use of the terms 'strong' and 'weak' eugenics:

Strong eugenics could be defined as population-level improvement by control of reproduction via state intervention, such as happened in the 1930s. It is motivated by the social judgement that disabled people's lives are unworthy of life, and/or that society should not have to bear the financial costs of supporting its non-productive members. Weak eugenics could be defined as promoting technologies of reproductive selection via non-coercive individual choices. It is motivated by the medical judgement that disabled lives involve unacceptable suffering (Shakespeare, 1998 p. 669).

However, Marteau (1995) points out that there is a great difference between the outlook of professionals involved in genetic screening and policy makers concerned with population health who, like the eugenicists, are concerned with the elimination of genetic conditions as opposed to being able to provide information that allows for choices to be made. Policy documents lying behind the practice of the new genetics specify the main objective of prenatal screening as that of 'reducing the number of infants born with Down's syndrome and neural tube defects' (cited in Marteau, 1995). Furthermore, such documents comment on parents choosing not to terminate pregnancies affected by foetal abnormalities in an extremely negative light:

This (genetic prediction) would make possible the routine diagnosis of vast numbers of genetic conditions, which should be eliminated where possible by abortion; the world must shed the idea that this is evil, as it is a true act of moral cowardice to allow children to be born with known genetic defects (cited in Marteau, 1995 p. 1216).

In addition to contributing to the sense of guilt experienced by some parents, such disparate messages inevitably feed their way into the general culture confirming the common association made between the eugenics movement and the new genetics (Kerr, Cunningham-Burley and Amos, 1998 (a) and (b); Ward, 2001). Indeed, the narrow line distinguishing the two is reflected by Kevles (1997) who refers to the 'new genetics' as the 'new eugenics'.

New genetics

Generally, within the literature, the term 'new genetics' refers to both prenatal and genetic testing with the main focus of such tests being to search for traces of genetic conditions and/or foetal abnormalities. There is within this same literature scant mention of the 'other side' of new genetics – the search for 'perfection' in the possibility of being able to choose the sex and/or genealogy of the baby. With this aspect of the new genetics in the picture, there is a reflection of 'negative' and 'positive' eugenics. In respect of the argument throughout this thesis that the reluctance to engage with paradox prevents ordinariness in the lives of disabled families it is important to take this particular aspect of new genetics into account. Holding the possibility of reducing suffering at one end of the scale, it also promises the perfection of the human species at the other:

The injunction to be a particular sort of person is always bound up with an act of division: to be what one is, one must not be what one is not...The vicissitudes of identification are not ontological but historical and technical (Rose, as cited in Hughes, 2000, p. 558).

There is a clear tension here between the cultural concept of the 'perfect' human being and the fact that impairment, physical frailty and vulnerability is an unalterable aspect of the human condition. Ward (2001) points out that if society was serious about reducing physical suffering, rather than concentrate on genetics; we would do better to look at social and environmental factors contributing to impairment.

Returning to the new genetics

There is clearly a difference between searching for traces of genetic conditions and/or foetal abnormalities with the emphasis being on the individuals concerned making an informed choice and any programme of large scale 'population control'. The premise Shakespeare makes however, that genetic screening is being implemented in the west through 'the free choices of individual women and men' neglects the experience of women with learning difficulties and/or women from minority ethnic backgrounds who often find they are not afforded that same 'free choice' (Booth and Booth, 1994; Rakusen, 1981). Indeed, as Shakespeare acknowledges, the impact of cultural conditioning upon collective and individual beliefs makes it dubious that 'free choice' can ever be claimed in such issues. Highlighting the power of professional opinion, research conducted by Marteau (1995), reported that the choices made by parents as to whether to terminate a pregnancy or not were closely connected to the views of the health professionals involved in the

process. Ferri and Gregg (1998) put forward the view that informed choice regarding termination and impairment cannot exist without adequate social support and/or reliable information. Hubbard (1997) argues that the emphasis on individual choice obscures wider societal factors forming the backdrop to the making of that choice. In the eyes of a culture devaluing people on the basis of impairment, the individual making the choice to continue with their pregnancy in the knowledge that she will have a child with an impairment, is seen to be choosing to burden herself with impairment whilst also imposing that same burden on wider society.

Quality of life

Much of the debate as to whether to continue with a pregnancy in the knowledge that there is a foetal impairment, hinges upon arguments about the 'quality of life' for the individual to be born and the effects that individual will have on the quality of life of the family concerned. Such concerns centre upon both the consequences of impairment and living with impairment in a disabling world. A clear distinction needs to be made between the two because a disabling world makes it appear as if the reason for the lack of 'quality of life' lies within impairment. However, parents reporting on the reduced life opportunities both they and their disabled child face, cite 'the problem' being the lack of appropriate support rather than their child's impairment (Felce and Grant, 1998). Shakespeare (1998) highlights the position of parents making the choice for termination 'second time round', on the basis of the difficulties of living in a disabling world with more than one disabled child. In having a second child with

the same impairment as the first, parents are faced with problematic issues surrounding physical suffering, hostile attitudes and lack of support:

Nonetheless, I know that if I could still have children and was offered a cure for my unborn child, I would accept it. Much as I love my daughter and son, and see them as individuals I feel I could not refuse such treatment. I wish I could have spared them the surgery and the negative responses of some people that they have had to endure. Where does this leave my ethics? (Picton, 2001 p. 47)

Although support to families is something that can be changed and improved, physical suffering can be alleviated but not eradicated. It is to this second aspect of the debate that I now turn - that certain impairments involving a great amount of physical suffering, and perhaps having a poor prognosis, are said to deny quality of life.

When is quality of life not good enough?

There is no doubt that some impairments lead to a great deal of physical suffering and that others lead to death in childhood or early adult life. Deciding on the termination of pregnancy under such conditions leads to wider ethical questions connected to euthanasia and decisions to withhold/stop medical treatment. Such questions are of course not restricted to people with impairments but are faced by many living with terminal illness and/or incurable disease (Small and Rhodes, 2000). Recent publicity surrounding Diane Pretty who lost her battle for the right to die in her preferred manner (her husband giving her a lethal dose of medication) highlighted some of the moral and ethical issues to be addressed around physical suffering and euthanasia (Birkett, 2002; Arshi et al, 2002).

The issues surrounding pre-natal testing are even more complex as there is no certainty about the specific nature or degree of a specified condition whilst the foetus is in the womb. It is only at birth, or even later in life, that the nature and degree of suffering can be known. Whilst emotionally demanding, the acceptance of degenerative conditions as a fact, an ordinary part of the human condition, allows for the possibility of a different understanding to underlie the experience of physical suffering whereby acceptance co-exists with the acknowledgement that it is an unpleasant experience. In making this point, I do not argue for or against the termination of pregnancy based on foetal impairment; rather I suggest that different cultural attitudes towards impairment, physical suffering and death would undoubtedly provide a more supportive societal context for individuals having to make such heart-rending decisions.

Shakespeare suggests that there are some situations in which it would be 'right' to terminate pregnancy on the basis of impairment:

Where impairment causes few problems, and disabling factors are the main difficulties, then it is hard to argue for the termination of fetuses with that condition. In those rare cases where impairment causes inevitable neo-natal death or permanent lack of awareness, it might be more appropriate to screen out conditions prenatally (Shakespeare, 1998, p. 670).

Whilst appreciating Shakespeare's courage in publicly raising such difficult questions, and fully supporting his plea for a more 'nuanced' view, I have concerns about screening on the basis of a 'permanent lack of awareness'. Such worries are based on dominant attitudes towards people perceived as

having learning difficulties and communication impairment. In the past, as in the present, people perceived as having learning difficulties and communication impairments were often thought to 'lack intelligence and awareness'. As a social model understanding of communication as a two way process grows (Triangle, 2001), people who in the past would have been labelled as being 'unable to communicate', and therefore 'unaware', are proving that not only do they have the awareness to communicate very effectively, but also that they are highly intelligent (see for example the Nottingham Post, 2001).

Remnants of eugenics

Following the work of Anne McDonald and Rosemary Crossley (1980), there has been a great deal of interest in the method of communication known as 'facilitated communication'. This method challenges assumptions about lack of awareness and/or intelligence as many young people now using the method competently, were previously thought to have 'profound learning difficulties' and consequently be 'unable to communicate'. It is only on the discovery of facilitated communication that they have been able to demonstrate intellectual capability (Baworowski, 2000 (a); Williamson, 2002; Murray, 2002).

It is not only disabled people with perceived learning difficulties who are subjected to dehumanising treatment on the basis of their lack of ability to communicate through language in a conventional way. The writing of Bauby (1997) reveals the instantaneous change in the way he was treated when a stroke left him with physical impairments that meant that he could only communicate through blinking one eye. Bauby describes how his lack of power

in the communication process rendered him vulnerable to abuse through second-rate care. Arguing that segregated service provision, with its emphasis on instructional control and compliance, leads to the need for 'dependency' rather than the right to belong in the community, Kleiwer and Drake (1998) cite the reluctance of the 'system' to recognise the validity of 'unconventional' communication methods as an example of 'eugenic logic'.

It would be wrong to assume that it is possible to find a suitable communication method for all people with complex and severe impairments. Undoubtedly the consequences of impairment mean that some people have limited ability to communicate and/or to understand language. Families having positive relationships with such young people report that they are able to 'read' the wishes of their son/daughter or brother/sister through their body language and/or facial expression (Murray, 1996; Fitton, O'Brien and Willison, 1995; Whinnett, 2000). A disabling world means that such communication goes largely unrecognised leading people to conclude that the young person with learning difficulties and communication impairment has a poor quality of life.

A typical difficulty in deciding on 'quality of life' is evident in the case of a family who argued for the right for their child to be given medical treatment when medical professionals decided, on the basis that the young person had no quality of life, to withdraw treatment (Dyer, 1999). In the ensuing court battle, the family lost their attempt to obtain a declaration that doctors were not able to either treat or withhold treatment to her son against her will. In spite of the

medical prognosis that the young man would die, he did in fact live through the crisis and his family subsequently reported that he was 'happy and comfortable' at home; in their eyes, he had a quality of life worth fighting for. As in the case of Diane Pretty, the issue raised is that of the power of the medical profession and the courts when their recommendation differs from the choices being made by individuals and their families.

Legitimacy of suffering

In considering euthanasia, assisted suicide and termination of pregnancy, the issue is not of impairment alone, but of the physical suffering sometimes accompanying impairment. I suggest that although it is extremely difficult to make generalised categorical statements about physical suffering and 'quality of life', it would be useful in looking at such issues, to consider extreme and chronic physical suffering as an ordinary aspect of our human experience (however unpleasant for individuals to experience and distressing for others to witness). In his exploration of the 'communicative body', Frank (1995) suggests that physical vulnerability needs to be placed in the foreground in order to reach a pedagogy of suffering. Such recognition would help pave the way for suffering to be perceived as a legitimate part of the human experience (Neuberger, 2001).

Testing to identify treatment

Easier ground is reached in a different aspect of genetic testing – that of gaining information about conditions to allow for prompt treatment. An example of this lies in the Guthrie test for phenylketonuria (PKU) now routinely administered to newborn babies in the UK. This simple blood test (a prick on the baby's heel)

identifies a condition that, untreated, leads to brain injury resulting in cognitive impairment. A positive result allows for early treatment preventing subsequent brain damage. There is widespread acceptance of this test alongside a general agreement that it is both 'good and sensible'. In this instance both the test and any necessary treatment are straightforward; testing is related to the desire to prevent impairment but does not lead to questions such as 'is this person's life worth living because of the levels of physical suffering?' (Shakespeare, 1998; Picton, 2001).

With the advance of technology and an ever-increasing knowledge about physical conditions, such issues are not going to disappear, nor will they ever be easy. The highly emotive nature of the questions raised, the difficulties inherent in engaging with the paradoxical nature of the issues raised, in addition to the fact that we live in a world unwilling to accept impairment or physical suffering as an ordinary part of the human condition, means that it is extremely difficult to view the issues clearly.

Such questions affect everyone and yet it is only in recent years that policy makers or professionals have sought the views of disabled people – the people both directly affected by and implicated in such procedures. A project seeking to uncover the views of people with learning difficulties has allowed for the emergence of a refreshing approach to the question of genetic testing:

People with learning difficulties are different to other people. We get picked on – others make fun of us. People shout at us in the street

sometimes. Black people with learning difficulties get picked on even more. People with learning difficulties should be treated fairly and not discriminated against. Scientists should find the gene that makes people pick on those who are different. Then our lives would be better (Ward, 2001, p. 13).

This response is clearly a plea for diversity to be accepted as the norm and hostile, discriminatory behaviour to be the focus of change, rather than people with learning difficulties. This leads to the second major ideology affecting service provision for people with learning difficulties and communication impairments during the latter years of the 20th century – the concept of normalization . My first step in this exploration is to place normalization in the context of a normative society.

The context of normalization

In order to place normalization within the wider context of attitudes towards 'difference' within a normative society, I return to the writings of Patricia

Williams:

The drive to conform our surroundings to whatever we know as 'normal' is a powerful force – convention in many ways is more powerful than reason, and customs in some instances are more powerful than law. While surely most customs and conventions encode the insights of ancient wisdom, the habits of racial thought in Western society just as surely encapsulate some of the greatest mistakes in human history. So how do we rethink this most troubled of divisions, the fault line in our body politic, the fault line in ourselves? The ability to remain true to one self seems to me to be not only an ultimate goal of our political and social aspirations but must begin with the ethical project of considering how we can align a sense of ourselves with a sense of the world. This is the essence of integrity, is it not, never having to split into a well-maintained 'front' and a closely guarded inside? (Williams, 1997, p. 4)

Conforming to the rules of a 'normative' culture implicates everyone. The recent film 'Bend It Like Beckham' demonstrates the similar experience facing all of us who do not conform to the 'norm' as a result of race, sexuality, gender, and/or impairment. In a discussion about attitudes towards sex and marriage in different cultural groups, the central character dismisses any deep significance underlying apparent differences saying, 'It's only culture', thereby creating a space within which to question practices we accept as the given, unchangeable norm. The specific effects of normative issues impact on different groups of marginalized peoples in a variety of ways, because of differing cultural beliefs and accepted 'norms'. Within the overall context of a normative society, normalization was specifically introduced to challenge the widespread perception of disabled people with learning difficulties as belonging to a sub-human species (Brown and Smith, 1992; Felce and Grant, 1998).

Normalization

In many ways the roots of normalization lie in a reaction against the eugenics movement in that the early European exponents of the normalization principle were responding to the gross injustice and inhumane treatment of all those groups of people who had suffered as a result of the Nazi regime:

Inequality has expressed itself most strongly in the Third Reich, when treating certain groups differently, because of race, religion or handicap, had led to the elimination of these groups. This is unacceptable, and the only way to avoid a similar discrimination in the future is wholly and fully to accept all human beings as equal citizens, no matter how they were born or how they turn out to be (Bank-Mikkelson, 1980 p. 57).

Unlike the eugenics movement that affected all disabled people and their families, however, 'normalization' focussed on the specific barriers to social inclusion facing disabled people with learning difficulties. Following public outcry at the exposure of the inhumane treatment of disabled people with learning difficulties within long stay institutions (Morris, 1969; Oswin, 1978) the normalization principle was widely espoused as a way of facilitating the move from segregated to community living (Brown and Smith, 1992; Felce and Grant, 1998; Whitehead, 1992). The fact that the main proponents of normalization questioned the wide-spread acceptance of the view that disabled people with learning difficulties were sub-human (Wolfensberger, 1972), and argued that people with learning difficulties have the right to a 'normal' life and therefore should be treated 'with normal respect' (Nirje, 1980), meant that normalization held the promise of facilitating major change in attitudes towards people with learning difficulties. In fact, retrospective examination reveals how quickly the principled stand was assimilated into changing service provision without affecting the underlying ideology that people with learning difficulties are of less value. Perhaps this was due in part to the concentration on service provision without simultaneously tackling the deep-seated nature of the fear of cognitive impairment and therefore of people with cognitive impairments (Goffman, 1990). Although Wolfensberger (1972) questioned the supremacy of the medical model and the widespread belief that disabled people with learning difficulties are sub-human, his practical ideas for change focus on service provision rather than the lives of people with cognitive impairments.

For example, the Programme Analysis of Service Systems (PASS) as outlined by Wolfensberger implies that there is always going to be 'something odd' about people with cognitive impairments:

You can see here the effects of congregation when each person has a cultural oddity. It becomes odd when four or more stigmatised people get together, and the group as a whole becomes deviancy-imagined. Any one of these persons just might be able to pass, but as a group they will never pass (Wolfensberger, 1972, p. 27).

Having stated earlier on in the same text that deviancy was in the eye of the beholder, rather than within the person (p.13), it is confusing to read that people with learning difficulties should not be seen publicly together. In exploring the notion termed by Goffman (1990) as 'passing', Ferri and Gregg (1998, p. 435) argue that normalization relies upon the 'implicit assumption to be abled is normal, rather than calling into question the unsteady construction of normal'. Recognising that such an assumption would be totally unacceptable to other marginalised groups, for example, black and minority ethnic groups reveals the distance to be travelled in terms of the inclusion of disabled people with cognitive impairments. Robinson (1989) and Whitehead (1992) argue that Wolfensberger's reinterpretation of the normalization principle, based as it is on service delivery rather than the rights of the individual, has been responsible for the misunderstandings leading to the oppressive wide scale practice of helping people with learning difficulties to look 'normal', behave 'normally', and live 'normal' lifestyles. Far removed from any concept of rights, this definition of normalization assumes that disabled people with learning difficulties have to be changed to 'fit in', rather than asking why they are excluded in the first place.

Following Kliever and Drakes' (1998) argument put forward earlier in the chapter such a definition can be seen to be imbued with the logic of eugenics.

In spite of much criticism of normalization theory and the practice it has generated (Robinson, 1989; Chappell, 1992), there continues to be a debate as to whether it is a useful tool in the struggle for the emancipation of people with learning difficulties (see for example the dialogue between Stevens and Williams, 2001). Perhaps because of the failure of the social model to systematically examine the differential experience of disabled people with learning difficulties (see Chapter 4 for discussion on this point), there is a lack of a developed analysis within the literature of the original principles of normalization (Perrin and Nirje, 1989) and the way in which those principles have been developed and applied. In order to pinpoint some of the difficulties and contradictions encountered in the practical application of the normalization principle and to extend this examination into present attempts at 'inclusive practice', I return to the early days of putting normalization principles into practice.

Early days of normalization

There is much evidence that the lives of people within long stay mental handicap hospitals were characterised by abuse and low expectations (Smith, 2000; Barron, 1996; Oswin, 1998; Morris, 1969). During the 1970s and 1980s when the ideas of normalization were being incorporated into service provision (Kings Fund, 1982), the social model of disability was little known and relatively undeveloped. Set in the context of the medical model, the normalization

principle was corrupted to the extent of causing further division through misunderstanding and misapplication, rather than building bridges as had been intended. The dramatic practical changes of this time (i.e. the move from long stay hospitals to the community) masked the fact that the underlying ideology of service provision remained the same (Dyer, 1996).

As the locus of professional attention towards people with learning difficulties shifted away from the medical (long stay hospitals) to the educational sphere (Felce and Grant, 1998), without a questioning of the medical model of disability, it is perhaps not surprising that the education system has become imbued with normalization thinking and practice (Szivos, 1992). It is for this reason that I focus an exploration of the effects of normalization within the school system.

Normalization and education

From a medical model perspective, being valued depends on being able and willing to comply with largely unspoken, fixed standards of what is culturally accepted as being 'normal' (Oliver, 1994). There is no concept within the context of medical model ideology and practice of the stigma attached to 'learning difficulty' being seen as a social construct; thus implying that the difficulty lies within the individual (Chappell, 1992). The problem with such a construction is that there will always be those who do not fit into its parameters (Lovett, 1996). In addition to this, such a construction does not take account of the power dynamics between the individual, the prevailing ideology, and structural systems (Whitehead, 1992).

Within the mainstream

The widespread practice of 'integration', whether in education or in the community, is premised on the condition that it is possible to learn to be 'normal' and to then conduct oneself in a prescribed and accepted manner (Szivos, 1992). The pressure to fit in, at whatever cost to the individual, is the only means to be accepted:

Most of us live in a world where, in the most basic ways, we belong and would have to do something extreme to be sent away. Many people with differences are told from birth: "You do not belong. But, if you make an extreme effort, you might one day be allowed - in a limited way - to join in" (Lovett, 1996, p.13).

The 'need to fit in' however, is one that is rooted in a normative society based on the premise of separation between self and other, rather than a problem intrinsic to the principle of normalization . The concept of normalization and the pressure to conform to the norm have, therefore, become confused:

Normalization does not mean normality. A mentally retarded person is not normal – who is? What is normality and does anyone want to be normal at a time when there is so much understanding for people who are trying not to be uniform? (Bank-Mikkelsen, 1980, p. 56).

In spite of this attempt to make a distinction between the two, the pressure facing disabled people with learning difficulties to 'fit in' in order to be accepted are enormous. At present, such demands are particularly evident in the education system where, in the move towards 'inclusion', the emphasis on having to prove social and developmental progression in order to 'keep up' with their peer group (Warnock, 1978) creates a tension that threatens their

presence within mainstream schools (Brandon, 1997). In addition to this the pressure to behave in 'appropriate' ways can place impossible pressures on those disabled people who find it difficult to curb strong impulses (Williams, 1996).

Based on normative principles, integration depends on the ability of individuals being able to develop, to radically change their behaviour, and/or to communicate in socially acceptable ways. If, however, equality of value (the original normalization principle) is the goal *and* we have an understanding that it is the world that disables people we can only conclude that it is society and 'the system' which must be the focus of change rather than individuals within particular groups (Szivos, 1992).

The complexities inherent in looking at these issues are enormous.

Normalization has had a huge effect on policy and practice and has undoubtedly improved the quality of lives of many people (Williams and Nind, 1999; Szivos, 1992) and integration has undoubtedly made the school experience more positive for some children and paved the way for the presence of others. Yet, because the majority of young disabled people with cognitive impairments within a mainstream setting are integrated rather than included, their presence is that of being a guest rather than belonging by right. Having the status of a guest within a system that supports both inclusion and segregation (Education Act, 2001) means that some young people will never be invited in, whilst others will be under pressure to achieve in order to remain. On the grounds that the initial

sound principles of normalization (Perrin and Nirje, 1989) have been so widely misunderstood and misapplied, I argue that the experience has much to teach us about the development and implementation of 'inclusive' policies.

In order to identify the difficulties with being a guest (integration) rather than belonging by right (inclusion) I now look at the experience of those young disabled people most likely to be excluded from a mainstream education.

Making connections between the normalization principle and inclusion

As with the principles of 'inclusion', early normalization theory was based on the premise that disabled people with learning difficulties had the same rights to citizenship as all others, but were systematically denied those rights (Bank-Mikkelsen, 1976; Perrin and Nirje, 1989). In a review of services to people with learning difficulties during the 1970s, the Campaign for Mental Handicap (Tyne, 1980) wrote of the lack of clarity from government and suggested that the failure to deliver the promises of normalization lay within the fact that legislation, policy and practice were simultaneously pointing to opposing directions. Examples of similar confusion in the present can be seen through the maintenance of special schools on the basis that segregation is beneficial to some, whilst at the same time advocating inclusion for all. Similarly, in spite of the move towards inclusion health and safety regulations make it very difficult for young people with complex impairments to be in the community (Morris, 2001).

The present confusion about inclusive practice outlined by Murray (2002, p.16 - 18) bears an uncanny resemblance to the points of confusion about practice based on the principles of normalization as clarified by Perrin and Nirje (1989, p.

221 –223). Such confusion points to the importance of not underestimating the continuing strength of the cultural beliefs that to have learning difficulties means to be of 'lesser value' providing a reminder of the need to further explore what is meant by human rights for people with learning difficulties.

Who's not there?

Within the education system as it presently stands, the groups of children/young people who face the greatest difficulty in accessing the mainstream are those with complex impairments and high support needs; behavioural difficulties; communication impairments and chronic medical conditions (Abbott, Morris and Ward, 2001). In a study on the relationships between young people with serious medical conditions, parents and their teachers, it was found that some young people, despite extensive absences and poor prognosis, were fully included in their school community (Closs, 1999). The majority of young people however, felt excluded or marginalized. A major impediment to the young person's inclusion in the class, and therefore the school as a whole, were the fears and anxieties of the teacher concerned. Such fears and anxieties, although perhaps understandable, are allowed to dominate in a system that does not value all young people equally and therefore reserves the right to include or exclude at will.

Moving on from school

Continuing on the same theme of respectful relationship, Coles (2001) explores issues of support when he looks at the implication of 'social model practice' in

day services for young adults with learning difficulties. Crucial to the success of support workers engaging in a relationship within which the disabled person was valued and enjoyed, was the support workers understanding of the principles of 'ordinary living'. Emerging from an engagement with normalization, the principles of ordinary living claimed that disabled people with learning difficulties should live, work, and spend their leisure time in their local communities using ordinary facilities (O'Brien, 1987; Tyne and O'Brien, 1981; Kings Fund Centre, 1982). Coles returns to the original, rights based, principles of normalization within a social model framework to explore the support relationship as a crucial component in developing respectful service provision for disabled people with learning difficulties.

Finding an independent voice – the move to self-advocacy

The self-advocacy movement provides a useful example of the way in which there is a tension for disabled people with learning difficulties to conform to normative expectations (in this instance having a political voice) and having to live with the consequences of impairment (for some people, being unable to self-advocate in conventional ways). In saying this, I do not mean to detract from the very positive nature of the self-advocacy movement and the benefits it brings to both individuals and to people with learning difficulties as a whole in that it is a powerful tool with which to combat discriminatory attitudes and practice. Rather, I put forward a word of caution about viewing self-advocacy as 'the' answer in that it is not (and cannot be) suitable for 'all'. There is a tension for people with learning difficulties to conform to normative expectations (in this

instance to find their independent voice) when it may be very difficult (or impossible) for them, due to their impairment, to do so. Once again there is a fine line between having opportunities to 'stretch to the limits', to break through the ideology that to have learning difficulties equals 'not being able', and accepting the consequences and limitations of impairment. It is therefore, to the self-advocacy movement that I now turn my attention – a movement, welcomed by disabled adults engaging with social model theory, which is largely perceived as being the 'political arm' of disabled people with learning difficulties (Goodley, 2000).

The self-advocacy movement emerged from the trends of de-institutionalisation and normalization (Williams and Schoultz, 1982) in the USA at the same time as disabled adults in the UK were articulating the social model of disability. The early years of the self-advocacy movement were characterised by disabled adults with learning difficulties fighting to leave long stay institutions and live in the community. The experience of those leaving the institutions was that they then had to continually 'prove' to professionals that they were capable of living on their own (Langness and Levine, 1986). Compliance with normative expectations such as marriage and employment provided the most 'acceptable' evidence that they were capable of 'living independently' (Edgerton, 1967).

Self-advocacy in the UK started when a group of people with learning difficulties attended the first People First Conference in the USA and decided to set up a branch in the UK on their return (Walmsley and Downer, 1997). Since then it has spread in an ad-hoc fashion throughout the country with confusion

abounding between citizen advocacy and self advocacy (Felce and Grant, 1998). There has been criticism of the way in which self-advocacy has been 'hijacked' by professionals in institutional settings (Aspis, 1997; Goodley, 2000), because it has been used to look at existing services rather than looking 'outside the box', highlighting issues of power individual professionals have in the lives of disabled people with learning difficulties.

In the early days of the self-advocacy movement in the USA, it was common for non-disabled professionals to be involved in the meetings. As time progressed, however, it was noted that, just as professionals were likely to 'take over', so too were disabled people with learning difficulties looking to them to take the lead (Williams and Schoultz, 1982). It was recognised that the movement could only be successful if both disabled and non-disabled people stood against such cultural conditioning. This point stands in demonstration of the fact that meaningful change is not something 'done to' disabled people with learning difficulties but rather that we are all implicated in the process of change through the need to recognise the ways in which our cultural conditioning helps maintain the status quo. As a move towards creating an environment in which disabled people with learning difficulties could gain confidence and self-esteem, there was an increasing tendency for meetings to be held without non-disabled professionals (Williams and Schoultz, 1982). Whilst this undoubtedly benefited both individuals and the self-advocacy movement as a whole, the underlying assumption is that the removal of barriers (in this case, barriers within relationship) will allow for all people with learning difficulties to learn to 'self-

advocate'. Arising from the general belief that all people with learning difficulties are 'the same', the denial of the consequences of impairment can be seen to result in the exclusion of certain groups of people. As with 'integration', the group of people most likely to be excluded from the self-advocacy movement are those people unable to communicate through language in any of its many shapes and forms (Walmsley and Downer, 1997).

Self-advocacy for all?

Disabled people perceived as having learning difficulties, communication impairments and high support needs pose a great challenge to societies' norms. It is for this reason that individuals using facilitated communication have such difficulties in convincing professionals that they are genuinely communicating (Crossley and McDonald, 1980; Murray, 2002). Their appearance, behaviour and apparent lack of engagement with others, challenges the dominant concept of 'how people should be' and we generally find it difficult to believe that someone who may, for example, behave in very unconventional ways is highly intelligent and articulate (Triangle, 2001; Circles Network, 2001). Similarly, qualities other than intelligence can be displayed by people perceived as having learning difficulties – for example, being able to listen extremely well; being kind, patient, cheerful etc – and yet because their identity is totalised by the dominant view of cognitive impairment, such qualities generally go unrecognised.

The lack of value attributed to people who, due to impairment, are unable to 'speak up for themselves' in conventional ways, ultimately questions the value we place on human life as a whole. The requirement implicit in conforming to

the largely unquestioned cultural norm, motivated by a desire to eliminate the chaotic, unpredictable nature of life (Morris, 1981; Hunt, 1966), is that we relinquish an inner sense of integrity (see Williams, 1997). It is exactly this sense of losing touch with the inner self that Aspis (1997, p.653) alludes to when, outlining the dangers in the way in which service providers have adopted 'self advocacy', she describes how internalised oppression means that people with learning difficulties 'will do anything to be accepted by able-bodied people or people who are valued by society like service providers, social workers and professionals'. Following the argument of Fitzgerald (1994) that human rights exists to safeguard the 'intrinsic dignity' lying inside each individual, the large scale practice of forcing people with learning difficulties to conform to the norm in order to be accepted as a valued member of society, can be seen to deny rather than foster human rights (Williams and Nind, 1999).

Conclusion

Throughout this thesis, I argue that the basis for the discrimination and oppression experienced by disabled people with learning difficulties (as with other marginalized groups) lies within the distinction made between self and other. In this chapter I have demonstrated how the deep seated cultural belief that disabled people perceived as having learning difficulties are of less value has both promoted and served as a justification for practices emerging from the ideology behind the eugenics movement, alongside an oppressive pressure to conform to the 'norm'. Having demonstrated the principle ideologies maintaining the illusion of a fundamental difference between the non-disabled majority and disabled people with cognitive impairments, the next chapter explores the family

experience. As for all children, the family is the primary relationship for most disabled children and therefore holds the potential to challenge or re-enforce wider cultural beliefs.

Chapter Three

The Family Experience

Introduction

Disabled children and young people do not exist in isolation, but are usually part of a family structure both affecting and affected by the family in which they live (Foster et al, 2001; Knox et al, 2000; Hawley and DeHaan, 1996; Turbull et al, 1986; Bricker and Widerstrom, 1996). Families exist in a cultural context defined by assumptions suggesting a 'norm' that family life 'should' conform to (Sapsford, 1995). Lying at the interface between the public and the private, the family in turn affects and is affected by the community within which it is situated (Zohar and Marshall, 1994; Knox et al, 2000). The intertwining, reciprocal nature of close family relationships (Scott, 1997; Floyd and Costigan, 1997; Dunst and Trivette, 1986) provides an opportunity to look at both the difficulties our culture presents to the building of relationships between disabled and non-disabled people and ways in which families carry the potential to provide a powerful challenge to the status quo offered by the medical model of disability. In this chapter, I argue that the family experience of living with the issues of impairment and disablement provides invaluable exploratory ground as it takes us to the heart of a cultural ambivalence about impairment. In the context of the family, the impact of impairment and disablement is seen to be dynamic rather than static, presenting both the child/young person with impairment and their family members with a constantly changing experience affected by both the nature of impairment itself (Closs, 1999) the course of a family lifespan (Todd

and Shearn, 1996, 2000; Grant and Whitell, 2000), and a disabling world (Murray and Penman, 1996, 2000).

This chapter seeks firstly to place disabled children and their families within the wider context of families generally; secondly, to explore the family experience within the literature of both the medical and the social model of disability; thirdly and finally, to look at the ideas underlying support presently available to disabled children and their families.

In looking at these issues, it is important to state that although I consider the family as a whole, the main focus of the investigation is on the effects that a child's impairment has on the family. Within a disabling world, children with impairments are extremely vulnerable – both within the family and in wider society. A notable point of deviation from the general experience of childhood lies in the disproportionately high number of disabled children being brought up in the care system (Morris, 1995; DOH, 1998). It is easy to either apportion blame to families or to excuse them on the basis that their task was too great. The aim of this chapter is to explore the family experience in order that disabled children can be well supported within their families and that, in turn, those families can be well supported within their communities.

Families within a wider context

In spite of the fact that having a child with an impairment highlights issues of daily concern to all families – issues such as childcare; management of time; money; relationship to the community; work; education; housing; health; and the

division of labour within the home - sociological studies exploring the family pay little, if any, attention to issues of impairment and disablement (see for example the work of Morgan, 1996; Scott, 1997, Wyness, 1997). Within the main body of sociological theory, it is acknowledged that the strength of cultural, religious and moral beliefs associated with the family gives it the appearance of being a natural grouping within which status is largely attributed through gender and age (Bowlby, Gregory, and McKie, 1997). Deconstruction of this view reveals that families exist within a cultural context laden with normative assumptions aiming to produce citizens fit to serve the needs of wider society (Dallos, 1995).

Families finding themselves outside of this norm are:

- 1) forced to adapt in order to be assimilated;
- 2) excluded/segregated; or
- 3) allowed to exist alongside, but not included in the centre.

Zohar and Marshall (1994) argue that these three steps are the result of an individualistic society within which conflict, as the central metaphor of relationship in cultures based on 'self' and 'other', inevitably leads to fragmentation and isolation. In addition to being centrally situated in the dichotomy between self and other, the family is also commonly situated at the heart of a relationship of struggle between the individual/community; parent/child and male/female. Less commonly, but as a matter of course, families also encompass people grouped in the wider community as being disabled/non-disabled; black/white; and minority/majority ethnic group.

With these oppositional relationships stemming from the basic premise of separation between self and other, the opportunities for building barriers between different groupings of people can be seen to be part of an infinite, never ending process. In a world governed by notions of a division between self and other, self is almost always assumed to be the (largely unexamined) norm allowing for a subtle process of identity created out of a sense of separation. Whilst, within the West at least, the nuclear family forms the basis for the shaping of identity it also offers the opportunity for those who happen to conform to the powerful norm to be in close relationship with 'others', generally accepted as being inferior (Young, 1990). If viewed in a more egalitarian way than is currently the norm in western societies, such relationship carries the potential of 'valued' individuals experiencing through relationship, that being 'other' does not mean being of lesser value (Murray and Penman, 1996; 2000).

A theoretical position taking account of the inter-relatedness of family members is family systems theory (Turnbull et al, 1986; Bricker and Widerstrom, 1996).

Within family systems theory, the family is seen not as a collection of individuals but as a complex and dynamic system comprised of individual members who have their own characteristic and needs. It is recognised that things that impact on one family member are also likely to impact on others. Placing the family within its wider context, it is recognised that families are in turn embedded in a wider system and consequently influenced by a range of social, economic and political systems. Moreover, and crucially for the purposes of this thesis, an interpretive approach to family systems theory recognises families as experts in their own lives (Knox et al. 2000). Within the broad sweep of literature engaged

with family systems there is a body dealing specifically with the parental experience of having a child with learning difficulties (for example, Ell, 1996; Dunst, Trivette and Cross, 1986; Grant and Whittell, 2000). Whilst this body ties the specific experience in with the general family experience and acknowledges that parents are disadvantaged (Todd and Shearn, 1996, 2000) by the fact of having a disabled child with learning difficulties, and experts in their own lives (Grant and Whittell, 2000; Grant, 2003) the failure to make explicit the distinction between the experience of impairment and disablement leaves an ambiguity surrounding the nature of the hardship facing families. Whilst models of disability go unchallenged, there is a danger that hardship is perceived as being located within the disabled child. In spite of the fact that the focus of this literature lies within the inadequacy of service provision (Todd and Shearn, 1997; Knox et al, 2000) ambiguity remains. In addition to this, and crucially with respect to the central argument of this thesis, the assumption is that living with and alongside impairment is a 'non-normative' experience (Grant and Whitell, 2000)

The family in the UK

There is little doubt that the family is in a state of flux with children being brought up in a mixture of groupings – with both birth parents (either married or co-habiting), within step families, and by a lone parent (usually the mother) (Family Report 2 and 3, 1995; Dallos and Sapsford, 1995). Within such overall change, the traditional division of labour within families remains in tact with women taking responsibility for the majority of childcare and the running of the household – even where they also work outside the home (Wetherell, 1995). In spite of a general rise in income for the population as a whole, the number of children

living in poverty has increased affecting children and young people's health, education and housing.

The overarching view that the family provides the 'natural' system for childrearing masks the fact that parents do not always love their children and relationships between parent and child can (and do) break down under stress. Such is the extent of that breakdown that the family is the place where children are most likely to come to physical harm (Dallos and Sapsford, 1995). At the same time Dallos and Sapsford argue that when family relationships work well they provide:

...a sense of solidarity, of being part of a group rather than alone and vulnerable. As such, families can act as sites of resistance to public pressure, places where alternative ways of seeing the social world can be tried out and reinforced by the support of other family members (Dallos and Sansford, 1995 p.164).

The family then offers a wide range of experiences and gives the opportunity for an equally wide range of responses depending on a variety of factors from both within and without – this is no different for families with or without disabled children (Dunst and Trivette, 1986). It is unsurprising then, that whilst some disabled young people pay high testimony to their families (Baworowski, 2000; Williamson, 2002 (b)) others experience violence and abuse (Williams, 1995).

In line with the theme of paradox running through the thesis, placing families of disabled children within the wider context of all families, allows for a picture to emerge whereby their family experience can be seen to be 'the same but

different'. It is the same in as much as it contains elements familiar to all families; it is different because we live in a disabling culture that presents differential barriers to both disabled children and their family members being able to fully participate in their local communities, workplaces and educational establishments (see for example Beresford, 1994; 1996; Beresford et al., 1996; NCH Action for Children, 1994; Todd and Shearn, 1996, 1997, 2000). Disabled children and their families, alongside others who do not fit the norm (for example adoptive families, families of mixed race, families with lesbian/gay parents; families with disabled parent(s), families from minority ethnic backgrounds), do not easily fit into normative cultural expectations and therefore have a different experience of family life (Todd and Shearn, 1996, 1997, 2000; Grant and Whittell, 2000). It is to the specific differences facing disabled children and their families that I now turn.

The same but different

There are a number of circumstances that create a differential experience for disabled children and their families:

- impairment itself exerts an influence on the family experience (Beresford, 1994, 1996; Goodey, 1991; Mencap, 2001; Todd and Shearn, 1996, 1997; Dunst et al, 1989; Dunst and Trivette, 1988; Floyd and Costigan, 1997)
- extra costs associated with impairment and bringing up a disabled child in a disabling world (Dobson and Middleton, 1998);
- diminished employment opportunities (NCH Action for Children, 1994; Todd and Shearn, 1996; Ramcharan and Whittell, 2003)

- scarcity of appropriate and accessible housing (Oldman and Beresford, 1998);
- scarcity of appropriate and high quality childcare support (Beresford, 1994; Morris, 2001; NCH Action for Children, 1994; Todd and Shearn, 1996).

Because most families face a combination of these factors on a daily basis, their lives become notably different from the lives of others in similar circumstances (friends and neighbours) who do not have disabled children (see for example accounts of family life in NCH Action for Children, 1994; Dobson and Middleton, 1998; Mencap, 2001; Todd and Shearn, 1996, 2000; Knox et al, 2000).

Effects of impairment

Although it is extremely difficult to view impairment as neutral and not to attribute it with negative values as a matter of course (Frank, 1995), in order to make sense of the family experience it is important to acknowledge that impairment itself can have a dramatic effect on family life. For instance, trips to the park may be curtailed because the child with impairments gets cold very easily; cinema visits may not be possible if a child finds it hard to sit still; outings may be cut short with the onset of a seizure etc., it is reasonable to conclude from these examples that, although only one person is directly experiencing the impairment, family members frequently structure their lives around the consequences of that impairment (Roberts and Lawton, 2001; Foster et al., 2001; Todd and Shearn, 1996, 1997, 2000; Knox et al, 2000; Grant and Whittell, 2000). A recent study looking at the extra caring tasks routinely carried out by parents of disabled children found that, out of 40,000 records analysed, more

than 70% of the children needed extra assistance or supervision in multiple areas of daily life - for example, washing, dressing, and feeding (Roberts and Lawton, 2001).

Cost

It has been estimated that parents of a disabled child face three times the costs of parents of non-disabled children (Dobson and Middleton, 1998). Although additional benefits are available to families, they do not cover the actual costs families meet on a daily basis (NCH Action for Children, 1994).

In relation to the costs of bringing up a disabled child it is important to note that although some are related to impairment, others are the result of living in a disabling world. For example, the fact that a child is frequently sick might mean that high amounts of washing need to be done, frequent changes requiring larger than average amounts of clothes; at the same time, the fact of not being able to access public transport might mean that taxis become the main form of transport.

Diminished employment opportunities

Earning more money to meet the necessary additional costs presents challenges as both mothers and fathers of disabled children face difficulties in the world of work (DOH, 2001; NCH Action for Children, 1994; Todd and Shearn, 1996; 2000). In keeping with the general pattern of care giving within the family (Morgan, 1996) mothers of disabled children carry the main responsibility for the care and upbringing of their disabled children (Read, 2000; Beresford, 1994, 1996; Kagan, Lewis and Heaton, 1998; Shearn and Todd,

2000). Disabled families however have a differential experience with mothers of disabled children and young people less likely than other mothers to work outside the home and fathers finding the present system present barriers preventing their engagement in the world of work on an equal footing to fathers of non-disabled dependents (Kagan, Lewis and Heaton, 1998). Combining paid work with parental responsibilities related to the consequences of impairment is difficult because employers generally fail to take such responsibilities into account; parents face frequent appointments with health and educational professionals who assume that mothers of disabled children do not work; local support services are inadequate; and some disabled children/young people are frequently ill (Kagan, Lewis and Heaton, 1998; Read, 2000; Goodey, 1991; Mencap Report, 2001; Shearn and Todd, 2000).

Housing

Many disabled children and their families live in accommodation that is totally unsuitable (Oldman, and Beresford, 1998) adding unnecessary stress to family life. Many parents claim that the parenting of disabled children/young people becomes more (rather than less, as is the norm) difficult as their child gets older (Cowen, 1996; Grant and Whitell, 2000; Todd and Shearn, 1996). A major reason for this is the size of the disabled young person. Parents tell of the increasing difficulties they have with lifting and carrying upstairs as their child grows (Oldman and Beresford, 1996), whilst young disabled people tell of the way in which their homes do not allow for even small measures of independence from their parents due to lack of space (Murray, 2002). Such

situations put both disabled children/young people and their parents at risk, in addition to giving clear messages that their lives are not of sufficient value to warrant taking measures to reduce such risk. Morris (2001) found that families opting for residential education for their disabled children/young people on the basis that there was a lack of suitable local education were then denied grants to make their family homes accessible. In such instances, family homes can become physically unsafe as well as inaccessible, so contributing to the fact that the young person is unlikely to return home on a permanent basis.

Support

Whilst childcare arrangements are both difficult and expensive for many families, they hold additional and particular problems for disabled children and their families in that they receive less support within their neighbourhoods (Dallos and Sapsford, 1995; Dunst and Trivette, 1988); have greater difficulty accessing community child-care schemes (Petrie et al, 2000); and also require support through the teenage years and beyond (Murray, 2002; Todd and Shearn, 1996). Childcare services play and leisure activities open to non-disabled children and young people frequently exclude disabled children and young people (Petrie et al, 2000; Murray, 2002; Read, 2000). The ordinary sources of 'having a break' are therefore closed to parents who are consequently forced to look to specialist provision (Beresford, 1994; Shearn and Todd, 2000). Such specialist provision does not allow for parents of disabled children to work as families are offered care when it is available rather than when suits the families requirements (Read, 2000; Beresford, 1994; Todd and

Shearn, 1996, 2000). As children grow to teenagers - a time when non-disabled young people are experimenting with independence and developing strong friendship networks outside of the family - the effect of disablement means that young disabled people with high levels of support are forced into a relationship of high dependency with their parents (particularly their mothers) giving them a different experience from the majority (Murray, 2002; Grant and Whitell, 2000; Todd and Shearn, 1997; Knox et al, 2000).

The effects of the barriers

It becomes evident that each one of these barriers affects the other - for example, going to work is affected by the availability of childcare; not working means having less money; less money means having fewer available housing options as well as decreased opportunities to be 'out and about' in the community. At worst, the barriers mean that some disabled children live away from their families, at best disabled children and their families are unable to access the ordinary every day lives families of non-disabled children can take for granted (Knox et al, 2000; Todd and Shearn, 1996, 2000).

Exploring the family experience in this way, it becomes evident that family life is affected by both impairment and disablement. Whilst impairment is not necessarily fixed or given, it nevertheless carries features that cannot be changed. The following section explores the effects of impairment on individuals, their families and ultimately their communities.

Re-conceptualising impairment

In the previous chapter I argued that, in the same way that gender oppression affects both men and women (Morris, 1993) and racism affects all races (hooks, 2000), whilst impairment is an experience affecting a minority, disablement affects us all. Although impairment is clearly located in an individual, the family experience of living with impairment and disablement highlights ways in which disabled and non-disabled people are affected by both issues – in practical aspects of their lives and in relationship with each other (Shearn and Todd, 2000; Grant and Whittell, 2000; Floyd and Costigan, 1997; Knox et al, 2000). The extreme example of the death of a child due to impairment(s) illustrates the way in which, although the child is the individual directly experiencing impairment, the consequences of that impairment have a tremendous impact upon all family members suggesting that impairment, not just disablement, affects the life of individuals without impairments (Frank, 1995). Such an example allows for light to be thrown on some of the less extreme ways in which impairment, as opposed to disablement, affects the daily experience of the family. Similarly, taking a life course approach (Hawley and DeHaan, 1986; Grant and Whittell, 2000) allows for a wider view encompassing the very real concerns parents have for the future (Lloyd, 2003) whilst also making visible the cumulative effects of living with the consequences of impairment and the disabling barriers facing families of disabled children/adults with cognitive impairments (Grant, 2003).

As the idea that impairment affects more than the individual runs counter to assumptions in both the medical and the social model that disabled people exist as a homogenous group, I now examine the grouping of people based on impairment.

'Disabled/non-disabled'

Although as individuals we have a range of experiences depending on bodily limitations imposed through impairment, illness, or old age, it is difficult to draw a dividing line between people who have impairments and those who do not (Swain and French, 2000). The reality of the human condition is that very few individuals reach a level of physical perfection; most people live with minor impairments (such as long/short sightedness; stiff limbs; weak digestive systems; slight memory loss etc); and a minority live with significant impairments that impose greater than average physical and/or intellectual restrictions.

Viewed in this way, it appears that rather than falling into separate groups of people with or without impairment, we co-exist along a continuum of physical attributes and experience (Frank, 1995; Stone, 1995). This is not to deny limitations imposed by impairment or the discrimination and oppression currently faced by disabled people, but rather to continue the application of social constructionist theory (Foucault, 1977) underpinning the social model of disability in order to further deconstruct the social interpretation of a common human experience.

Living with paradox

Frank (1995) explores the paradoxical nature of illness and impairment from the perspective of the individuals directly affected. Similarly, having a child with impairment produces a tension for parents between ordinary parental love of the child just as s/he is, and a desire to erase the impairment:

I am not happy because (...) I believe the hardest thing is having a son with a problem I know that I can never solve. (But on the other hand) I am at peace; I am content with my son because with the limitations he has I have learned to know him, to love him and to understand a new way of living (cited in Larson, 1998, p. 870).

This conflict, present in the majority of families made up of non-disabled adults and disabled child, becomes particularly pronounced (and more generally accepted) when impairment leads to a shortened life expectancy and/or chronic physical suffering. Worry and concern about a child's health and future prospects can all too easily be viewed as a measure of a lack of acceptance of impairment and the embodiment of ambivalent attitudes towards the child. Some parents state that the worry they have for their child is not related to impairment itself, but rather because they know that their child will suffer lifelong rejection (Tonight (1) 2002). The emphasis in the medical model of the problematic nature of impairment leads to the assumption that it is difficult for parents to love their disabled child:

I knew her condition was serious and her prognosis poor but, to me, she was my firstborn, beautiful child. Every time I expressed my joy to the staff at the hospital, they said, 'She's denying reality'. I understood the reality of my child's situation but, for me, there was another reality (cited in Kearney and Griffin, 2001, p. 585).

Parents expressing a view of their child deviating from the tragedy interpretation are often labelled by professionals operating within a medical model as pathologically dysfunctional (Larson, 1998; Cowen, 1994; Goodey, 1992). Alternatively, the dominance of the medical model makes it possible for the natural love parents have for their disabled children to be viewed as an indication of special values within the parents (parents as saints), so contributing to the dehumanisation of disabled children (Goodey, 1992). While most parents will inevitably experience a conflict between parental love and internalised cultural values (Larson, 1998), many discover that the relationship they have with their child challenges previously held values and quickly leads to a different, positive perspective (Goodey, 1992). Such is the challenge to their previous set of beliefs that many parents report the rearing of a child with impairments operating as a catalyst for profound emotional and spiritual growth (Ball, 1999; Larson, 1999). This is compatible with the growing literature on resilience within oppressed groups and families that demonstrates ways in which dispositions, capacities and resources can be called upon by individuals and families to maintain buoyancy and self-esteem in the face of challenge:

Resilience enabling family processes allow a family to create a path that is adaptive and may even permit them to grow and thrive in response to their stressors. As such resilience should not be conceptualised as a static set of strengths or qualities as much as a developmental process unique to each family. (Hawley and DeHaan, 1986, p. 65)

Such an approach allows for families to respond to changing circumstances in a positive way – learning from and growing with as opposed to being victimised by

their experience (Grant, 2003). The fact that parental accounts cover a broad spectrum of responses accords with Mason's (1995) assertion that 'we are at a fork in the road in terms of our approach to disability and disabled people'. As with others, parents face a choice of going with the natural bond and thereby challenging the status quo or succumbing to the pressure to conform to the cultural norm. Examples of a wide range of parental responses can be seen from comparing the accounts of Featherstone (1980); Hannam (1988) and Rose (1998) to those of Fitton, O'Brian and Wilson (1995); Goodey (1991) and Murray and Penman (1996; 2000).

Early days of parenting a child with impairment

In a culture placing high value on intelligence, beauty, youth, and independence, the birth of a child with impairments is commonly viewed as a tragedy from which the family may never recover (Kearney and Griffin, 2001). As outlined in the previous chapter, the Abortion Act (1967) introduces a tension between a non-disabled parent and their disabled child before the child's birth. In a deeply segregated society, parents often find themselves thrown into the world of impairment and disablement having little or no personal experience of either (Goodey, 1991). Generally, the only reference points parents have are those of impairment being 'undesirable' and therefore 'bad'. At the same time, the majority of non-disabled parents experience feelings of love, protection, and 'wanting the best' for their disabled child/children (Tonight (2), 2002; Mencap, 1998; Oswin, 1991; Murray and Penman, 1996; Knox et al, 2000). Such positive emotions conflict with internalised beliefs, dominant cultural values, widespread policy and practice based on the medical model of disability.

Perhaps the most damaging feature of the medical model with regard to the family lies in its emphasis on the disabled child as a 'burden', thereby creating a barrier to the disabled child being equally valued and fully included within the family (Hannam, 1988; Meyer, 1995; Featherstone, 1980; McCormack, 1992; Rose, 1998). As the medical model makes no distinction between impairment and disablement, it is easy for non-disabled parents to confuse issues inflicted by disablement (stigma, lack of value, second rate treatment, segregation and isolation etc) with the possible limiting effects of impairment.

The social model, on the other hand, with its reluctance to explore the consequences of impairment, has also rendered the paradoxical nature of the parental experience invisible (see Roberts and Lawton, 2001). In taking the view that 'special care needs go beyond the bounds of ordinary parenting' (Beresford, 1994, p. 9), literature challenging a medical model perspective places the experience of parenting a child with impairments as outside of the ordinary thus reinforcing the view that impairment is an 'extraordinary' aspect of the human experience. Additionally, the dichotomous nature of the social model results in parents being stripped of the role of parenting in that their prescribed (supportive) role in relation to their child with impairment is given as that of 'ally' or 'advocate'. Whilst such a role is clearly different from the role of 'carer' imposed by the medical model, it holds similarities in that it strips parents of the primary role of parenting, once more denying them an ordinary experience. The result of the partial explanation offered by both the medical and the social models of disability renders the total experience invisible.

Positive relationships rendered invisible

Despite the lack of literature concerned with the family experience during the early part of the last century (the emphasis being on the institutional experience), there is evidence that positive family relationships existed in spite of the dominant ideology. For example, in her compelling study of the largely unacknowledged grief experienced by people with learning difficulties, Oswin gives us a beautiful glimpse of 'ordinary' family life so hard to find at that period:

Peggy had always had a very loving family life. Her father had died in the 1930s when she was 19 years old. She had continued living at home with her mother. She was 35 years old when her mother died, and then she went to live with her sister and brother-in-law, Mr and Mrs Cossett, and their three year old little girl. She lived with her sister for 34 years until her admittance to the mental handicap unit for terminal nursing care (Oswin, 1991, p.118).

The invisibility of the family experience alongside the indisputable evidence that many disabled children spent their lives in long stay institutions (Morris, P. 1969; King, Raynes and Tizard, 1971) makes it easy to assume that families were happy to 'get rid of' their disabled children. Such a conclusion is all the easier to make as it colludes with medical model ideology that disabled children, particularly those with learning difficulties, are of lesser value than non-disabled children. There are, however, indications that the removal of a disabled child from the family home caused much stress and heartache for all family members (Oswin, 1998; Dyer, B. 1996; Molloy, 1996) in addition to evidence that the majority of disabled children and young people did in fact remain with their families (Ryan and Thomas, 1987). The process of rendering the experience of parenting a child with impairment both extraordinary and invisible often begins at birth when mothers of newborn babies are frequently moved into side rooms on

hospital wards where they have little contact with other mothers (Goodey, 1992). Set apart from the experience of the majority, they enter into a world in which both they and their child are given 'extraordinary' treatment.

Early signs of conflict – disclosure

Although there is no evidence to suggest that the way in which a parent is told about a child's impairment has any lasting effect on the relationship between parent and child (Beresford, 1996) the time and manner of disclosure is undoubtedly important for both parents and children (Goodey, 1991, 1992; McCormack, 1992; Mencap 2001). Mason (1995) explores the messages given to parents immediately after the birth of a disabled child, highlighting the way in which initial professional intervention often has the unfortunate effect of feeding into ambivalence about having a child with impairments, so making the bonding process more difficult. In spite of numerous reports recommending guidelines for good practice in telling parents about their child's impairment (for example, Jupp, 1992, Quine and Pahl, 1986; Spastic Society, 1994) parents continue to report dissatisfaction about the information they receive about their child and the manner in which such information is given (Beresford et al, 1996).

Responses to disclosure

A common parental response to the news that their child has an impairment is to look for a definite 'diagnosis' (Gillman, Heyman and Swain, 2000; Cowen, 1994) and then to embark on a search for treatment or 'cure' (Dyer, 1996; Brereton, 1994; Scotson, 1983; Featherstone, 1980). As both these responses carry the

potential to increase the divide between disabled child and non-disabled parent (see for example, Oliver, 1993; Beardshaw, 1993) I now look at each in turn.

From diagnosis to labelling

In an attempt to understand their child and to seek for the best and most appropriate treatment, parents commonly seek for a diagnosis of their child's 'condition' (Cowen, 1994). Because a diagnosis can open the doorway to access appropriate resources and support (Gillman, Heyman and Swain, 2000; Contact a Family, 2002) many parents perceive the label as having a beneficial effect on family relationships as they are relieved from a sense of 'not parenting well enough' and can 'get on with the job' without the burden of guilt (Bovell, 2001). Unfortunately, however, the labelling of an individual is usually used as a means of totalising identity (Sutcliffe and Simons, 1993) as opposed to being a useful diagnostic tool (Gergen et al, 1996). Parents themselves, being part of the culture that de-values people on the grounds of certain impairments, can respond negatively to the diagnostic label resulting in an emotional distancing from their child (Harris, 1995). This can introduce a tension between parents of disabled children (who are seeking a diagnosis) and disabled adults (who are rejecting the labels) that contributes to a gap in understanding between non-disabled parents and disabled adults so giving credibility to the disabled/non-disabled divide.

Having found a label, or frustrated by not being able to find one (Contact a Family, 2002) parents commonly go on to look for the best 'treatment' for their

child. Although on reading such accounts it is easy to draw the conclusion that parents are failing to embrace their children 'just as they are' and are desperately looking for them to be more 'normal' it is worth pausing for an instant to consider additional motives behind such parental searches. In a culture devaluing disabled children it is all too easy for professionals to take a negative view and dismiss children with impairments as inherently worthless. Often parents seeking for treatment possibilities for their child have been told by professionals that there is little point as their children are unlikely to benefit. When these parents persist, they might be told they have an 'unrealistic' view of their child (Larson, 1999; Goodey, 1991; Kearney and Griffin, 2001). Parents then find themselves facing the choice of following the advice of professionals and colluding with negative attitudes, or entering into a relationship of conflict with professionals and 'trying out' alternative approaches and treatments with others who view their child in a more positive light (Williamson, 2000; Scotson, 1985). The paradoxical nature of the family experience (Larson, 1998), rooted in a medical model culture, means that it is very easy for parental motives to be both confused and misunderstood. For example, parents following the generally accepted parental role of wanting to give their child opportunities to stretch to the limits of their capabilities can easily be misunderstood as 'not accepting their child' (Beardshaw, 1993). This holds credibility because many parents, representing the wide range of views towards impairment that exist in the general population, do indeed find it difficult to accept their child 'just as they are' (Roll-Pettersson, 2001; Cowen, 1994).

The invisibility of the family experience, the concentration on fixing the child with impairment, has meant that scant attention has been paid to the relationship between disabled and non-disabled brothers and sisters. In spite of research evidence to the contrary (Grossman, 1972; Howlin, 1988; Kaminsky and Dewey, 2001; Stalker, 2003), it is largely assumed that sisters and brothers 'suffer' from the experience.

Brothers and sisters

Whilst parents play a major part in the lives of children/young people, the sibling relationship is one that can be equally important – not least because it carries the potential to span an entire lifetime. In keeping with the parental experience and in accord with family systems theory (Dunst et al, 1986; Knox et al, 2000) Schopler and Mesibov (1984) assert that issues applying to non-disabled siblings apply equally to disabled/non-disabled brothers and sisters.

Describing relationships between non-disabled siblings Dunn points to bonds that can equally exist between disabled and non-disabled siblings:

Sisters and brothers understand each other well not only because from the earliest days they have shared a familiar world and are daily exposed to each other's ways and wishes, but also because of the emotional urgency of their relationship. It really matters to a child that he should understand what his sibling is feeling and intending to do (Dunn, 1984. p. 144).

For disabled children who generally are not valued and are often thought to be incapable of forming close relationships, the bond between siblings goes largely unacknowledged (Murray, 1996). One result of the lack of recognition given to

this relationship is that service provision takes little or no account of the importance of such bonds. Whilst the dominance of the medical model leads to an acceptance of the view that non-disabled siblings must inevitably 'suffer', research over the years has shown that there is a wide range of responses to the presence of a sick or disabled child within the family (Schopler and Mesibov, 1984; Closs, 1999; Connors and Stalker, 2003).

In looking at the experience of siblings it is necessary to consider issues of power within the family. Literature demonstrates that children are likely to pick up on the attitudes of their parents – where the parents view their disabled child positively, there is a greater chance that non-disabled siblings will follow suit and vice versa (Garbarino, Brookhouser and Authier, 1987; Gath, 1992; Howlin, 1988). In this instance, parents can be seen to hold the power to shape the attitudes of their children. In addition to this, and in accordance with a culture de-valuing children, dynamics within the family have meant that the voice of parental experience is given a greater space than the voice and experience of children and young people. Listening to the emerging voice from non-disabled siblings indicates a discrepancy between parental reports of the non-disabled sibling's experience and the direct reports of siblings themselves (see for example the contrast between parental accounts in NCH Action for Children and those given by siblings – Hoskins, 1999; Jenkinson, 2000).

The small amount of literature written by siblings reflects an experience that is full of contradictions but ultimately positive (Hoskins, 1999; Closs, 1999; Zammit, 2000) reflecting the main thrust of research findings on the topic

(Kaminsky and Dewey, 2001; Grossman, 1972). In addition, siblings of disabled children are recognised as being more caring and concerned about their brother and sister with impairment than non-disabled siblings (Abramovich et al, 1987; Lobato, 1985). This aspect to their emotional growth is apparent later on in life when a high proportion of siblings enter into 'caring professions' (NCH Action for Children, 1994).

A major preoccupation within the literature written by parents is that of the worry about 'what happens when I am no longer able to look after x' with many parents articulating that they do not wish to 'burden' their other sons/daughters with responsibility for care (Hannam, 1988; Featherstone, 1980; Dyer, 1996). A disabling world viewing parents of disabled children as 'inadequate' or 'to blame' for their child's impairment can lead to parents feeling guilty about spending more time with their disabled child than with their non-disabled brothers and sisters (Dyer, 1996). It is all too easy for such guilt to be misinterpreted and for parents to assume that the presence of a disabled child has an automatically negative impact on brothers and sisters.

When placed in a positive context, the experience of siblings carries the potential to teach us a great deal, as it can be free of the many relational barriers existing between disabled and non-disabled people of all ages (see for example, Ellen and Michael Goodey, 2000). Whilst non-disabled parents have to question the set of beliefs they grew up with, siblings (especially those younger or close in age) have the opportunity, within the family at least, of

experiencing impairment as 'just a part of life' (Gath, 1992). For siblings, then, their early family experience is both normal and ordinary (Philp and Duckworth, 1982). It is only as they become aware of the differential treatment of disabled and non-disabled young people in the wider world that they learn their experience is viewed by the world as 'extraordinary'. When sibling relationships are placed within the sphere of the ordinary there is room for the well-documented range of brother/sister experience –love; protectiveness; jealousy; competitiveness; irritation and affection (Dunn, 1984).

I started this chapter saying that the family affects and is affected by wider societal values and practices. Within such an intertwining process, it often becomes difficult to disentangle the 'chicken from the egg'. However, if families can disentangle the mixed messages they receive, whilst simultaneously taking responsibility for their potential to influence change, the disabling attitudes and practices of wider society become increasingly visible and lose their hold as the accepted norm. Having attempted to uncover some of the complexities of the family experience, I now turn my attention to the ideology underlying service provision.

The nature of support available to families

At the time of writing, the nature and provision of support to disabled children and their families is undoubtedly at a point of change (Stalker, 2003). Whilst families have long recognised ways in which their lives are made harder by difficulties including housing, transport, child-care, leisure opportunities,

education, and physical access to community buildings, family support has traditionally been understood to mean the provision of 'respite care' (or short term breaks as it has recently been renamed). Minutes from the newly convened Disabled Children's External Working Group (part of the National Service Framework for Children) reflect a broadening in understanding of the traditional view of family support to encompass other aspects of family life including housing, leisure, education, and health. Similarly, Valuing People (DOH, 2001) recognises the wide range of discriminatory factors affecting disabled children and their families:

Families with disabled children have higher costs as a result of the child's disability coupled with diminished employment prospects. Their housing needs may not be adequately met. There is little evidence of a flexible and co-ordinated approach to support by health, education and social services, and there is significant unmet need for short breaks (Valuing People 2001 para.1.18, p.19).

There is a growing recognition that service provision to families is no longer solely about relieving the non-disabled family members from the 'burden of care', but rather is aimed at enhancing the quality of life of all family members (Knox et al, 2000; Hawley and DeHaan, 1986; Ell, 1996; Dunst and Trivette, 1986, 1988; Floyd and Costigan, 1997; Beresford, 1994, 1996; Kagan, Lewis and Heaton, 1998). Whilst such a shift is welcome, it has not yet filtered down in any significant way to the daily lives of the majority of disabled children and their families. Although there is growing recognition amongst policy makers that families require support on all fronts, the common experience of families is of 'family support' being limited to 'respite care'. For this reason, I end this chapter looking at the problematic nature of the ideology underlying the provision of

respite care arguing that a greater understanding of the effects both impairment and disablement have on families is needed to underpin policy change before practice can have a more positive effect on the lives of disabled children and their families.

In spite of the fact that literature questions the nature of service provision on the grounds that support is organised for one person (the disabled child) for the benefit of another (usually the mother) (Beresford, 1994; Prewett, 1999), whilst also identifying the gains to be made from basing support services on the premise of building on strengths rather than compensating for weaknesses (Dunst and Trivette, 1988) there is no questioning of the fact that family support is embedded in issues of child protection. This issue is however of crucial importance to the central concern of this thesis, as there is a direct contradiction between being able to live ordinary lives and being forced to access support services on the basis that the family is on the verge of breakdown because they are 'unable to cope with their disabled child'.

The basis of service provision to families being that of 'crisis prevention' means that:

- accessing 'short term breaks', 'family link placements' or 'respite care' leads to the young person becomes a 'looked after child';
- crisis becomes the accepted norm rather than on-going support being provided as a matter of course;

- with resources planned to accommodate crisis, families are forced into a position of competing with each other on the basis of 'having the worst time'(Knox et al, 2000);
- on going support to families is seen as preventing breakdown rather than allowing for 'ordinariness';
- professionals and parents are pitted against each other as the role of professionals becomes that of protecting the child from their parents;
- parents and service providers have different agendas, therefore dissatisfaction and conflict is inevitable;
- professionals are in a powerful position as gatekeepers to services.

At present, there is a move towards leisure provision in the form of after-school and holiday clubs as an alternative to 'respite care'. Whilst this undoubtedly gives disabled children a welcome experience of being in their own communities and therefore tackles some of the disabling barriers they face, it does not take into account the full range of disabling barriers facing them or other family members. For example, it does not necessarily support working parents or siblings being able to do their chosen activities; nor does it allow for flexibility – young disabled people attend activities at the time they are provided and they and their families have to 'fit in'. It does not, therefore, allow for 'ordinariness'. The emerging model of service provision, although providing a move towards the greater inclusion of the disabled child in the community, is inherently limited as it continues to view disabled children in isolation and therefore leaves the

'problem of impairment' with the individual rather than seeing it, unproblematically, as belonging to individuals, families and communities.

Conclusion

I have argued in this chapter that disabled children and young people do not exist in isolation; it is through relationship that they are either valued or de-valued. The primary relationship for most disabled children and young people is based within their families. Disabled young people have no choice but to live alongside the consequences of impairment within a disabling society. Whether young disabled people are supported to take a positive view of impairment depends, in the first instance, on messages they receive from their parents. As a microcosm of larger society, families offer a range of responses to the dual experience of impairment and disablement. Whilst some parents view their disabled child positively, others remain deeply ambivalent. Such responses hold the power to alternatively weaken or strengthen the status quo. Positioned as a link between the individual and community, the family is then, ideally placed to take a lead role in the process of the deconstruction of discriminatory cultural values, attitudes and practice.

Many parents report their attitudes towards impairment radically changing as the result of parenting a disabled child, indicating that relationship is a powerful vehicle for the disintegration of widely accepted views about self and other. Acknowledging the paradoxical nature of the experience of impairment reveals that it cannot fit into the confines of 'either/or' but rather demands to be grounded in a wider, more chaotic view encompassing 'both/and'. In contrast then to 'celebrating the difference' whilst maintaining the essential position of

'otherness', the family provides the opportunity for the paradoxical nature of the experience of impairment to be wholeheartedly embraced and for difference to be accepted as the norm. In addressing oppression and discrimination resulting from racism, Patricia Williams places the responsibility for change in the hands of both individuals and institutions:

...let me just say that I am certain that the solution to racism lies in our ability to see its ubiquity but not concede its inevitability. It lies in the collective and institutional power to make change, at least as much as with the individual will to change. It also lies in the absolute moral imperative to break the childish, deadly circularity of centuries of blindness to the shimmering brilliance of our common, ordinary humanity (Williams, 1997, p. 66).

In arguing for the collective ownership of and responsibility for a culture discriminating on the grounds of physical difference from an assumed norm (white/black; non-disabled/disabled; male/female; adult/child) we are all implicated individually and collectively.

At present, although there are changes in the nature of service provision available to families, support is piecemeal and isolated. Consequently, it supports the negative view of the status quo and does not allow for ordinariness in the lives of disabled children or their families. I have argued that in order for services to allow for ordinariness, the consequences of impairment, for both the individual and their family, need to be taken into account. In view of the fact that the identification and dismantling of disabling barriers is central to this task, the following chapter examines the social model and cognitive impairment.

Chapter Four

The Social Model and Cognitive Impairment

Introduction

There is little doubt that the increased attention and positive changes in legislation and policy relating to disabled people over the last 30 years is largely due to the work of disabled adults with physical impairments engaged in explaining the experience of living with impairment in a disabling world. Social model ideology, first expressed through the writings of Paul Hunt in 1963 and later developed by disabled academics (Abberley, 1987; Barnes, 1991; 1996; Barnes, Mercer and Shakespeare, 1999; Finkelstein, 1980; Oliver, 1990, 1996 (a)) has, in a relatively short space of time, had a major effect on legislation, policy and practice. This impact can be seen in legislation such as Valuing People, 2001 and the Disability Discrimination Act, 1995 (Barnes, 1991); the establishment of a Disability Rights Commission and Independent Living Centres; and the implementation of a scheme for Direct Payments. In these ways, the social model of disability has played a significant role in putting issues affecting the lives of disabled people firmly 'on the map' and has thereby changed the face of our society through assuring a greater presence of disabled people within the mainstream. Prior to this, normalisation had greater effects on policy and practice relating to disabled people with cognitive impairments (Tyne, 1980; Brown and Smith, 1992).

In spite of this sphere of influence, however, it is noticeable that people with physical or sensory impairments have a greater presence within the mainstream than people with cognitive impairments, whilst it is also clear that disabled people having 'success' in the mainstream do not necessarily live 'ordinary' lives (Campbell and Oliver, 1996). Reflecting this greater presence within the mainstream, a review of the literature of the social model indicates that disabled people with cognitive impairments remain marginalized within the social model – widely perceived as 'other' (Chappell, 1998; Walmsley, 1993). If, as has been suggested by many disabled theorists, fear of impairment is the root cause of hostile attitudes towards disabled people (Morris, 1991; Hunt, 1966; Wendell, 1996) then judging from the stigma ascribed to cognitive impairment it appears that we fear the consequences of this particular type of impairment over and above any other (Goffman, 1990; Edgerton, 1967). Tackling the fears surrounding cognitive impairment opens up the opportunity to identify the underlying cause of some of the more subtle discrimination facing *all* disabled people.

In recognition of these issues – the positive effects of the social model, the lack of ordinariness in the lives of the majority of disabled people, and the failure of social model literature to 'take on board' the full range of barriers facing disabled people with cognitive impairments - it is my aim in this chapter to:

- a) explore the social model in order to better understand why it provides a partial explanation of the experience of disablement, highlighting areas

that would contribute towards people with cognitive impairments moving from the margins to the centre; and

- b) identify conditions enabling ordinariness in the lives of disabled children with cognitive impairments.

It is important to point out that the emphasis within this chapter lies within an exploration of the social model from the viewpoint of disabled children with cognitive impairments. I do not, in this chapter, attempt to present an overall critique of the social model – this being beyond the remit of this particular piece of work.

The difference a model makes

The clear distinction the social model of disability makes between the experience of impairment as a physical reality and disablement as a social construct provides a vantage point from which to view the experience of living with impairment in a disabling world (Oliver, 1990). Similarly, the ever increasing number of voluntary organisations working from a ‘social model’ perspective (for example, Parents for Inclusion; Disability and Equality in Education; Triangle; Circles Network; Scottish Human Services, and the Centre for Studies of Inclusive Education)² provides clear evidence that social model theory and practice makes an enormous difference to the daily experience of disabled children and young people with a range of impairments in many parts of the country. For example, the decision taken in 1993 by the London Borough of Newham to close all special schools and to aim to educate *all* children within

² See Appendix 2 for details of the work of these organisations

the mainstream by 2004 (Jordan and Goodey, 1996) was based on the belief that *all* children (disabled and non-disabled) have the right to be together.

Whilst a mainstream education remains out of the reach of many, there is little doubt that it has become more possible in the last 15 – 20 years to secure an education in the mainstream (CSIE, 2002). Although the pace seems agonisingly slow for families fighting for their children to be given a place within the mainstream of their communities, it is sobering to remember that it was not until the 1971 Education (Handicapped Children) Act that disabled children with 'severe' and complex learning difficulties had the right to an education. The rapid move in the last thirty years, from being viewed as 'ineducable' to that of being (albeit occasionally and not without difficulties) accepted into mainstream education is in part due to possibilities opened up by the social model of disability but more significant was the role of normalization particularly up to the 1990s. (For details of present day experience within the mainstream, see Chapter 8).

Whilst not all the families involved in this research had heard about the social model, those who had, agreed that it made a tremendous difference to their lives as it has allowed them to make sense of the conflicting emotions of loving their child whilst also having internalised attitudes of a disabling society. Making sense of such conflicting ideas supports parents to make positive choices for their children - for example, one participating family who were not familiar with the social model or organisations working on a social model ideology, has found that exposure to the ideas (through conversations about this work) of the social

model has given them energy to 'look for something different' (Helen, London, 2002) whilst becoming increasingly unhappy (and angry) about the limitations present services impose on their lives. As a result they have made contact with two organisations based on social model ideology and, through the contacts they are making, are building relationships with other like-minded people and gaining confidence in 'going for something different'.

In order to fully appreciate the effects the social model has had on the lives of disabled children/young people with cognitive impairment, I first take a brief look at the experience of living with impairment in the early years of the 20th century when the medical model of disability reigned supreme.

Medical model ideology throughout the 20th century

For the greater part of the 20th century, impairment was largely viewed as a personal tragedy affecting unfortunate individuals and their families (Oliver, 1990; Dyer, 1996). The only 'escape' offered to people with impairments was through the hope of a cure (or at least some improvement in the condition) offered by the medical establishment and its allied professions. Looking for a cure, receiving treatment to improve the condition, meant that disabled children and young people were often 'handed over' to institutions where they spent their entire lives (Mason and Rieser, 1990). In this way, theoretically 'for their own benefit', disabled children and young people were incarcerated within institutions, thereby cut off from mainstream society (Horwood, 1988). The emphasis in the medical model, of impairment as the only limiting factor in the

lives of disabled people serves to exacerbate fear of impairment, and results in the perpetuation of discrimination and oppression through segregation, political disenfranchisement, and social stigmatisation. The strength of opinion that 'doctors know best' was so strong that families giving up their child for 'treatment' believed they were doing the best possible thing – in some cases thinking that they were giving their child the only opportunity of life (Dyer, 1996). Although there is evidence to support the claim that the majority of disabled people lived with their families (Ryan and Thomas, 1987), such was the strength of the ideology that institutions were the only option for disabled people, that there is little information about the experiences of disabled people remaining in their own families during the first half of the 20th century. As we saw in Chapter 2, this means that individuals remaining with their families were effectively 'hidden from sight', rendered invisible to the majority (Napolitano, 2000).

Beginnings of the social model

The invisibility of the experience of disablement (as distinct from that of impairment), continued largely unabated until the writings of Paul Hunt (1966) openly challenged the status quo by making public the experience of exclusion as a result of impairment. By stating that impairment was not the most unfortunate aspect of his life, but rather that it was the denial of the material and social benefits open to the majority, Hunt placed the emphasis on impairment being an ordinary part of the human experience and so positioned the 'problem' as lying within socio/cultural fears surrounding impairment and leading to disablement. Impairment itself, he argued, did not mean that he was intrinsically

useless but rather he was rendered apparently useless because he could not easily contribute to the economy. It is this distinction between impairment of function and relationship to the outer world that formed the basis of what has become known as the 'social model of disability'.

The social model gathers momentum

Ten years after Hunt's writings, the Union of the Physically Impaired against Segregation (UPIAS) further clarified the distinction between impairment and disablement with the following definition:

Impairment: 'lacking all or part of a limb, or having a defective limb, organ or mechanism of the body'.

Disability: 'the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities' (Oliver, 1990 p.11).

Having made this distinction, the emphasis in the early years of the social model was of disablement as the result of material, social, economic, and cultural barriers facing people with physical impairments (Abberley, 1987; Oliver, 1990; Barnes 1990). Such an analysis, in the main developed by white male disabled academics and activists (Marks, 2000; Williams and Nind, 1999), presented the illusion that it covered the experience of all disabled people when in actual fact the developing theory was largely based on the experience of people with physical impairments (Williams, 1998; Humphrey, 2000; Marks, 2000). Indeed, it was not until ten years later that the definition of impairment was extended to include cognitive impairment. By default then, the social model in the early years was based on the assumption that the social construction of disability is

the same, regardless of the nature of the impairment or other cultural factors. In presenting one aspect of the experience of impairment and disability as if it were the whole, this explanation renders partially invisible the experience of disabled people with a wider variety of impairments and/or a cultural experience outside the accepted norm. This partial explanation led to the social model being criticised for rendering invisible the disabling experience of women (Crow, 1996; Morris, 1991), minority ethnic groups (Begum, 1990), children and young people (Morris, 1998 (a) and (b)), elderly people (Proctor, 2001) and people with cognitive impairments (Williams, 1998; Humphrey, 2000). Given the context and time in which the social model was unfolding (the UK in the 1970s and '80s) it is perhaps not surprising that it was disabled feminists who, whilst appreciating the overall viewpoint presented by the social model, challenged the pervading male perspective.

The effects of feminism

The new perspective that feminism offered to the male dominated disability movement in the early 1990s was that of the 'personal is political':

...there is a tendency within the social model to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying. A feminist perspective can help to redress this, and in so doing give voice to the experience of both disabled men and disabled women (Morris, 1991 p. 10).

Feminist thinking within disability discourse paved the way for a dialogue about the embodied experience of impairment (Crow, 1996; Thomas, 1999; Wendell,

1996; Campling, 1981; Morris, 1991; Mason, 1992; Keith, 1994). Prior to this, the emphasis the social model carried on disability, as opposed to impairment, meant that a silence surrounded the embodied experience of impairment (Hughes and Patterson, 1997). Increasing attention was placed on the argument that the lack of exposition given to a body that may itself be inherently limiting, the cause of fatigue and/or pain, serves to deny part of the experience of living with impairment and consequently only provides a partial explanation of the lived experience of impairment and disablement (Thomas, 1999; Wendell, 1996; Marks, 1999).

In spite of this fresh perspective however, early feminist texts surrounding the experience of impairment and disability (Morris, 1991; Keith, 1994), whilst including the experiences of black disabled women, women from minority ethnic backgrounds, and disabled women perceived as having learning difficulties - groups whose experience is notably absent from earlier social model writings - continued to make the core assumption that 'disability' = physical impairment (see for example Morris, 1993). In doing so, people with learning difficulties are 'there but not there', placed alongside but not included in the centre, acknowledged but kept at a distance, in much the same way as hooks describes the experience of black American women in relationship to the white feminist movement:

Much feminist theory emerges from privileged women who live at the centre, whose perspectives on reality rarely include knowledge and awareness of the lives of women and men who live on the margin. As a consequence, feminist theory lacks wholeness, lacks the broad analysis that could encompass a variety of human experiences. Although feminist theorists are aware of the broad need to develop ideas and analysis that encompass a larger number of experiences

that serve to unify rather than to polarize, such theory is complex and slow in formation (hooks, 2000, p. xvii).

Similarly, it is not until people with the entire range of impairments are placed in the centre of the social model that it can offer a complete explanation of the experience of impairment and disablement. The process of including people with cognitive impairments is difficult precisely because the cultural barriers are deeply internalised (Walmsley and Downer, 1997; Aspis, 1997, 2000; Chappell, Goodley and Lawton, 2001; Goodley, 2000). Following the lessons of the social model so far, it will not be until we explore such issues alongside people with cognitive impairments that we can fully realise the range of barriers facing disabled people with cognitive impairments (Veck, 2002).

Barriers within the social model

Implicit in social model theory is the assumption that the removal of certain barriers will enable disabled people to fully participate within society and claim their right of citizenship (and therefore personhood) as it is largely understood for the majority of non-disabled people. Whilst people with cognitive impairments may require issues of physical access to be addressed, they also face specific social and cultural barriers to personhood/citizenship (Gillman et al, 1997; Williams and Schoultz, 1982) based on the way in which they are perceived to be incompetent. The emphasis within the social model on the socio-economic reasons for disability has rendered such socio-cultural barriers largely invisible (Jenkins, 1998; Davies 1998). For example, although all disabled people are subject to the pressure of conforming to the norm in one

way or another (Abberley, 1987), people with learning difficulties are under the additional pressure of having to 'fit into' norms of intellectual and social competence. Whilst there has been much written about the oppressive aspects of normative expectations for people with learning difficulties within wider society (Stone, 1995; Chappell, 1998; Sutcliffe and Simons, 1993; Walmsley, 2001), social model theory has not yet considered the ways in which its own normative assumptions raises barriers to the participation of people with cognitive impairment (Chappell, Goodley and Lawton, 2001). An example of this lies in the assumption that contributions to theory can only be made through engaging in social/political discussions through language. This two-dimensional approach ignores the fact that some people with learning difficulties can only participate in a three-dimensional way. In order to explain the notion of 'three-dimensional participation' further, I turn for a moment to explore the (often subtle) ways in which we influence each other through 'being' and the little acknowledged effect this has on us individually and collectively.

Different ways of participating

In a culture depending on language as its main form of communication, the ability to both understand and communicate through language is generally perceived as a necessary pre-requisite of being able to fully participate, and therefore in terms of cultural engagement, to claim citizenship. Whilst the social model allows for the unveiling of a perspective valuing different ways of communicating and the recognition of communication as a two way process (Triangle, 2001), there has not as yet been a similar exploration of different

ways of participation that allows for people with cognitive impairments to be recognised as having valued contributions to make to mainstream processes because of their very presence, rather than on a commentary made through language.

In her exploration of a political concept of care, Tronto points to ways in which the human qualities emerging through a caring relationship have much to inform the practices of democratic citizenship:

The qualities of attentiveness, of responsibility, of competence, or responsiveness, need not be restricted to the immediate objects of our care, but can also inform our practices as citizens (Tronto, 1993, p. 167).

Similarly, positive human qualities evident in relationship with people with cognitive impairments who cannot communicate through language, have much to teach us about ways of 'being together' and ways in which the encompassing of such qualities might enhance our social organisation. Whilst the ability to use language is a precious human attribute, so too is the ability to 'fully listen' to others through 'how they are' as well as through 'what they say'. Positive attributes reported as emerging in some non-disabled children who attend schools welcoming children with cognitive impairments, are increased patience, tolerance of difference and willingness to 'care for' (Alderson and Goodey, 1996). Such qualities, pulled out of us through the presence of people with cognitive impairments hold the potential to greatly enhance our social relationships generally. With the normative assumption being that language is our principal means of engagement, then other aspects of human relationship

(such as the ways in which we influence each other through our presence and our behaviour) are rendered invisible and therefore not seen as being importance.

Possibilities of ways and means of participatory action have much to do with the particular ways participation is open (or closed) to us as the result of our embodied experience of impairment. For example, just as physical impairment might lead to fatigue and/or pain due to frequent muscle spasms, so cognitive impairment might lead to unexpected vocalisation, difficulty in staying still, or an inability to give an appropriate response (Baworowski, 2002). Whilst the effects of impairment are unique within the individual, and although we can never be entirely sure of the experience of people unable to communicate through language, the explanations given by people with cognitive impairments who use language provide invaluable clues to aspects of the embodied experience of cognitive impairment:

I want to write about my inside life – it is very different from outside. It is always there and I can see it always will be. I struggle all the time against confusion which is so tiring. I try so hard to concentrate on what is going on but sometimes I can't remember what people say. It is like a fast film going wrong and getting all scrunched up. The fast films are about the years when I couldn't talk to anyone. The conversations inside are about people talking to each other about something I don't understand. It is very muddled but the main feeling is despair of ever being understood (MacKeith, 2000 p. 246).

Whilst this description is unique, it bears resemblance to the experience of others with cognitive impairment – (see for example Sellin, 1995; Williams, 1993). For those people who, unlike MacKeith, are not able to communicate

through language, it is impossible for them to 'explain' what is happening to them and thereby to have their experience acknowledged. Consequently, it is impossible for others to ever be completely sure of their experience and we then have to get to know them well to see what works through 'doing with' rather than 'asking of'. The very act of engaging with someone in this way demands that we pay detailed attention to their experience *and* their responses to that experience. Such engagement provides invaluable opportunities to focus attention on listening to others in a respectful manner – an attribute that enhances *all* relationships.

A consequence of the lack of attention given to the embodied experience of impairment means that there is an absence of an examination of the social construction of impairment within social model theory (Freund, 2001; Overboe, 1999; Wendell, 1996; Manion and Bersani, 1987; Sutcliffe and Simons, 1993; Lea, 1988). Whereas there is within sociology a body of literature documenting disabling socio-cultural factors (Langness and Levine, 1986; Edgerton, 1967; Bogdan and Taylor, 1982; Humphrey, 2000) there is little that examines the effects of cognitive impairment from a social model perspective. The acknowledgement of both the distinct effects of the embodied experience and the social construction of learning difficulties (Koegel, 1986) allows for cultural attitudes to be examined, whilst also recognising the limitations cognitive impairment might impose.

Social construction of impairment

The fact that the categorisation of learning difficulties can vary for one individual at any one time in different settings (Mercer, 1973; Langness and Levine, 1986)

evidences the impact the social construction of impairment can play in the lives of people with cognitive impairments. The instances that some individuals 'become more capable' when they are treated as 'being more capable' (Whitemore, Langness and Koegel, 1986) indicates that attitudes towards cognitive impairment can influence the manifestation of impairment. Within this project, one young man was refused entrance to a mainstream secondary school on the basis that his behaviour was 'too difficult' whilst a school five miles away was happy to accept him and he has since returned home with certificates for 'good behaviour'. Such an example – the same boy, the same impairment, at the same time of his life, viewed so differently by the two establishments – demonstrates the way in which the social construction of impairment can have an enormous effect on the opportunities open to the individuals concerned.

It becomes evident then, that the social construction of impairment produces barriers to ordinary relationship (Bayley, 1997 (b); Goffman, 1990) that in turn, affects both social and political participation – including an engagement (in the widest possible way) with the social model. It is therefore, to relationship that I now turn.

Exclusion from relationship

The BBC radio programme 'Today' recently included an item about the social isolation of a four year-old boy described as 'autistic'. Although the boy attended a mainstream playgroup he had not made friends there and therefore spent much of his time alone when not in playgroup or in the company of his

mother. The marker taken for his perceived inability to make friends was that of not being able to engage in play with other young children through language:

Interviewer: He's autistic; presumably he can't get on with other children at all?

Mother: No. He's got no language, so he just can't get on with the other children... (Today, 2002).

The solution his mother decided to try was that of buying friendship (£5.00 an hour) –a desperate measure for a desperate situation. This snapshot from the life of a young boy goes to the heart of the barriers to friendship facing people with cognitive impairments:

- the assumption that without language we have little to contribute to relationship;
- the totalising of identity through a diagnostic label;
- being seen to be 'so different' that we cannot expect to develop friendships in ordinary ways; and
- a lack of concern about how people with cognitive impairments feel about their experience – for example, how would we feel if we had to resort to paying for friendship?

This story of today returns us to the old, but nevertheless extremely powerful, perception that cognitive impairment renders individuals less than human.

Being less than human leads the majority to assume that an equal relationship is neither possible nor desirable:

...it is so sad for me that nobody understands me but it is important for a lot of people to understand me a bit but achim (support worker) does not understand me enough and the others don't take any trouble with a person like me any more its enough to drive me to despair (Sellin, 1995, p. 78).

It is this despair, emanating from a deep sense of loneliness, echoed in the writings of so many people with cognitive impairments (see for example, Bauby, 1997; Williams, 1993; Barron, 2000; Smith, 2000) that has to be addressed as *the* major barrier to the social inclusion of people with cognitive impairments. The lack of real engagement within the social model as it presently stands colludes with the widespread silence surrounding the issues – a silence that renders people with cognitive impairments invisible. The social model has not yet reached out to large numbers of disabled people – at present most disabled people are isolated and live with the understanding of the medical model. Veck suggests that the way to fully engage with the issues is to move from asking questions solely about the external experience of exclusion, to that of considering the internal experience:

I had been so blinkered by what was happening to Ray; I had failed to understand his reaction to and his feelings about the pressure he was under. I had not thought to consider Ray's feelings about his own life and so I failed to respect his dignity (Veck, 2002, p.536).

Having made this discovery, Veck goes on to describes how he was enabled to enter into a mutually enjoyable, respectful relationship with Ray – a relationship based on human empathy as opposed to discursive othering.

A theme running throughout this thesis is the way in which meaningful relationship with people with cognitive impairments highlights areas pertinent to all relationships. For example, the vulnerability that almost inevitably runs alongside cognitive impairment highlights issues of trust and power in relationship – issues at the heart of all human relationship. The trust demanded as a result of the embodied experience of cognitive impairment and the ease with which such trust can be abused provides fertile ground on which to explore issues of importance to us all – vulnerability and power within relationship.

Vulnerability

An aspect of the widespread appeal of the film 'Iris', lies in the portrayal of an exceptionally intelligent, successful, and well respected woman living with and dying from, Alzheimer's disease. As a consequence of impairment, Iris becomes unable to do many of the things she had previously taken for granted; as a consequence of living in a disabling society Iris (and her husband) became socially isolated. Running parallel to Iris's loss of cognitive functioning was an increase in her vulnerability in the world. This particular aspect of her experience was demonstrated in a scene when she wandered out of the house on her own and was in danger from a) traffic and b) being abused by others who did not know her. Whilst physical impairment necessarily brings an increased vulnerability (for example, how to get out of a building in the case of a fire and not being able to use the lift), the vulnerability facing individuals with cognitive impairment is of a different nature as the impairment might affect their ability to give information about themselves or to understand the consequences of their

actions. In addition to this there is the added vulnerability of not being able to tell other people what has happened to them, thus rendering them entirely dependent on the good nature of family members, friends, support workers and other professionals.

During the course of this project when Owen and I were talking about support workers he suddenly became very distressed. It took some time for me to understand the sudden onset of his distress but eventually Owen told me how (at a time he had no means of communicating his experience to others) a support worker in a special school had abused him. Understandably, Owen felt very nervous about the thought of putting himself in the hands of new support workers. At the same time, Owen is aware that the only way he can 'create a life for himself' is by taking such risks – the alternative being a lifetime of institutionalisation (knowing he could be abused there as well). Such vulnerability, arising as a consequence of impairment, means that it is impossible for Owen, as with others, to not only be independent but also to consistently and reliably exercise autonomy.

Although there is debate within the social model about the difference between independence and autonomy (Reindal, 1999; Oliver, 1989; Morris, 1993) there is an assumption that we are all capable of exercising autonomy. For some people with cognitive impairments, exercising autonomy is only possible with the support and facilitation of someone who knows them well and is familiar with their 'ways of being'. In this way, cognitive impairment can, on occasion, pose a challenge to the way in which we understand independence *and* autonomy.

Once again, in order to fully 'unpack' such difficulties there is a need for public engagement with the issues from a social model perspective.

Independence and autonomy

Traditionally, independence and autonomy are seen as doing something on ones own, being able to make decisions and carry those decisions out. Social model theorists have challenged such assumptions by arguing that there is an important distinction to be made between independence and autonomy (Shakespeare, 2000; Finkelstein, 1998). This argument rests on the assumption that whilst physical independence is not always possible (due to impairment) the ability to be autonomous cannot be affected by impairment. In the case of cognitive impairment however, although the ability to take autonomous decisions is not always affected, it can be affected by both the effects of impairment and the social construction of impairment.

As I wrote earlier in this chapter, some young people with cognitive impairments report the sensation of confusion as the result of their impairment. In addition to this, many people with learning difficulties experience an extreme lack of self confidence due to the cultural association between cognitive impairment and incompetency. This presents a major challenge to achieving autonomy. The absence of engagement with this issue alongside people with cognitive impairments within the social model means that the explanation of autonomy and independence presently given fails to make sense for all. Whilst it is impossible to predict the results of positioning autonomy alongside

interdependence, until the tension lying between the two is fully explored, our understanding of the experience of cognitive impairment and disability will inevitably remain partial.

Earlier in this chapter, I described the way in which the feminist movement had impacted upon the development of social model theory. It is therefore interesting to note that although the dynamic of being considered to be incompetent, and therefore to have low self-esteem and difficulty in exercising autonomy, has much in common with women's experience there is an almost complete silence within the literature of such a link. An exception to this lies in the work of Walmsley (1993) when she demonstrates similarities, based on notions of incompetence, between the experience of women and people with learning difficulties.

Perhaps, and indeed the same could be said to be true for women, the most disabling aspect of being perceived to be inherently incompetent lies in the fact that it so negatively affects the self-esteem of those affected (Aspis, 1997; Sellin, 1995) thus making it difficult for the individual to recognise the oppression and take a stand against it. Such cultural conditioning, similar to the concepts of 'internalised oppression' (Rieser, 1990) and 'internalised racism' (hooks, 2000), holds true with regards to cognitive impairment resulting in people with learning difficulties believing in their incompetence and thus lacking the confidence to 'have a go', to try things out, to break out of relationships of dependency (Williams and Schoultz, 1982). It is all too easy, therefore, for a self-fulfilling circle of dependency to arise in relationships between those people perceived

as having learning difficulties and those people without. Aspis (1997, p. 653) argues that internalised oppression leads people with learning difficulties to 'do anything' to be accepted by those with power and influence in their lives. The socially conditioned lack of confidence on the part of disabled people perceived as having learning difficulties means that there are barriers for them to overcome in finding whether or not they have preferences, what their opinion is or in being able to say what they want (Mosley, 1994; Sellin, 1995; Rector, 1982).

Self-advocacy challenges assumptions

During the 1970s, the self-advocacy movement of people with learning difficulties was expanding on an international basis (Dowse, 2001) and thus challenging the widespread assumption of the incompetence of people with learning difficulties (Goodley, 1996, Williams and Schoultz, 1982; Sutcliffe and Simons, 1993). Ironically, this preceded the more widespread articulation of social model ideas. Whilst the original aims of self-advocacy were directed towards conventional notions of citizenship for people with learning difficulties (Williams and Schoultz, 1982) questions are now being raised about ways in which disabled people whose impairments exclude them from such conventional notions might be included within the movement:

We as disabled people need to look at ourselves. Don't segregate people but try to let them belong in a different way. I find it hard understanding them. We don't know how to do it. I would love people to integrate but don't know how to do it (Downer cited in Walmsley and Downer, 1997, p. 44).

Such an honest approach allows for the possibility of further exploration of how to include all within the self-advocacy movement and therefore contribute to an understanding of participation and citizenship based on a social model perspective. In practical terms, the issues of including people with complex cognitive impairments in the self-advocacy movement as within social model understanding come to light in the experience of access to Direct Payments. Whilst for some people with cognitive impairments the issue surrounding direct payments is about gaining confidence in their ability to 'manage' their lives and thus being able to 'prove competence', for others no amount of exposure to self-advocacy as we presently understand it will enable them to 'take control' in this way.

Being seen as incompetent in the private sphere impacts upon the way in which we are viewed in our communities and wider society. With the pre-requisite of both 'being a full and valued human being' and citizenship being that of competency, people with learning difficulties are automatically denied access to such status:

The traditional assumption is that, having few of the needs or abilities considered to be intrinsic to citizenship or the capacity to exercise conventional legal rights, people with intellectual disabilities have had no basis for a claim to equality: only to the extent that they can approximate other citizens can they establish such a claim. (Rioux, 1994 p. 68).

It follows from this that a social model perspective on the citizenship of people with cognitive impairments, requires present notions of citizenship/personhood to be reconceptualised (Walmsley, 1993). A failure to do this results in the many

people with cognitive impairments who cannot reach the required levels of perceived competency to be seen as 'failures', 'eternal children', 'different from the majority', 'a special case' and 'not quite human'. Such reconceptualization requires searching questions to be asked in the public domain – for example, what does it mean to make a valued contribution when an individual is entirely dependent on others? What does it mean to be responsible, if we cannot look after ourselves? How do people perceived as having 'severe learning difficulties' contribute to society as a whole? What does being a citizen mean if we are unable to vote? Does intellectual impairment mean that we are incompetent? Such questions return us, once again, to the thorniest question of all – are disabled people with learning difficulties really human? (Ryan and Thomas, 1987).

Why the gap?

Having traced the positioning of people with learning difficulties through different aspects of social model theory and practice, the question remains as to why, beyond seemingly intransigent cultural barriers, the social model fails to fully incorporate the experience of people with learning difficulties within its developing theory. The degree to which the majority disassociate themselves from people with cognitive impairments is an indication of the fear engendered by this particular impairment (Wendell, 1996; Overboe, 1999; Goodley, 2001). Over the years, disabled people with physical impairments have been wrongly thought to have learning difficulties and consequently treated in inappropriate and inhumane ways (Sinason, 1992). Being able to prove intellectual

competence has provided a welcome passport to better treatment and greater participation (Davies, 1998). The fear of being ascribed the label of learning difficulties, therefore, creates a strong deterrent from people with physical impairments associating themselves with people with cognitive impairments. Placing this within a wider context, Dowse argues that their experience of representation within the social model has been that of 'discursive othering' and calls for a 'new détente between the social constructionist analysis of disability and the role that impairment plays in the lived experience' (Dowse, 2001 p. 138). Such a détente, she argues can only be inclusive with the breaking down of oppositional factors such as mind/body or nature/culture. It is, therefore, to such binary distinctions that I now turn.

Looking at self and other

At the same as social model theorists were rejecting their own status as 'other' (Morris, 1991; Shakespeare, 1994) the social model itself has been built on the implicit binary distinction between disabled and non-disabled people. Within the model itself, a similar dichotomy allows for a distinction to be made between physical impairment (body) and cognitive impairment (mind) too easily allows for the possibility of positioning people with learning difficulties as 'the other'. In this final section of the chapter, I put forward the idea that a model based on binary distinctions (disabled/non-disabled; young/old; black/white; physical impairment/cognitive impairment; etc), does not allow for difference to be recognised as an inherent part of the human experience and therefore, whilst it can improve the standing of disabled people within our present society, it cannot facilitate ordinariness. I argue that it is only when difference is placed in the

context of commonality that we can move towards practice that encompasses the experience of all on an equal basis (Philipps, 1999; Taylor, 1992).

Moving beyond the binary

By making the claim that, as human beings we are fundamentally connected with each other, that we share the human experience in a multitude of different physical forms (Gleason, 1994, p. 248), I suggest that the actual differences between disabled and non-disabled people are both superficial and transitory - superficial because they ignore our essential connection with each other on the basis of being human; transitory as we are all physically vulnerable and therefore subject to the possibility of impairment at any point in our lives. Whilst a few individuals might come to the end of their lives without having experienced any significant illness or impairment, each one of us faces the possibility of both at any point in our lives. In addition to this, the one certainty we all face in life is that we shall at some point die. Disabled theorists have long suggested that the fear we have of our human frailty culminating in the certainty of death is the main reason for the marginalisation of people with impairments (Hunt, 1966; Morris, 1991; Wendell, 1996).

In their exploration of an affirmative, as opposed to a personal tragedy model of disability, Swain and French (2000) challenge the rigid division between disabled and non-disabled people. By presenting the argument that some people with impairments do not suffer from oppression whereas many people without impairments suffer from oppression due to poverty, sexism, racism, and/or sexual preference Swain and French demonstrate that a divide between

people is not created by impairment itself but rather through predominant perceptions of disability and impairment and the meanings these have in people's lives and social identity. Unlike the majority of impairments, perceptions are subject to change depending on information available at any one time, fluctuating fashions and outside influence. This means that the divide existing between disabled and non-disabled people is not of a fixed entity but rather exists as an ideological creation supporting the status quo.

In looking at commonality and difference it makes little sense to deny the very real differences lying between us – differences of gender, race, ethnicity, age, impairment, and illness. In stating that our differences are secondary to our commonality I argue that whatever our differences in physical shape or form, we are all equal as human beings (see Raymond Williams, 1967). Whilst we regard others as *fundamentally* different from ourselves we allow for the possibility that we carry a different intrinsic value dependent on our external physical characteristics. It is on this basis that, over the centuries, women, minority ethnic groups, and disabled people have been afforded lesser value and status (Shakespeare, 1994). Whilst it is helpful to make the link, as Shakespeare does, between disabled people and other oppressed groups, it is also important to examine the ways in which the experience of impairment, differs from the experience of oppression on the basis race, class, culture and/or gender. Firstly, as has already been mentioned, impairment does not always lead to disability (Swain and French, 2000); secondly, impairment crosses boundaries of race, sex, age and class in that, although there are strong links to poverty

(Mason and Reiser, 1990), it can affect any individual at any time in life; thirdly, impairment may carry with it unpleasant physical experiences and/or physical limitations (Crow, 1996); fourthly, people with impairments face structural as well as attitudinal barriers; and finally, the principle of equity of law is abandoned through the Abortion Act 1967 which allows for termination on the basis of foetal impairment at a later stage than for other fetuses and at a stage when the foetus is viable as an entity outside of the womb (Bailey, 1996).

Before moving on to explore an approach concentrating on commonality I am going to briefly look at one of the most confusing aspects of impairment, the way in which it is viewed and our emotional responses to it which often goes unmentioned in the literature. Throughout the world, the largest causes of impairment are poverty and war (Mason and Rieser, 1990). One of the tragedies of war and extreme poverty is the physical suffering they inevitably inflict on large numbers of people – suffering leading to both impairment and death. In this country many people suffer from impairment as the result of poor working conditions and industrial malpractice. Whilst it is possible to see impairment in a positive light few people would choose to take a drug such as thalidomide when pregnant knowing that it would lead to the impairment of their child. The questions become confusing and complex – ‘How can it be that impairment is OK when it involves so much suffering? ‘How can it be good, when it is so bad?’ The only possible answer to such seemingly paradoxical questions lies in the acceptance that impairment is an ordinary part of the human experience – neither inherently good nor bad in spite of the fact that it

carries certain limitations and can be unpleasant. Such a perspective allows for impairment but does not imply differential status for the individual.

In her writing about impairment, disability and human rights, Fitzgerald (1994) argues that the essence of our humanity lies, not within our physical form but rather is an 'intrinsic dignity' embedded within the human condition. Such a perspective allows for our physical bodies to be viewed as an outer shell beneath which we share the same human experience. By concentrating on commonality as opposed to difference, it is possible to view difference as superficial and all human beings of equal value:

If we dwell at superficial layers of being, we'll be overly conscious of the apparent differences in human beings on the physical and mental level, and of superficial differences in cultures and behaviour. If we penetrate to the essentials however, we will discover that there is nothing fundamental that differentiates any human being from another...All are manifestations of life, created with the same life principles and nurtured by the same life support systems (Thakar, 2001, p74.)

Such a view does not deny the existence of the many differences between us but places those differences in the context of a universal experience.

Conclusion

To the extent that the disabling consequences of the medical model are deeply entrenched and exist in a multitude of gross and subtle forms – for instance, from lifelong incarceration to 'Does he take sugar?' – then the social model offers a vantage point from which to view the wide variety of factors contributing towards disability within an ever changing culture (Crow, 1996). The

unquestionable value of the social model lies in its use as a tool with which to engage with the complexities surrounding impairment in a disabling world. To return to the words of Paul Hunt:

We are challenging society to take account of us, to listen to what we have to say, to acknowledge us as an integral part of society itself. We do not want ourselves, or anyone else, treated as second-class citizens and put away out of sight and mind. Many of us are just beginning to refuse to be put away, to insist that we are part of life too. We are saying that being deformed and paralysed, blind or deaf – or old or mentally sick for that matter – is not a crime or in any meaningful sense of the word a divine punishment. Illness and impairment are facts of existence, diminishment and death are there to be thought about and must be taken account of in any realistic view of the world. We are perhaps also saying that society is itself sick if it can't face our sickness, if it does not overcome its natural fear and dislike of unpleasantness as manifested by disability (Hunt, 1966 p.17).

This perspective suggests that whilst impairment might directly affect the minority, disability affects everyone, as it is a reflection of the values and practices making up our everyday life. The extent to which people with disabling impairments (the minority) are excluded from the mainstream is a reflection of the extent to which people without disabling impairments (the majority) fear the possibility of impairment (Morris, 1991). Such fears, manifest in our present culture through the values of 'body beautiful' and the desirability of 'physical perfection' present an unresolved tension for all, as they are not in accord with our bodily experience which is one of physical vulnerability. To the degree that people with impairments are excluded from the mainstream, to the same degree are people without impairments denied their company and experience. Whilst this denial offers the illusion of being able to ignore the fact of our physical

frailty, the inclusion of people with impairments allows for all of us to openly accept and live comfortably with the undeniable fact of physical vulnerability and difference (Morris, 1991).

In this chapter, I have argued that although the social model has allowed for a move to be made from a bio-medically dominated agenda to a discourse about politics and citizenship (Hughes and Patterson, 1997), the failure to place the experience of people with cognitive impairments in a central position has meant that it provides a partial explanation of the experience of impairment and disability. Moreover, I have argued that a theory based on binary distinctions is limited in its capacity to provide an explanation encompassing everyone and therefore to allow for impairment to be seen as an ordinary part of the human experience. In order to step beyond the binary and in so doing to provide a basis on which to build a theoretical framework supporting ordinariness in the lives of disabled children and their families, the following chapter explores the possibilities offered by engagement with paradox.

Chapter Five

Ordinariness, Interdependence and Power

Introduction

This chapter explores the themes of the ordinary nature of impairment and the consequences of placing vulnerability at the centre of the understanding of our human experience. My purpose in undertaking this exploration is to place the experience of impairment in the biggest possible context on the basis that, as an ordinary part of the human experience our understanding, and therefore our relationships and social organisations, remain incomplete because we deny our physical vulnerability. Including those of us who are perceived to be the 'most difficult to include', takes us to the heart of perennial questions about the way in which as human beings we relate to and live alongside each other, so bringing the experience of impairment from the 'margins to the centre' (hooks, 2000).

Crucial to the argument that it is possible to support disabled children and their families to live 'ordinary' lives, is the view that impairment is an ordinary part of the human experience (Hunt, 1966; Wendell, 1996; Morris, 1991). As an ordinary part of the human condition impairment, alongside illness and death, is recognised as something affecting all of us for, as Frank states, 'sooner or later, everyone is a wounded storyteller' (Frank, 1995, p xiii). The fact that the experience is both universal and inevitable suggests that serious engagement with the experience and its emergent issues carries the potential to more completely inform our understanding of our own humanity. The domination of fearful attitudes (Morris, 1991) that results in the stigmatisation and

marginalisation of people with impairments (Goffman, 1990) means that there is an essential part of our humanity that is denied on both an individual and collective level.

The positioning of physical vulnerability as a central aspect of the human experience (rather than something to be avoided or denied) provides an opportunity to throw fresh light on 'big' questions. For example, a full acknowledgement of physical vulnerability suggests that the 'natural' relationship between human beings is that of interdependence as opposed to independence (Morris, 1993; Lloyd, 2003; Shakespeare, 2000). In turn, the recognition of interdependence as central to human relationship challenges the construction of relationships, communities, and societies built on the dichotomy of self and other (Tronto, 1993). There is little doubt that structuring societies around the weakest member would result in very different organisations and 'ways of working' than are presently in place, whilst also allowing for communities to be complete in that the inclusion of the weakest makes it possible for all to be included (Frank, 1995).

Impairment as ordinary

People say that it must be so hard for you and that, but I don't think it is. It's my life and this is how it's always been, it's nothing difficult to me (Alison, Gloucester, 2001)

Implicit in Alison's understanding of her life is that the experience of having a sister with severe impairments and a chronic illness is, because that is the life she leads, completely ordinary. Alison does not just say this, but the way in

which she lives her life reflects her understanding. Instead of going to after-school clubs as many of her friends do, Alison goes straight home in order to help her mother get her sister out of the taxi from the day centre, lift the chair into the house and make sure that Leanne is happy and relaxed:

Usually when she comes home she's a little grumpy, that's when we talk to her and sit with her and use pillows as punch bags, and she laughs about that. We might get her arm, get her to hit you or the dog or something....She's got a wicked sense of humour...And then sometimes I make the tea and then after that I just do some homework and watch tele... (Alison, Gloucester, 2000)

Alison has no memory of being jealous of her sister – in her younger years she did not understand why Leanne (who is two years older) got more attention than she did, but as she grew up she realised that the answer was both practical and straightforward – her sister simply needed more attention. Alison's lived experience and her interpretation of that experience does not 'fit' with the dominant messages our culture gives us about living with someone with severe impairment – those dominant messages being fuelled by the belief that 'people like' Leanne, are sub-human, unlovable and a burden. Alison, at the age of 15, living with and loving her disabled sister, has a different view – her sister is both valuable and fun; impairment just is. The denial of Alison's lived experience (only made possible through the denial of Leanne's lived experience) is the reasoning behind the plea Raymond Williams makes for a 'new equation' to inform our social organisation, one that fits 'the observable facts' (Williams, 1967). The dominance of the prescribed and fixed ideas commonly held by those who are not in close relationship with disabled people negates the lived experience of impairment which is that it is, as a part of the human experience,

completely and utterly ordinary. The fact that disabled people and their families are, throughout the world, a minority does not alter the ordinariness of the experience.

It is through our bodies that we live the human experience; it is in communicative relationship, in its myriad of forms, we realize the commonality of that experience. Unable to communicate through language, Leanne's body tells her story (Frank, 1995). Chronic illness and impairment combine to give her the experience of not knowing what is going to happen to her body (constantly going into spasm and/or having seizures) and consequently never being able to take her body (or her life) for granted. Her experience told in this way, tells the story of all bodily experience – that of physical vulnerability, unpredictability and eventual death.

Frank focuses attention on the ethical responsibility of listening to the story of physical vulnerability, for in the experience of listening to others we hear our own story:

One of our most difficult duties as human beings is to listen to the voices of those who suffer. The voices of the ill are easy to ignore, because those voices are often faltering in tone and mixed in message, particularly in their spoken form before some editor has rendered them fit for reading by the healthy. These voices bespeak conditions of embodiment that most of us would rather forget our own vulnerability to. Listening is hard, but it is also a fundamental moral act; to realize the best potential in post-modern times requires an ethics of listening. I hope to show that in listening for the other, we listen for ourselves. The moment of witness in the story crystallizes a mutuality of need, when each is for the other (Frank, 1995, p.25).

Used as we are to valuing speech that is articulate, free of contradiction, tidy in its delivery and message, Frank reminds us that listening to the voice of physical vulnerability is hard precisely because we do not want to recognise what we know, through our own experience, to be true. Listening to what we know to be true, the storyteller and the listener become one, moving from the dichotomy of 'either/or' to the paradox of 'both/and' (Zohar and Marshall, 1994) creating a path on which we journey, as a diverse whole, towards a more complete understanding of our individual and collective experience. Indeed, in the move beyond the dichotomy towards the paradox, the individual and the collective are seen as one and the same in the sense that one lies within the other.

Following my son's death, I wrote of the experience of receiving the (non-verbal) communication coming from his deteriorating body (in synchronicity, I think with human consciousness) (Murray, 2001). In retrospect, and now having read Frank's work, I recognise we shared what Frank terms as communicative communion – through our bodies and our consciousness (whilst I wanted him to die as peaceably and comfortably and in the comfort of my familiar presence, I sensed that he eased himself into death for my benefit as well as his own).

Frank's analysis holds echoes for me of this shared experience:

The communicative body realizes the ethical ideal of existing for the other. The communing body might be more precise, but I retain 'communicative' as the more general term. The communion of bodies involves a communication of recognition that transcends the verbal. Bodies commune in touch, in tone, in facial expression and gestural attitude, and in breath. Communication is less a matter of content than of alignment; when bodies sense themselves in alignment with

others, words make sense in the context of that alignment (Frank, 1995, p. 50).

In the years following my son's death, I have been haunted by the questions of what such communion means to our human lives for, contrary to my expectations, I experienced the moment of his death as the most precious moment of life. In that moment all dichotomies were swept away leaving me with the ultimate, incomprehensible paradox of life and death being one. Lacking for me in Frank's analysis is any mention of human consciousness, for whilst our bodies were going through different experiences (albeit part of the same human experience) our consciousness was not just merging but was one – without boundaries, division or separation. It is that same merging of consciousness I recognise in Alison's story of her life with her sister.

Difference becomes ordinary

Accepting impairment, illness and death as ordinary parts of the human experience raises fundamental questions of in/equality and therefore power. There is no doubt that certain impairments render individuals physically weak, whilst others affect intellectual capability. Yet, is it not simply a fact of being human, that we have different attributes, strengths and/or abilities? For example, a young child or an elderly person does not have the same strength as a grown woman or man – there is a basic inequality of physical prowess. In the acknowledgement of inherent physical and/or intellectual inequality lies the recognition that some people have more power than others. For example, Leanne has no power unless and until equality of being (Williams, 1967) is recognised and, with that in place, she will be respectfully listened to and her

preferences carried out. Embracing inequality, vulnerability and diversity in this way demands a new way of looking at issues of power. Williams argues that inequality in any particular faculty or unequal development of knowledge does not deny 'essential equality':

The only equality that is important, or indeed conceivable, is equality of being. Inequality in the various aspects of man is inevitable and even welcome; it is the basis of any rich and complex life. The inequality that is evil is inequality which denies the essential equality of being. Such inequality, in any of its forms, in practice rejects, depersonalises, degrades in grading, other human beings (Williams, 1967, p. 317).

In this way, inequality arising from difference can be seen to be part of the diversity of the human experience. The problem being that, unwilling to face the vulnerable and impermanent nature of our experience, basing our individual and collective lives on the false premise of a dichotomous relationship between self and other, we have used this kind of inequality as a means of wielding power over one another. However, the radically different approach as described by Raymond Williams, whereby such inequality is seen as inevitable, allows for a radically different response based on mutuality and respect – akin to the concept of mutual authority outlined by Polanyi and Prosch (1975). The next section of this chapter explores issues of power, moving from a position of viewing power as abusive (power as domination or denial) to responsible (power based on an acknowledgement of equality of value, interconnectedness and mutual authority).

Power as a creative force

Crucial to this exploration of power are the concepts of embracing the paradox of 'inequality' and 'equality of being'. How do we as the human collective organise ourselves in a way that avoids the common and longstanding abuses of power that have caused so much damage in the world? In the distinction she makes between power, strength, force, authority and violence, Hannah Arendt (1958) describes power, strength and authority as essentially positive, useful and creative, with force and violence leading to an abuse of power. This is analogous to the view elaborated by hooks (2000) when she brings attention to an understanding of power as creative energy, positive strength and effective interaction with rather than domination over others. Similarly Raymond Williams discusses a creative as opposed to a dominative form of power:

The struggle for democracy is a struggle for the recognition of equality of being, or it is nothing. Yet only in the acknowledgement of human individuality and variation can the reality of common government be comprised. We stress natural growth to indicate the whole of potential energy, rather than the selected energies which the dominative mode finds it convenient to enlist. At the same time, however, we stress the social reality, the tending. Any culture, in its whole process, is a selection, an emphasis, a particular tending. The distinction of a culture in common is that the selection is freely and commonly made and remade. The tending is a common process, which then, within itself, comprehends the actual variations of life and growth. The natural growth and the tending are parts of a mutual process, guaranteed by the fundamental principle of equality of being (Williams, 1967, p 337).

The appreciation of diversity (embracing inequality) allows for a radically different view of power to emerge – one that recognises the possibility of individual and collective power to hold the potential of contributing towards a

society through creativity rather than coercion. Situating power within the individual in this way, it can be seen as something belonging to all of us irrespective of impairment, gender, race, age, class, or ethnicity. The outward appearance of this creative power emerges in and through relationship. In a recent newspaper article describing the life of a young disabled man and his mother (Sheffield Star, 9/7/02) the young man, exuding positivity, put his 'success' down to the fact that his mother gave him 'self-worth'. In reclaiming his own power (inherent dignity and self-worth), nurtured through positive relationship, he is able to live his life to the full – doing things that he enjoys, fulfilling his ambitions, whilst also paving the way for others and in so doing 'giving back' to his mother and his community. As the young man says, 'there is one world, one community' and he puts the fact that he has a place in that world down to his mother. Similarly, his mother acknowledges that she is a 'different person' to the one she was 'before her son'. Through their relationship, through the fact that they both want to 'give' to the other and in so doing to the community, they exercise a creative power. In doing this, there is an implicit recognition of the way in which both the young man (who has impairments rendering him dependent on others for his survival) and his mother (who would not have reached her understandings without her son) are realizing their 'mutual authority' (Polanyi, 1958) and in so doing contribute to the development of their community and therefore, the world. In this relationship, difference as a result of impairment is not used as a claim to essential superiority or inferiority but rather is seen as an ordinary part of our human experience.

In considering differences between groups Young (1990) argues that an alternative to an essentializing, stigmatising meaning of difference lies in an understanding of difference as a relative variation. The fact that the maintenance of binary distinctions is tightly woven with the use of dominative power suggests that moving beyond the binary would produce different ways of living with diversity and unpredictability. In their exploration of the 'quantum society', Zohar and Marshall (1994) introduce radical alternatives to our present social structures:

Quantum holism may be telling us, for example, that power relations are not the only, or perhaps even the most effective, way that people and events can be linked in society. The politician or the manager who tries to 'influence' or 'control' events may be less effective than one who can be sensitive to the spontaneous emergence of social or political 'trends'. The individual who realizes that parts of his or her own identity emerge through relationship with others may be less guarded and defensive (Zohar and Marshall, 1994, p.40).

The attention placed on the relationships between seemingly distinct objects gives the new science from quantum physics a focus on holism. Points of connection – both visible and invisible - are looked for:

You think because you understand one you must understand two, because one and one makes two. But you must also understand and. (Meadows, 1982, p. 23).

Such a view recognises each being as a separate entity yet simultaneously part of a whole system. As we move into the acceptance of paradox offered by the new science it becomes impossible to attribute value to things on the basis of difference. Neither normal or abnormal is primary – both are necessary (Wheatley, 1999).

Such a view opens the door to a new understanding of the family experience of impairment. Each being is noticeable as a separate entity, yet it is simultaneously part of a whole system. It is relatively easy to evidence this in close family relations. At the age of 15, Alison displays qualities of maturity, patience and sensitivity to the needs of others that she puts down to her relationship with her sister who is dependent on others for her physical survival. Similarly, my daughter has been inspired through relationship with her brother to 'make the most of her life' – meaning that she wants to 'give something back' and push herself to the limits as she is lucky enough (and forever grateful) to be alive and well. Stories such as these – of positive qualities emerging through relationship - abound in families of disabled children (Murray and Penman, 1996, 2000; Goodey, 1991) accentuating the possibility lying within each and every relationship. The physical dependence and vulnerability of one, the necessity of relationship for survival highlights the interdependent nature of human beings. Indeed, the possibilities expand further when we take a cosmological view in which scientists argue that interdependency is the nature of the universe:

We begin to understand our human identity with all the other modes of existence that constitute with us the single universe community. This one story includes us all. We are, everyone, cousins to one another. Every being is intimately present to and influencing every other being.

We see quite clearly what happens to the nonhuman happens to the human. What happens to the outer world happens to the inner world. If the outer world is diminished in its grandeur then the emotional, imaginative, intellectual, and spiritual life of the human is diminished or extinguished (Berry, 1999, p. 200).

I am aware that such considerations might seem far removed from the central concern of this thesis and that such a brief overview does not do justice to the enormity of the topic. However I make no apology for this as it is only through placing the experience of living with impairment (in whatever role we happen to play) in a universal context that we can fully appreciate and value the lessons of inter-relationship so evident when we admit to our physical vulnerability. As a result we discover an ease of access to a positive, creative power lying within relationship. Taking such lessons to the heart of our social organisations not only facilitates the inclusion of disabled people with cognitive impairments within the mainstream but also holds the potential to radically improve our social organisation.

Chapter Six

Developing a Methodology: Making Visible the Invisible

Introduction

Recognising and understanding the diversity of experiences reported by disabled families in their everyday lives are difficult and complex tasks. As I outlined in Chapter One, this work began as a conventional piece of research with fieldwork as primary. However, in the early days I found myself confronted by a wide range of theory level questions about how family support, as currently delivered, creates disabled families. This discovery led to a shift in emphasis in the whole direction of the work as I realised that the work I needed to do was around explaining and developing theory about the family experience which would not further pathologise that experience. For these reasons the work 'changed tack' and I found myself primarily engaged in a comparative exploration of literature around disabled family experience, augmented by a small amount of fieldwork to explore the basis for constructing alternative family support provision.

In order to accommodate the wide range of issues arising from the literature review and to allow a flexible explanatory framework for the way participants negotiate their relationships with the world around them I found it necessary to adopt an anti-foundationalist stance permitting me to use a range of analytical tools. For example, while a modernist approach allows for the recognition of structural barriers identified by the social model of disability, a post-modernist perspective embracing pluralism permits the deconstruction of rigid boundaries

between disabled/non-disabled identities. Similarly, engagement with works on social justice allows for the incorporation of theories of diversity and difference; while the reading of feminist texts permits an exploration of gender. In addition, the experience of other marginalised groups – reported for example in the literature on race and ethnicity – can inform the understanding of marginalisation experienced by disabled children and their families. Through the engagement with such texts, contact with families, and the articulation of ideas through the process of writing I found I was gaining a depth in the understanding I had of my own experience.

Having outlined the overarching theoretical exploration in previous chapters, this chapter discusses some of the methodological issues shaping the development of the fieldwork. As the chapter reveals the chosen approach embodies a qualitative research methodology with a strong commitment to a participatory mode of inquiry. Within this, dilemmas were encountered arising from the fact that the topic does not easily fit into existing methodological paradigms, crossing as it does, boundaries between the sociology of the family and the sociology of impairment and disablement. The main body of sociological work on the family has largely failed to include the experience of families with disabled children, thus rendering their experience invisible whilst the social model of disability, with its concentration on the individual with impairment, has not yet explored the family experience of disablement. Some work has been done (Grealey, 1994; Finger, 1991; Murray and Penman, 1996; 2000) but this is mainly

autobiographical and has not yet connected at the level of theory, a process which this thesis seeks out to explore and add to.

In this way, the work fails to fit well within existing 'disability research', extending as it does the social model of disability through both the involvement of people with cognitive impairments and the assertion that all family members are likely to suffer from disablement when one family member has a disabling impairment.

Neither does the research fit neatly into the main body of work on the sociology of the family, arguing as it does, that impairment is an ordinary part of the human experience and it is disabling factors (economical, structural, social, cultural, emotional and psychological) that serve to produce the experience of isolation, extraordinariness and exclusion. It has been necessary, therefore, to extend existing research boundaries using the social model as a methodological tool within a social science perspective.

Quantitative versus qualitative

The objective of this research has been to explore the experience of a group of people whose subjective experience to date has either been devalued or denied. Because of this denial, the family experience of living with impairment and disablement is either rendered invisible or is widely misunderstood in that it is generally perceived that the disabled child is the 'problem' for the family. Being invisible, it is difficult, if not impossible, to uncover the nature of the experience through large-scale qualitative methods such as surveys or questionnaires. In keeping with arguments put forward by Morris (1992), Stone and Priestly (1996), and Proctor (2001) that there is value in exploring the subjective realities of individuals within the wider context of a political and social

model, the aim of this piece of work has been to uncover the family experience and to situate that experience within a wider context. In this respect, the nature of the project has demanded a qualitative as opposed to a quantitative methodology in order to focus on the subject's frame of reference (Bogdan and Biklen, 1992) and to access the insider's perspective (Fetterman, 1988).

Although quantitative research has provided valuable reference points for some of the issues raised by participants, (see for example the work of Beresford, 1994) my two main concerns in this piece of work, both served better by a qualitative approach, have been to:

1. make an in depth exploration of some of the barriers families face in living ordinary lives; and
2. identify ways in which to facilitate such ordinariness.

The second reason for deciding on a qualitative approach lies in the fact that I was keen to include the views and/or experience of all family members – including children and young people with a variety of impairments. For young children and/or disabled children and young people with learning difficulties and communication impairments, methods such as a questionnaire would immediately bar their access to the research. To explore possibilities of including disabled young people unable to express themselves through language in any of its many shapes and forms demands a qualitative approach (Morris, 1998 (a); Ward, 1997; Abbott, Morris and Ward, 2001).

Methodological dilemmas

Having decided on a qualitative approach it was then challenging to find appropriate methodological strategies on which to base the research. Given that the point of departure for this exploration of the family experience lies within the explanation of disablement offered by the social model of disability, the obvious and desirable starting point for 'finding a home' for the project lies within disability research. This has proved problematic, however, on two counts:

- 1) the project sought to explore the experience of non-disabled as well as disabled people – attributing equal value to both groups; and,
- 2) the majority of disabled participants have cognitive impairments whose experience to date has only been partially explained by the social model of disability.

Exploring the family experience of disablement

This work poses challenges to current research in the assertion that family members, without impairments, suffer from disablement. Such a statement breaks away from present explanations of disablement in its implication that there is no firm category of 'disabled people'. In other words, it is suggested that disablement is something affecting both people with and without impairments.

One of the families participating in this research poses interesting challenges to accepted categories of both impairment and disability. The mother has an invisible physical impairment (infertility) which although not disabling, has played

a significant part in her life and caused much emotional upset. Because of her impairment, she adopted two children – the first child, James, had an identified impairment at birth. At the age of 14, James is perceived as having learning difficulties, emotional and behavioural difficulties and a communication impairment. He attends a mainstream school out of his community, has no friends from school that he ‘hangs out with’ out of school, and is dependent on adults to supervise him at all times. Because of the way in which he is perceived and treated he suffers from the effects of a disabling world. The third family member is Elizabeth who has a visual impairment that, although it is obvious and results in many bumps and falls, does not disable her. Elizabeth has received the support she requires in school and is generally perceived as a child who does well ‘in spite of’ her impairment. Within this family, then, are three people with impairments. Two of the three are not disabled by their own impairment whilst all three are disabled as a result of the impairment of the third family member. This family throws a light on the complex nature of impairment and disability, indicating that impairment does not always lead to disability, whilst at the same time showing that some impairments lead to disability affecting more than the individual with the impairment.

Exploring ways of including people with cognitive impairments

Whilst there is increasing engagement within the broad field of ‘disability research’ with the inclusion of people with cognitive impairments (Williams and Nind, 1999; Knox, Mok and Parmenter, 2000; Stalker, 1998; Goodley, 2001; Proctor, 2001), the main body of research concerning disabled people perceived

as having learning difficulties, lies within the broader field of sociological research (Chappell, 2000; Bogdan and Taylor, 1982; Edgerton, 1967). This division between people with physical impairments and people with cognitive impairments reflects an apparent reluctance within disability theory to embrace the experience of people perceived as having learning difficulties (Chappell, 1998; Chappell, Goodley and Lawthorn, 2001; Goodley, 2001). In addition to this, the (understandable) enthusiasm for disabled researchers to 'change the social relations of research production' (Oliver, 1992) has resulted in the marginalisation of people with learning difficulties within the main body of disability research as they are often not able, due to the nature of their impairment, to engage with the issues in the same way (Chappell, 1998). The inclusion of people with cognitive impairment within a social model poses challenging questions regarding empowerment (a pre-requisite of emancipatory research), and participation (Proctor, 2001; Goodley, 1996; Stalker, 1998). There is, therefore, a need to find new ways of including the voice of people with learning difficulties in the research process (Murray, 2002; 2004 forthcoming).

In order to place such problematic issues within a broader context, I now look at the relationship between 'disability research' and the main body of sociological research; the way in which research about the lives of people with learning difficulties has developed; and the positioning of the family in such research. I then go on to look at two of the main research paradigms within disability research, examining the ways in which this piece of work fits into neither category whilst claiming to embrace the underlying values of both.

Sociology and the social model

Whilst disability studies are generally considered to be located within the discipline of sociology, the social model has been largely ignored by the majority of mainstream sociologists (Barnes, 1998; Barton, 1996; Oliver, 1996). The emphasis on impairment in mainstream sociology is largely interpretive, concentrating as it does on “the meanings people attribute to their impairment, how they negotiate their daily lives and how they cope, or come to terms with, their impairment” (Watson, 1998). The fact that impairment is seen as something to cope with and/or to come to terms with, indicates that it is placed within an individual model of disability, largely ignoring structural and contextual issues (Parsons, 1967). Furthermore, disabled researchers have argued that sociological theory has been used to reinforce and justify the exclusion of disabled people (Abberley, 1998). It was not until disabled people, responding to the way in which research on their lives was being carried out (Hunt, 1966), articulated their experience, placing it within a sociological context, that mainstream theorists began to break away from an individual model of impairment towards the wider explanation offered by the social model (Oliver, 1996). Within this broad framework, however, it is argued that disability issues have remained on the sidelines rather than being incorporated into the main body of sociological enquiry (Barton, 1996).

At the same time as such debates were going on, non-disabled researchers were engaging with the experience of people with learning difficulties and in doing so posed a challenge to the work of disabled researchers and theorists

(Chappell, 1998). Perhaps a reason for the relative neglect of the experience of people with cognitive impairments in the social model lies within the virtual lack of attention given in the development of the social model to the effects of impairment (Paterson and Hughes, 1999; Thomas, 1999). As I argue in Chapter 4 it is very difficult for many people with cognitive impairments (and impossible for some) to either 'change the social relations of research production' or to engage in a discourse on theory and practice. As a consequence of the effects of impairment being different, the barriers facing people with different impairments vary in nature, subtlety and degree (Murray, 2002). One of the barriers facing people with learning difficulties is a perceived lack of competence resulting in a reluctance to 'take the lead' or 'have a go'. To aim to 'change the relations of research production' is for many people with learning difficulties akin to asking for the impossible. It is hardly surprising then, that the bulk of research concerning the lives of people with cognitive impairments has been carried out by non-disabled people or by disabled people with physical impairments. Much of the initial interest in engaging with the experience of people with cognitive impairments lay within the changes in service provision from institutions to the community and has largely been based upon the theory of normalization (Chappell, 2000). The acceptance of normative principles within the main body of sociological work with people with cognitive impairments directly contradicts the claim in this work that impairment is an ordinary part of the human experience. While the widespread understanding of normalization has led to practice based on the insistence that people with learning difficulties must learn to fit in, I argue that some people will never be able to 'fit in' and

therefore only an acceptance of difference in the context of commonality will allow for the valued inclusion of all.

Having outlined such general difficulties, I now take a brief look at two of the research paradigms (emancipatory and participatory) used in work concerning the lives of disabled people, exploring the ways in which this piece of work, whilst adopting elements of both, fails to fit neatly into either.

Emancipatory and participatory research paradigms

Over recent years, largely as a result of the research and writings of disabled academics, there has been much debate within disability research as to research methodologies (Oliver, 1992; Morris, 1992; Zarb, 1992). The result of such lively engagement has been the adaptation of two research paradigms for use in disability research:

- 1) 'emancipatory research' – research aiming to 'change the social relations of research production' (Zarb, 1992); and
- 2) 'participatory research' - research aiming to improve the lives of disabled people by including them in the research process (Chappell, 2000).

Emancipatory research

As the name suggests, emancipatory research is viewed as a process that ideally is controlled by disabled people and contributes towards their emancipation. Research, therefore, becomes a tool through which the lives of disabled people are improved (Chappell, 2000). Taking an unashamedly

political stance, the key to such improvement is that disabled people are in the role of experts – experts in their own lives. Emancipatory research has emerged mainly through the experience of research involving people with physical impairments and precedes debate amongst researchers, both disabled and non-disabled, about the way in which people with cognitive impairments can be included in the research process (Chappell, 1998; Aspis, 2000; Rodgers, 1999; Walmsley, 2001; Stone and Priestly, 1996).

Participatory research

Whilst the roots of participatory research are to be found within a social science tradition, its emergence within disability research is largely due to the fact that researchers with an interest in people with learning difficulties have increasingly used and adapted participatory methodology in research involving people with cognitive impairments (Chappell, 2000). Participatory research, again as the name suggests, makes the demand that disabled people, whilst not necessarily in control of the research, nevertheless participate in the process. There is a growing literature on the participatory paradigm in relation to people with cognitive impairments (Ward and Flynn, 1994; Rodgers, 1999; Reid, Ryan and Enderby, 2001). Within this literature, there is an increasing tendency for participation to lead towards empowerment (Ramcharan et al, 1997; Stalker, 1998; Rodgers, 1999).

Difference and commonality between the two models

In spite of overall differences between emancipatory and participatory research, proponents of each have made connections between the two models. For example, Zarb (1992) states that participatory research can be viewed as a first step towards emancipatory research while Stalker points to underlying ideological similarities:

...each model is based on three main beliefs: first, that conventional research relationships, whereby the researcher is the 'expert' and the researched role is merely the object of investigation, are inequitable; secondly, that people have the right to be consulted about and involved in research which is concerned with issues affecting their lives; and thirdly, that the quality and relevance of research is improved when disabled people are closely involved in the process (Stalker, 1998 p. 6).

Whilst acknowledging and appreciating such similarity, there is an important distinction to be made. Importantly for research looking into the experience of disabled people, emancipatory research is based on the social model of disability whereas within participatory methodology for learning difficulties researchers 'the social model is rarely mentioned' (Chappell, 2000). The 'lack of fit' of people with cognitive impairments within the social model (see Chapter 4) is true for the application of the emancipatory paradigm in relationship to research concerning the lives of people with cognitive impairments. Similarly, the social model has been under-utilised in the broader sphere of social science research.

...back to this project

According to the definition given by Zarb (1992), Morris, (1992) and Oliver, (1992) this research project does not fall into an emancipatory paradigm. Firstly, the research was not directed or controlled by people with impairments. Indeed, it would not have been possible to give full control to participants due to their age and the nature of their impairment. In addition to this the multiple commitments of parents and the time and energy they invested in fighting for their entitlements left the majority with little will or inclination to take on a research project. Secondly, the research did not arise from questions posed by disabled people coming as it did from my own personal experience and knowledge gained through extensive networking, that it was difficult (if not impossible) for disabled children and their families to live ordinary lives. However, it is important at this point to note that the claim running through the thesis of parents suffering the experience of disablement allows for a different light to fall on my role in the research process. Although I do not have a disabling impairment, my own role is not confined to that of a researcher, living as I have done with the consequences of being directly and negatively affected by a disabling world. Indeed, part of my motivation for doing this work lies in the fact that with my son's death I no longer had a fulfilling role at home. In addition to this, in accordance with benefits rulings, I was left on income support several weeks following his death. Having chosen to give up work some seventeen years ago in order to care for my son, my opportunities for returning to well paid, interesting employment were slim. Engaging with research around the issues of the family experience of living with disablement gave me the opportunity to 'build

a new life for myself', whilst simultaneously 'making sense' as it allows me to maintain a connection to the life I had with my son. My personal experience of carrying out the research has without question been challenging, creative, interesting, healing and, most importantly from a methodological viewpoint, empowering. Finally, largely because the project had no funding, there have been no opportunities for disabled people to criticise the research and finally their influence in future projects is again indirect and dependent on my interpretation of their experience. In making these points I am not saying that people with learning difficulties and/or their families cannot carry out emancipatory research rather that this project did not lend itself, for the reasons outlined above, to such an approach.

Perhaps the only points of contact the project has with emancipatory research is that it is based on the social model of disability and that I, as a non-disabled researcher, have learned from disabled participants. However, Zarb makes it clear that such a point of contact is insufficient to define a piece of research as emancipatory, stating that participation alone:

...will never by itself constitute emancipatory research unless and until it is disabled people themselves who are controlling the research and deciding who should be involved and how (Zarb, 1992, p.128).

Similarly, in terms of participatory research, the project falls short of ideals given by Cocks and Cockram (1995) on two counts:

- 1) it was not accountable to a group of disabled people (other than in the broadest sense); and

- 2) no collective analysis was made of the research question (again other than in the broadest sense).

Having failed to 'find a home' within either the emancipatory or the participatory paradigms it is perhaps useful at this stage to explore the second difficulty the project had in fitting into disability research. Although the project did not solely look at the experience of people with impairments, all participants were directly and negatively affected by disablement resulting from the impairment of one of their close family members. I now outline the complexities of exploring this particular dynamic through the lens of the social model of disability.

Research attributing equal value to all family members

Attributing equal value to all family members in the research process, whilst at the same time acknowledging power differentials within the family, poses a problem for research placed within a social model framework. Whilst there is a large body of literature about the family experience (Boston, 1981; Featherstone, 1980; Hannam, 1988; Meyer, 1995; Rose, 1998) there is little to place that experience within the context of a disabling world. Mason (1995; 2000) explores the tensions within the family situating the, sometimes oppressive, attitudes of parents within the context of disablement illuminated by the social model. Such a perspective allows families to understand their experience of loving their disabled child whilst at the same time being aware of the negative messages they have both grown up with and are likely to receive about their child on a daily basis (Murray and Penman, 1996, 2000). This understanding allows families to begin to make sense of the experience they are

living and consequently to construct lives for themselves where their experience is viewed (within the family at least) as ordinary.

It is perhaps understandable and appropriate that engagement with issues of impairment and disablement to date has largely concentrated on the experience of disabled people. No doubt the invisibility of positive aspects of the family experience (Birkett, 2000), alongside the publication of literature from a parental perspective describing the family experience as 'difficult' and the disabled child as a 'burden' (Hannam, 1988) are largely responsible for the apparent chasm between disabled people and parents of disabled children. However, as most children and young people grow up within the family setting, and as that setting has the potential for providing young disabled people with a positive springboard from which to engage with a disabling world, it is important to recognise that full inclusion within the family is the first step towards inclusion within the wider community. As one young man taking part in this project states:

Family is the core of life for everyone. It needs to be a priority for those that don't know what it feels like to belong (Ben, Sheffield, 2002).

For disabled children and young people excluded from so much in their local communities and the wider world, families might be the only place where they can truly experience 'belonging'. With that belonging in place they at least have the opportunity of having a place of 'safety' from which to experience the largely unwelcoming outside world. Families therefore hold the potential:

- a) to provide individual disabled children with the positive experience of being valued and belonging (Shearn and Todd, 2000) and, having done that;
- b) to challenge the status quo through examples of positive relationships between disabled and non-disabled people.

In this assertion I do not presume to make the claim that families of disabled children and young people should be regarded as living the same experience as their family member with impairment(s). The direct experience of living with impairment is clearly personal with the resulting discrimination and oppression affecting individuals directly and deeply. My argument lies in the fact that all family members are directly affected in a negative way, as a consequence of living in a disabling world. As yet, their potential for playing a full, equally valuable, and valued, part in the struggle to dismantle such disablement has not been fully recognised or made use of.

One young disabled man involved in this project talked about the way in which his sister had been bullied at school, just because she was his sister. Similarly, my daughter has written about the way in which her (positive) relationship with her disabled brother was ignored:

When I was little I was teased about my little brother being seen as 'different'. I had no friends that could understand the pain it gave me as everyone thought that I was too little to understand. But I still remember (Murray, 1996 p. 88).

Dowling and Dolan (2001) argue that placing the gaze of the social model of disability on the family, allows for a broad range of inequalities facing families with disabled children to be made visible – inequalities in the areas of work, leisure, finance and general quality of family life. Families living the experience are aware that they live with such inequality (Murray and Penman, 1996; 2000). The present situation, in which such inequalities are generally understood to be part and parcel of the 'burden of care' arising from impairment does not help families make sense of their 'whole' experience which generally includes loving their disabled child.

The development of methodologies and theories reflecting this experience would serve to help families better understand and make sense of their lives (Dunst et al, 1989). In making sense of their lives they are in a better situation to value the role their disabled child plays within the family unit:

Katherine's sister described Katherine as 'the centre of the family, the glue that binds them together'. She said that her sister's needs bring the family together in a very practical way, because Katherine always needs someone around to look after her but 'also because of the sort of person she is, she is a very loving sort of a person, she likes cuddles, she likes physical contact and she likes being around everyone...I think because she is a very loving sort of a person, she keeps us all together' (Morris, 2001 p. 7).

This description leaves us with no doubt that Katherine's sister feels positively about her and values her presence within the family. The making visible of positive family relationships between disabled children/young people and their family members directly challenges the medical model of disability whilst

simultaneously creating opportunities for the building of bridges between disabled and non-disabled people.

The way ahead

There is no doubt that including people with cognitive and communication impairments in the research process is extremely challenging. In her exploration of research issues as they affect disabled people perceived as having learning difficulties, Walmsley introduces the concept of 'inclusive research' – a model she defines as 'research in which people with learning difficulties are involved as more than just research subjects or respondents' (Walmsley, 2001, p188). Whilst welcoming the breath of fresh air Walmsley breathes into the debate, I suggest that only an acceptance of difference will allow for a resolution of issues she raises such as making theory accessible or the role of the non-disabled ally. A welcoming acceptance of difference, in the context of commonality, offers the opportunity to pose questions such as:

- If research is viewed as a process, does each individual have to be involved in every aspect and to the same degree in order for their contribution to be of equal value? Is it not by playing our different, complementary parts that we make up the whole?
- Does it matter if some people are unable to access or contribute to the development of theory through language? Does this mean that they are not part of the theory making process? Does this mean that they are of less value?

- What does participation mean? Is it impossible for disabled people with severe cognitive impairments to fully participate in society? Do our current ideas of participation deny the participation of those people whose impairments mean that they cannot be 'actively involved'? Could participation be re-defined as a positive interaction between people, allowing relationships to develop and issues to be explored?
- What do we mean by citizenship? How do the dual notions of rights and responsibility affect people with cognitive impairments? What does this mean for others? Does citizenship rely on culturally defined notions of competence – i.e. being able to work, to vote, to lead the life of the majority? If so, does this mean that those of us unable to display such competence are not citizens?

Such questions have been raised by the presence of some of the young disabled people taking part in this project running alongside the assertion of equality of value. To fully engage with the issues requires us to ruthlessly examine deep-seated cultural beliefs. Engagement with such questions allows for an in depth exploration of issues arising from both the use of emancipatory and participatory research paradigms. I suggest that an acceptance of the differences lying between us, placed within the overall context of our commonality, provides fertile ground from which to explore the issues further. It is my hope that some of the issues raised here contribute to the debate presently taking place, and I look forward to further explorations alongside people with cognitive impairments.

Having explored methodological concerns arising within this research I now go on to look at the ethical issues arising from and in turn informing the methodological approach.

Ethical considerations: being valued in the research process

The integrity of any research becomes apparent in the way in which the work is carried out. The question at this point is how to put the ethical principles of equality of value, ordinariness and uncovering voice into practice - it is only by doing this that the work can claim to move away from the dominant ideology that perceives disabled children with learning difficulties as 'lesser than' and denies disabled families a voice. An overriding priority has been that the process of the research is positive for the participants in that it provides an experience of being valued. For this reason I consider the question of ethics alongside that of methodology.

Engaging with power dynamics

Engaging with work around equality of value necessarily means that close attention has to be paid to issues of power in all areas of the research. This piece of research involves both non-disabled and disabled children – two groups of people who have, until fairly recently, been largely invisible in the research process (Morrow and Richards, 1996; Alderson and Goodey, 1996; Mahon and Glendinning, 1996). The principal dilemma involved in carrying out adult designed research looking into issues which affect children and young people is

the fact that, in our culture, in return for having general responsibility towards children we assume a position of superiority and power over them (Alderson, 1995). In addition to this, research carried out by non-disabled adults looking into issues of living with impairment carries with it the danger of the assumption of superiority. Such attitudes can manifest in every aspect of the research - design, carrying out, writing up and dissemination (Marchant et al, 1999). Within the family setting, power dynamics were variously challenged between:

- men and women;
- adults and children;
- parents and their son/daughters;
- family members of different race/ethnicity; and finally,
- the absence or presence of visible impairment.

Within any one family, at any one time, a variety of power differentials might be in play, making equality issues complex and multi-faceted (Tregaskis, 2004).

For example, two of the sets of parents taking part were from different race/minority ethnic backgrounds meaning that, in addition to gender differences, the families were living with issues of race and ethnicity. To afford equal value to each individual within the family meant that while it was necessary to acknowledge different experiences and roles, no one experience or role was inherently superior to the other.

Three further issues add to the complexity embedded in issues surrounding power:

- a) Although traditional gender politics are in play, the picture is skewed somewhat by the power that women traditionally have both around childcare and within the home. The reluctance of fathers to engage in the research process was an indication of the role afforded to women as the key player in issues concerning family support (Beresford et al 1996).
- b) The deeply seated cultural perception of incompetency accompanying the label of 'learning difficulties' poses great barriers to both people perceived as having learning difficulties giving their opinions and those seeking to understand them (Murray, 2002).
- c) Finally, there is the power inherent in the position of the researcher – in my own case a white, middle class researcher without impairment. Although I attempted to be 'open to the process' in that I constantly adapted plans to accommodate different circumstances, I nevertheless have made the choices over the way in which the process developed, the questions to be asked, the material that has been made visible and the analysis of that material. My own position has not, however, been without complexity. As part of the initial exploration of the issues, I visited a hospice for disabled children. Although I arrived in role as a PhD student researcher from the University of Sheffield I left, having learnt little more than could have been gleaned from watching a television programme about the institution, in the role of a recently bereaved parent. In such a role, I was asked if I would like to participate in a piece of research they were engaged with at that time. (The

experience taught me I had much to learn about how I presented myself as a researcher!) Similarly, I have been aware of inequalities of power when participating alongside high-ranking professionals on committees such as the Quality Protects Reference Group for disabled children that I found I had much to learn about such issues on a personal level and have welcomed the opportunity to examine the ways in which my own deep-seated beliefs have kept me tied into the role of the 'powerless parent'

Power in the research process

The first question of power I encountered in my role as researcher in relationship to participants concerned the asking of questions and the listening to the answers. In order to reduce any power inherent in my role and to make the research accessible to all, I found it necessary to problematise the way in which I carried out both these activities. The following section provides an exploration of this process.

Asking the right questions

In order to attribute equal value to all contributions, regardless of impairment, sex, age, gender, and/or ethnicity, it was necessary to problematise both the questioning and the listening of the researcher (Goldsmith, 1996). It was vital that the questions asked were meaningful to the participants and the response given (or withheld) was recognised and listened to.

To this end, it was necessary to engage in a constant refining of the research question. For example, while the initial focus of the work lay around the question *'What type of support allows all family members to live 'ordinary' lives?',* as the work developed it became obvious that although this question held meaning for me as the researcher it was not useful to participants – either adults or children. The question held little meaning for adult family members as there is no example of support that allows for this possibility. It was the ensuing conversation that allowed important issues for families to emerge – questions about employment; about going out; and having a 'social life'. When these responses were compared to the expectations of someone in a similar situation but who was not living with issues of impairment and disablement, then disabling barriers could be identified.

Following the interests of children and young people involved, necessitated the formulation of a different question *'What do I like to do best?'* Having identified this as a main research question, it was possible to enquire about the type of support necessary to put the favourite pastime(s) in place. This question had the added advantage of allowing for the exploration of ordinariness to take place. Over the course of the research, it allowed me to engage with all family members regardless of age or the effect of impairment. Having formulated a question suitable for all, I became aware that I had to be open to hearing the response in whatever way it was presented.

Learning to listen

I found many ways in which I was able to 'listen' to the stories of participants unable to communicate through language. The key to this lay in the view that communication is a two way process between people (Triangle, 2001; Reid, Ryan and Enderby, 2001). It was crucial to constantly be alert to different ways participants might be expressing themselves, whilst simultaneously being aware of the (largely normative) expectations I brought to the process (Goldsmith, 1996). As Reid, Ryan and Enderby (2001) point out the same is true to listening to 'experience', i.e. the observations I made throughout. On some occasions, I was able to engage with participants conventionally through spoken language; on others the answer was given to me verbally by one person on behalf of another. Sometimes the answer became obvious through 'hanging around' and closely observing the dynamics of relationship, at others I found it implicitly within the description of an experience. On occasion, the answer became obvious through looking at photographs or drawings; on others, by engaging with children and young people through play or 'working' with the photographs.

From power to empowerment

This exploration of power dynamics within the research process leads naturally to issues surrounding empowerment. If the research is successful in attributing equal value to participants then, by default it challenges the status quo, turning it into an empowering experience. For some families taking part in the research it was the first time that a professional had come into their house wanting to meet their disabled family member, enjoying the experience and valuing their

company. Whilst not wanting to over inflate the role of researcher, such a position carries with it certain responsibilities. I found I constantly had to be aware of the possible effects of what I might say or do. Whilst this is perhaps always true in the role of researcher, particular care is needed when dealing with the lives of a group of people that have for so long been devalued.

Listening to the experiences of individuals and families was, on occasion, hard – I so much wanted to 'fix things' for the young disabled people (an example of my own frustrated mothering desires coming to the fore). To have given into that temptation would have been wrong, not just because I could not possibly have kept it up, but also because it denies families opportunities for self-empowerment and so stands in direct contradiction to the aims of the research. It was therefore, with great difficulty at times, that I limited my role to that of asking questions, chatting, exploring the issues, taking an interest, and listening. The only deviation made from this general rule of thumb was to give information – for example, on where to get the best information about direct payments – and to provide families with opportunities for networking.

Looking for opportunities for empowerment

As the project developed and I gained confidence in the research process and in my role as researcher I relaxed somewhat and began to offer participants experiences that might both be empowering whilst also contributing towards the research process. Such activities however, have remained within the general remit of networking. One example of this lies in the interview that took place between Owen and Ben – two young men who both use facilitated

communication and neither of whom had ever had a 'conversation' with anyone else using the same method of communication. The success of the venture is reflected in Owen's reflection of the meeting:

I am very glad that I have been able to express myself in the way that I have, and feel that my consciousness has been raised by the experience (Owen, London, 2002).

A further example is to be found in the visit Owen and his mother made to Aberdeen University. During the course of the conversation between Owen and Ben, Owen said that he wanted to study theology. I remembered a letter I had received a year or so before, from a lecturer in theology at the University of Aberdeen. Knowing that this lecturer was interested in the communication of young disabled people perceived as having learning difficulties, with Owen's permission, I contacted him asking for any ideas. The upshot of the ensuing communication was that Owen was invited for an interview and at the time of writing is set to embark on a distance learning course in theology.

Such involvement in the lives of disabled children/young people and their families leads to further ethical issues, for example, the risks of intrusion and 'saying goodbye'. I now turn my attention to these issues.

Consent, confidentiality and protection

Two of the main discussions about research ethics with children involve the issues of consent, confidentiality and protection. A traditional view of gaining consent, that of asking whether a participant would like to be involved in the

research and gaining a yes/no answer, is simply not possible for some of the participants in this project. Throughout the project such issues have had to be dealt with in a variety of ways:

...disabled children and young people vary enormously in their abilities, interests, ways of communication and backgrounds, and each stage of the process of involvement will need to be tailored and adapted to individual needs (Ward, 1997, p24).

I am unable to say whether some children, due to their age and/or the consequences of impairment, have fully understood the nature of the research process. In such instances I cannot claim to have their informed consent to being involved in the process. The options of excluding such children did not seem to be ethical (Mahon and Glendinning, 1996), nor did such exclusion stand comfortably alongside the stated aims of equality of value. On the occasions when I was unable to gain full consent from participants, due to either age and/or impairment, I ensured I had the consent of one of their parents and that participants were showing no signs of distress as a result of my presence. In the case of any sign of distress, I stopped the interview immediately, chatted for a bit and left. On occasions when this happened, the next visit went well and it appeared that stress was related to tiredness or ill health. Consent then became something that could be withdrawn and replaced at any point during the research. Such an approach relies upon the conscience of the researcher to constantly monitor consent as part of the research process (Reid, Ryan and Enderby, 2001).

The second ethical position to be considered is that of confidentiality and protection. In keeping with principles and procedures regarded as good practice in research with adults, present practice recommends that children be ensured that confidentiality will be respected unless protection is an issue (Marchant et al., 1999; Morris, 1998(b); Ward, 1997). I was fortunate in that, during the course of the research, no significant issues emerged in which parents and their children were in conflict with each other and wanted 'secrets' to be kept.

During the course of the fieldwork, however, I was at times painfully aware of different, more subtle, aspects of the question of confidentiality and a research process involving different family members. This was made particularly delicate because of the fact that the research was focussing on the results of living in a disabling world. For all families involved their engagement with a disabling world was as a direct consequence of the impairments of one family member. This person was inevitably in the most vulnerable position – both within and without the family. The following section describes some such uncomfortable moments.

Uncomfortable moments

The most uncomfortable moments I had during the research process in terms of confidentiality concerned the way in which parents, on occasion, talked about their child, in the child's hearing. Such incidences were in part due to the way in which parents generally put their own needs to talk above any sensitivity for the feelings of children; in part due to the lack of access to family support in that the interviews took place at home when mothers were usually looking after their

child/young person. On one of these occasions the bias of my own position as an adult (without a disabling impairment) was brought sharply into focus as it was not until I transcribed the interview that I realised the content may have been upsetting to the child concerned - her mother had been talking freely about the (negative) effects the child had on the marriage. On a second occasion, the mother talked in the presence of her daughter about the fears she had for her death, yet did not address her daughter directly. Reflecting on such situations drew my attention to the way in which we, as adults, are often casual in the conversations we have in front of children and young people - not just disabled children and young people. There is, as Mason (2002) points out, a great danger in talking in this way in front of disabled children and young people as so often the way in which we (as non-disabled adults) talk, reflects a disabling world. Such unfortunate instances reflect the subtleties of the issues as well as demonstrating the potential we all have of 'making a difference'. In addition to this, it is important to note that both of these issues – lack of sensitivity to child's feelings about the consequences of their impairment upon the family and the lack of support – are directly related to living with impairment in a disabling world (Barnes, 1991; Finkelstein, 1980; Oliver, 1996; Thomas, 1999; Morris 1991; Reeve, 2002; Thomas, 1999).

Risk of intrusion

Most of the time spent with families took place in their homes and as such held the potential for being intrusive. In order to minimise the risks of this, I kept the number of visits to a minimum, went at times of their convenience (often this

was when the father was out), and generally did not stay for more than an hour and a half. The only exception to this rule was if the family requested my presence for any reason – for example, attendance at a Circle of Support meeting or wanting to talk. I found that most families were happy with this arrangement and welcomed me into their homes. They were glad to have someone take an interest in their lives and keen to take part so that others might benefit. This issue required both sensitivity and flexibility, as on several occasions, I arrived at someone's house at the appointed time to find that it was an inappropriate time and decided to cut the visit short. In many ways, working flexibly demanded that I enter into the unpredictable flow and nature of the lives of participants.

Saying goodbye

The subject of this project meant that I was asking participants to share details of their lives with me that were often painful and difficult. Initially I worried greatly about entering into people's lives, building a relationship, and then leaving. There are no easy resolutions to these issues although as the project developed, I discovered that the initial laying out of boundaries was important, as was being clear and honest about the work and ways of working with them as individuals.

In this area, I think that the multi-tasking nature of the approach adopted helped in that there is only one family taking part that I no longer have any contact with. With this family, I intend to re-establish contact – by means of a card to once again thank them for their involvement – when the work is completed. The other families, even those I have lost personal contact, I continue to see from time to

time through our mutual involvement in different organisations or general loose knit, but well established, networks.

Influences and bias

It would be foolish and misleading not to acknowledge the way in which my personal experience of the research area has influenced the direction of the project as there have been both positive and negative aspects to my close relationship to the research topic. On the positive side, such personal experience gave me a feeling of 'being at home' with the issues that enabled me to pick up on details holding clues to larger questions and build easy, relaxed relationships with participants. It is important to acknowledge, however, that such personal experience also has the capacity to limit the investigation. The way in which I readily identified with the experience of other family members, especially mothers, may well have obscured important points along the way. The fact of my being a mother may also have type-cast me in a certain way, inhibiting the response of other family members. On occasion, I was aware that my response to young people came from being a 'mother' rather than 'researcher'. Interestingly this only happened when I was with both young people and their mother. It appears that when put in the position of identifying with a young person or a mother, my 'auto-pilot' position was as a mother. It is likely that such a default position runs through the entire work.

A further point of caution lies in the possibility that, having lived one aspect of the family experience, I adopt a position of 'knowing best'. Such arrogance may prevent me from recognising and/or validating viewpoints emerging from

different perspectives both from within the family and/or in the professional arena.

There was, within the work, a constant dilemma of how much of my own experience I should reveal - both in written work and in the contact I had with families - knowing that revealing it has both positive and negative effects. I am also aware that the way in which I reveal the experience has an impact - this is especially true in light of my son's death. As a general rule, when asked about my interest in the issues I would tell participants some of my own story; when I was not asked, I would remain silent about my personal experience.

I was aware when engaging with some families who knew of my son's death that their reaction to his death played a part in the way in which they responded to me - this was most notable at the beginning of the research and when the families themselves were concerned about the life of their disabled family member. On occasions, this appeared to be very positive as it allowed for deep-seated fears about health issues to be brought into the open. On other occasions, however, it produced a barrier of sympathy and fear that made it difficult to establish meaningful communication.

At the same time, I became aware as the research developed that some of the very difficult issues for families, issues that greatly affect attitudes towards the disabled child/young person, depend very much on the health of that child/young person. For example, there appeared to be a high degree of

protectiveness towards children/young people with shortened life expectancies. Such a factor goes largely unrecognised in the literature dealing with the family experience. The brief exploration of these issues in this work demonstrates that there is little recognition of the impact of the emotional and psychological effects of living with a chronic illness when that illness runs alongside, or is connected to, severe or complex impairment. This general lack of recognition means that it is not usually taken into account in the delivery of service provision, or acknowledged by professionals in their interactions with families. Such factors, emerging as a result of my own experience meeting the experience of participants, give the work an added depth in addition to making it a mutual exploration, a live process of 'finding out'.

Influences affecting the broad sweep of the research in this way inevitably affect the detail. According to Cohen and Manion, the major source of bias in qualitative research is embedded in the researcher:

The sources of bias are the characteristics of the interviewer, the characteristics of the respondent and the substantive content of the questions. More particularly, these will include: the attitudes and opinions of the interviewer; a tendency for the interviewer to see the respondent in her own image; a tendency for the interviewer to seek answers that support her preconceived notions; misperceptions on the part of the interviewer of what the respondent is saying; and misunderstandings on the part of the respondent of what is being asked. Studies have also shown that race, religion, social class and age can in certain contexts be potent sources of bias. (Cohen and Manion, 1980, p. 282).

Such bias affects not just the process of the research but also, as I explore further in the following chapter, the analysis of data and the presentation of material.

Conclusion

The methodology of this project is placed within the realms of a multi-faceted, flexible, and open-ended investigation. Given the apparent inability of any one existing explanation to cover all aspects of the family experience of living with and alongside impairment in a disabling world, I have adopted an anti-foundationalist stance allowing me to draw on a range of sources to help me explain how disablement is variously constructed and replicated within the family. Whilst it does not fit neatly in the realms of established research methodologies, it nevertheless carries key components of both emancipatory and participatory research in that it has been empowering for both participants and researcher (Chappell, 2000). In addition to this, an underlying flexibility was crucial (Ryan, Reid and Enderby, 2001) not only as a means of being open to the issues raised by participants but also as a way of allowing participants to influence the nature and the course of the investigation.

The process of the research has raised questions of a theoretical, ethical and practical nature. The continual asking of questions facilitated a live enquiry dependent on the dynamic engagement of researcher with the participants, the research question and the developing theory. The process became as important as the end result in that it allowed for a dynamic relationship to

emerge between the participants, myself as researcher, the practical experience of the living with and alongside impairment in a disabling world and the development of theory. With participants insisting (as we shall see in following chapters) that inclusion lies within relationship, I was not able to go into families and just talk about the theory but was actually having to put demonstrate through my actions that I valued their children and enjoyed being with them. Engaging with the issues in this way allowed for the complexity of the subject area to emerge. The fact that the project was a fluid exploration, rather than something aiming to produce ideas for change, gave the rare opportunity of being able to follow emerging leads without the constraints of having to 'produce an answer'.

It is important to emphasise that the story to emerge from the fieldwork will not be the whole account. First of all the story told depends upon my ability to ask the right questions in the appropriate manner; secondly, on how much and what participants choose to say about themselves; and thirdly, on what I choose to report. In this way it may be the story of the participants but it is very much "the researcher's dressing" of that story (Stake, 1995, p.93). In an attempt to make the dressing as transparent as possible, the following chapter looks at data collection and analysis.

Chapter Seven

Getting down to business: data collection and analysis

Having established that a qualitative methodology based on the understanding of social model principles best fits the aims of the research this chapter outlines the overall stance underlying data collection, categorisation and analysis.

Due to the fact that this entire project takes place in relation to the knowledge gained from my own experience I make no claim to present an objective account. In my search for a suitable backdrop for data gathering, categorisation and analysis, I found positivist analytical models characteristic of ethnographies that adopt analytical induction or grounded theory did not suit my purpose as they not only assume a 'neutral' empirical observer but an external, independently knowable and verifiable social reality. My own position as a parent of a disabled child, and so *living* much of the experience 'under the microscope', clearly does not permit such detached engagement. It was therefore, something of a relief to come across literature recognising the inevitability of the 'researcher effect' on the field of study (Coffey, 1999; Fine, 1994; Ozga and Gewirtz, 1994; Tregaskis, 2004; Wheatley, 1999).

The backdrop to the data collection, categorisation and analysis lies in the reflection on my own experience running alongside preliminary work in the literature review. As the project developed and I undertook work with families, fluid relationships developed between reflection, reading, continual returns to the research question and emerging data. Within this context, initial analysis involved

categorising data on the basis of its relationship to the primary research question: How can families be supported to lead 'ordinary' lives? Making selections of organised data in this way I started to develop preliminary themes: for example, impairment as 'ordinary'; interconnectedness and relationship; the instinctive appreciation of diversity articulated by family members; and the way in which the family experience of living with impairment and disablement (when viewed positively) has the potential to inform wider society. On the basis of this preliminary analysis of the whole data set, I then studied individual cases looking for similar themes lying within and between the cases. For example, in looking at the differential experience of access to the mainstream between Louise and Andrew, I began to see that the consequences of impairment impact upon opportunities for being present in the community. At the same time it became evident that Ben and Owen, in spite of having similar impairments, had very different opportunities for accessing the mainstream. Questioning the similarities and the differences in this way helped me to refine the emerging themes in a way that allowed for the development of a more encompassing analysis. For example, it was the focus on the descriptions of the impairment being ordinary – just one of those things - and the experience of having a child with impairment bringing joy and heartache; being welcomed and acknowledged as being 'hard work', that led to the emergence of paradox as a central theme. Similarly, the differential experience to their peers in mainstream settings reported by disabled young people led me to concentrate on positive relationship as **the** necessary harbinger for an ordinary experience.

The case for subjectivity

The argument presented in the thesis that impairment is an ordinary aspect of our human experience and one that impacts upon us all in one way or another – even if only as an apparently instinctual fear and dislike of the idea – means that it is not possible for any of us to be an independent arbitrator standing outside of the experience I am describing. Further to this, my own family experience makes any claim to such an independent stance impossible – I am truly ‘up close’ to the issues. Justification for this position lies in the recognition of subjectivity as a central part of human social engagement and understanding:

Observation then, is a very complex and important issue. Whatever we call reality, it is revealed to us through an active construction in which we participate (Prigogone and Stengers, 1984, p. 293)

Acknowledging my own intimate connection with the experience in this way, the process is not one of grounded theory (Glaser and Strauss, 1967), but rather an approach structured by a process of dual interrogation. With the starting point for this process being my own experience, supplemented and interrogated through critical engagement with the literature, the data gathered from families has been used to develop my thinking. In order for the thesis to gain the necessary credibility, I have had to turn my close position to the data into a positive aspect through critical engagement with the ideas put forward and an ongoing, rigorous self-reflectivity. I have found this to be so challenging that, at times, it has only been a determination to further understand in order to better explain the experience to those who have not had the benefit of being ‘close up’ that has kept me going. In order to minimise the inevitable bias and to maximise critical

self-reflection I showed appropriate sections of the text at a draft stage to contributors and made adjustments as necessary. Suggestions made at this point were generally to give more data to help me further explain a point and so develop the theory. Inevitably, such a process means that the strength of the argument I present is grounded in subjectivity and that the truthfulness presented is contestable to a different interpretation of the data. Indeed, it is highly likely that a different approach would not have brought up the same challenging questions.

Having outlined the ground on which data collection and analysis took place, I now go on to look at the central importance of the social model of disability within the process.

Social model and analysis

Inevitably, the context within which the data is placed colours the analysis and presentation of material. In keeping with the vantage point of the social model of disability providing the basis for the research, it also provided the point of departure for the analysis of the data. With respect to data analysis this perspective allowed for the recognition that disabled children are seldom fully respected, given choices, or used to being listened to (Ward, 1997; Morris, 1998). Recent work points to the fact that these conditions make it very difficult for young disabled people perceived as having learning difficulties to have their voice acknowledged (Murray, 2002). Unless this is taken into account when analysing data, it is all too easy to slip back into the gaze of the medical model

and conclude that such young people have little to say about their experience. As subsequent chapters reveal this is very far from the truth. The extension of the gaze of the social model (see Chapters 3 and 4) to cover all family members allows for that same perspective to be placed on their experience.

A stark example of the way in which social model thinking was used to shape analysis is found in the different ways in which Owen describes himself. On one occasion, feeling very anxious and insecure, Owen gives the following description of himself:

I am a bit worried that I am too handicapped to study at Aberdeen itself. I would love to if I were normal but as I am severely autistic and I depend on others to help me communicate and lead the most stimulating life possible, given my difficulties in motor control and behaviour. I am nevertheless intelligent, and able to do academic work.

...we are a bit apprehensive because I am rather hyperactive and sometimes get asthma, and I hope that I will be able to behave when I am with you (Owen, London, 2002).

In this letter of introduction, Owen apologises for the effect of his impairments.

On a different occasion, however, any apology is blown away in the wind:

I am awfully dependent in my impaired state, but it is made worse by a culture which has little value for a person who cannot stand up on his own two feet. I can stand in the literal sense but I need help with my communication, and I am appalled that my dependent state is seen as a reason for my being killed as a foetus if the defect had been known before I was born.

I think that I have something to offer other people, in that I am lacking some of their cynicism and sophisticated attitudes, which often mask an ignorance of the essential aspirations that should be the first preoccupations of all people (Owen, London, 2001).

In this instance, Owen sets his experience in the context of a struggle for human rights. How should such a difference be interpreted? My own interpretation, taken from within the context of a disabling society and knowing that Owen is very anxious about how he will be perceived at Aberdeen University, is that the difference can be accounted for by the concept of 'internalised oppression' (Rieser, 1990). Believing the oppressive attitudes he has grown up with and which are reinforced every day, Owen at times views his own impairment, and who he is as 'the problem'. The apparent contradiction within these self-descriptions provides a painful example of the damaging effect a disabling world has on the identity of children and young people with impairments.

Given the exploratory nature of the research and its focus on 'getting to the bottom' of the story, the most appropriate method was to obtain detailed accounts of family life from a small sample of families. At the outset, intending to build on past work with families (see Murray and Penman 1996, 2000) I had envisaged that I might involve families in a process of building and analysing narratives. Whilst families were interested in such a project, it proved impractical due to time constraints. For the most part, mothers taking part in the fieldwork barely had time to sit down and do nothing for half an hour every day, never mind sitting down to write about their experience of living in a disabling world. Responding to this, I decided to build a series of case studies, making use of a variety of methods (including ethnography, semi-structured interviews, play, and conversation) through which to engage with and learn from all family members. My first task however was to find families willing to engage with the research process.

Strategies used to select participants

In order to make visible the present family experience I chose to involve families through two national organisations – Circles Network and Parents with Attitude. These organisations were chosen primarily because of their underlying philosophies based on human rights and the social model of disability (see Appendix 2); their practical work around family support and; the fact that I had close links with both organisations giving me an ease of access.

Each organisation sent out letters of invitation to a small number of its members – three from Circles Network and four from Parents with Attitude. Both organisations chose to invite families on the basis of their dissatisfaction with conventional models of family support. Consenting families comprised a variety of groupings – a two parent family with one child; three single parents with one child; a single parent with two children; a single parent with three children and finally a two parent family with two children. The ages of the children and young people with impairments ranged from 4 – 22; some families had close extended family nearby giving support on a regular basis, whilst others were very much on their own in terms of both family and supportive friends. Families lived in a range of geographical locations – city, small town and rural community.

Over the course of the research (some 18 months in all), there were two major changes affecting participation. The numbers fell from 7 to 6 when one family decided they did not, after all, want to take part. This family was under a lot of pressure with issues of health, recent bereavement and access to services of

their choice – one more professional coming into their house was, in the end, too much. The experiences of this family are not, therefore, included within the thesis. The second change was due to the death of one of the children – Sarah. Sarah's family had known that she might die during the course of the project but had chosen to go ahead anyway, feeling comfortable with me being in their home, as I 'knew all about it'. In fact, I have maintained contact with Sarah's family and, with their permission, have included their experience in the thesis up until the point of Sarah's death.

Involving the whole family

Initially I intended to explore the experience of living with impairment and disablement with all family members, identifying what might support them to lead 'ordinary' lives. As it happened, the particular make up of the families involved in the project did not allow for this full exploration to take place – for example, only two of the seven families had fathers and neither of these two fathers wanted to participate. Also, it had been hoped that the project would explore the experience of non-disabled brothers and sisters. Again, because of the particular make up of the families, an in-depth exploration was not possible – three of the disabled children had no siblings, one had a newborn baby sister, leaving only three families with brothers and sisters old enough to participate. Of these three families, three sisters chose to participate.

Having set out to involve a range of family members, it was tempting to look for other families who might 'fill the gaps' in terms of involvement of both fathers

and siblings. I rejected such an approach, however due to the practical constraints of time and money. In addition to this, emergent findings indicated that choosing organisations embedded in the social model of disability was simply not enough to ensure ordinariness. Families were telling how the already well documented barriers lying within our social structures - such as employment, housing, careers, health, education, leisure pursuits etc. (Marchant et al, 1999; Morris, 1998 (a); Tozer, 1999; Noyes, 1999; Beresford, 1994) acted as barriers to ordinariness. For this reason, I re-adjusted the focus of my gaze and put the bulk of my time and energy on an exploration of the theoretical underpinnings that might support services to enable disabled families.

Data collection methods

In line with the multi-dimensional nature of the support needs of families (Dunst and Trivette, 1988) the methods adopted to engage with families, young disabled people and allied professionals has necessarily been wide ranging. In addition to the six family case studies, an approach similar to that adopted by Reid, Ryan and Enderby (2001) has included:

- engagement with disabled children/young people seeking opportunities for 'inclusive leisure';
- involvement with parent support groups;
- networking with other researchers working with disabled children and young people and their families;
- drawing on personal experience;

- involvement in both a hands on and an advisory capacity with research and development projects concerned with disabled children and young people and the family experience;
- participation in national policy-making forums - for example, the Quality Protects Reference Group;
- attendance at a variety of conferences, giving opportunities for wide ranging networking; and finally,
- engaging in collaborative work with organisations providing 'alternative' methods of supporting families

The aim of such diverse engagement has been to immerse myself in the issues from a variety of perspectives in order to increase my understanding, to broaden my perspective and to fully explore the broad range of theoretical concerns outlined in earlier chapters. For the work to include the experience of such a wide range of people with an equally wide range of ages and impairments, the data collection methods demanded variety, flexibility and creativity.

The three main groups of people involved in the research were families, young disabled people outside of family context, and allied professionals working in health, leisure and social services. With each of the three groups, different methods of gathering data were used. These methods included: semi-structured interviews, peer interviews, participant observation, talking with others (about the disabled child/young person), hanging out with, spending time with, babysitting, 'helping out', chatting, playing, art work, written stories,

photographs, video recording, engaging in leisure pursuits with, and attending Circles meetings (For description of work of Circles Network see Appendix 2).

Engaging with families

The principal means of engagement with parents included in-depth and serial qualitative interviewing. Over a period of 18 months, parents were interviewed on between three and four occasions in their own homes. A non-standardised semi-structured interview approach was used to cover a range of topics that had been built up over the course of the study. Interviews followed the perceived priorities of families.

The approach taken with children and young people centred upon their wishes and preferences for involvement in the process. Whilst some children/young people chose to be interviewed on more than one occasion, others preferred me to glean information from them through spending time together. Whilst this varied from one child to another work with Sarah typifies the approach. Over a period of nine months, I visited Sarah once a week, giving her mother 'a break' whilst I had the pleasure of bathing and feeding her. During this time I was able to build up a relationship with her and find out what she did and did not enjoy. After a few months I was delighted to be able to recognise the signs of Sarah's happiness through the particular way in which her body relaxed. Although I was unable (due to geographical location) to spend as much time with all the young people, the time I did spend with them revolved around their interests. For example, I sat and read books with Leanne; Owen allowed me to accompany him to the beach;

Ben took me on trails round the countryside to find horses; Andrew let me spend time sitting beside him whilst I chatted to his mother; whilst James and I frequented cafes and parks making up magical stories that involved ladies being told off for 'bad behaviour'. During such times – having ensured that we were doing what the young person wanted to do - I would observe, ask questions (where the young person could give an answer), and play.

With regards to teenage brothers and sisters I carried out one semi-structured interview, but typically would spend some time chatting with them on each visit. When the child was younger, as with James' sister, I spent time chatting and playing – keeping my ears and eyes open all the while.

The involvement of professionals was less intense and centred around networking, listening to issues as they were raised at meetings and/or conferences, delivering training on issues relating to engaging with disabled young people and listening to their experience, questions and perceptions.

Throughout the period of data collection, I found myself 'listening for the emergence of themes' (Wellington, 2000; Wheatley 1999). Interviews were audio-recorded and transcribed. Notes were made of each meeting, conference, workshop etc whilst I also kept a journal recording impressions, meetings, conversations and observations. Families gave me photographs, drawings and art work – these too were collected and added to the 'data pot'. As time went on the complex data sets were ordered manually through the identification of

themes and the grouping of these themes on topic sheets. I attempted to connect the theory with daily experience through 'theoretical memos' written alongside the thematic topic sheets. In this way analysis and data collection occurred in parallel, with decisions concerning appropriate lines of questioning derived from on-going theoretical analysis. For example, in the early stages of the research it emerged that families were making connections between different parts of their lives in a way that traditional research does not allow for. In asking questions about 'family support' allowing for ordinariness, it became evident that all family members described their experience in a much wider way than traditional notions of 'respite care', 'short breaks', or 'family support' allows for. Topics covered by parents included 'respite care'/babysitting/short breaks; housing; employment; transport; money; health care; education; and relationships – both in the family and with the wider community. When asked the same question, children and young people, disabled and non-disabled, with and without learning difficulties, immediately talked about a wide range of topics including education; family, friends; and leisure.

Family support was clearly not seen in isolation from other aspects of their lives, forming as it did, an integral part of their experience. As I listened to the wide variety of topics emerging from participants, I became aware that in order to give an accurate reflection of the issues concerning them, I had to break away from traditional concepts of family support.

Strengths and weaknesses

As with all research projects, a retrospective look at the methods adopted allows light to be cast on the positive and negative aspects of the approach. In keeping with the central theme of paradox running through the thesis, many of the positive aspects of the approach also generated the negatives. The most striking example of this was in the amount of data generated. Although the amount of data generated gave me the opportunity to connect with a complex range of theoretical perspectives (see Chapter 5) it also made it very difficult to keep 'scope specific'. In this respect, the free flowing nature of the semi-structured interviews with parents might well have benefited from a more directive approach. Similarly, whilst the extensive networking and engagement with different professionals groups undoubtedly brought a breadth to the research and contributed to the development of the theoretical exploration, at times it simply seemed as though I had been too ambitious in scope.

With respect to the work carried out with families, there is no doubt that the person specific approach adopted is not one that is universal but is one which, with the use of 'in depth' methods of investigation, demonstrates a particular experience (Cohen and Manion, 1980). Whilst it is not possible to make generalisations from such an approach it has provided the flexibility to adapt the research process to suit individuals and so to explore the range of theoretical issues emerging through the literature review. Without doubt, the process of listening to families enabled me to relate to and learn from the experience of

participants, rather than having to rely on large-scale generalisations (Wellington, 1996).

The flexible use of a range of methods gave room for exploration whilst also allowing families – parents and children/young people - to set their own priorities. In addition the range of methods used allowed for a comprehensive mapping of the issues as they affected different family members – disabled child/young person; parents; and siblings.

Due to the new and exploratory nature of the work, the complexity of the issues, the many different skills required to gather data, the sensitivity required in working with families living with difficult issues, and the fact that I am so close to the issues, the work would have benefited enormously from the sustained input of more than one person. To this end, it would have been helpful to have had an advisory group and to be working alongside other researchers. Indeed, on many occasions I wondered how the exploration might have taken shape were I to be working alongside a disabled researcher. Similarly, and in light of the fact that the work sought to explore the experience and gain insight into the views of young people, it would have been interesting to have engaged young disabled people more fully in the process. An exploration of such issues was limited through lack of funding.

Conclusion

The backdrop to the data collection, categorisation and analysis lies in reflection of my own experience running alongside preliminary work in the literature review. As the project progressed, fluid relationships developed between reflection, reading, continual returns to the research question and emerging data. Within a context informed by the social model of disability, initial analysis involved categorising data on the basis of its relationship to the primary research question: How can families be supported to lead 'ordinary' lives? As the following chapter reveals participants, without exception, identified positive relationship as **the** necessary harbinger for an ordinary experience.

Chapter Eight

Focusing On Relationship

Introduction

All the young disabled people taking part in this project identified positive, mutually valued, and respected relationship as a necessary foundation for social inclusion. Within the spectrum of relationships generally, positive family relationships were identified as crucial:

Family is the core of life for everyone. It needs to be a priority for those who do not know what it feels like to belong. (Ben, Sheffield, February, 2002)

Ben's feelings about the importance for disabled children/young people of the experience of positive family relationships to provide a springboard from which to engage in a disabling world are mirrored by the rhetoric of policy (Department for Education and Skills, 2002). However, the experience of participating families was that of feeling isolated and 'on their own', inhabitants of a 'different world' having to struggle with, rather than be supported by, service providers. For example, whilst Ben's mother was negotiating for support in college, Owen and his mother were engaging in a debate about direct payments; James' mother was carrying on a longstanding battle with social services about support for James after school and in the holidays, whilst Andrew's mother was going through the process of an appeal tribunal in an attempt to secure a mainstream education for Andrew, and Louise's mother had been engaged in a protracted discussion about a motability vehicle. Leanne's mother meanwhile, wanting to

minimise stress in the family, has given up fighting for any support from services:

I just want to make sure that Leanne has the best quality of life possible. If this means doing it on my own, then so be it (Jean, Gloucester, August, 2000).

The price Jean and her family pay for 'going it alone' is that of extreme vulnerability if/when 'something goes wrong'. On the other hand, parents wanting access to mainstream services, a first step towards ordinariness, are inevitably forced into a relationship of struggle with service providers. This relationship of struggle gives weight to Mason's (1995) assertion that current service intervention actually militates against positive relationships between disabled children and their families. The disabled children/young people of the families taking part in this project are all perceived to be amongst 'the most difficult to include' and therefore, following the concept of eugenic logic (Kliewer and Drake, 1998) discussed in the previous chapter, 'the most difficult to love'. Although some of the parent participants were ambivalent about their son/daughter's impairment, relationships with disabled children/young people were predominantly loving and supportive.

As previous chapters have shown, positive relationships between disabled and non-disabled people have largely been rendered invisible, thus contributing to their 'extraordinary' status. This stands in direct contradiction to Alison (Leanne's younger sister) assertion that she did not see anything extraordinary about her life – 'to me it's all normal' (Alison, Gloucester, August, 2000). The

extent to which her family is 'different' to others lies in the fact that not every family includes a disabled person:

...I've always known that, not that our family is different or anything, but not everybody has a disabled brother or sister (Alison, Gloucester, 2000).

Alison's understanding of the ordinariness of her experience – ordinary, because that is how her life is – gives testimony to the strength of relationship as a means of challenging the messages from the status quo. The widespread concentration on the difficulties impairment imposes on family life running alongside the lack of distinction made between impairment and disablement, has meant that the many positive relationships, such as that between Alison and Leanne, have been hidden from the view of the majority, making it appear as if the disabled child has nothing to contribute to family life and the wider community. (For examples of positive relationships throughout the last century, see Oswin 1984, 1991; Murray and Penman, 1996, 2000; Atkinson, Jackson and Walmsley, 1997; Atkinson and Williams, 1990). Asked why the majority see people with impairment so negatively, Alison answered:

It's because they've not been brought up with a disabled person, they've not got any disabled people in the family and maybe they just don't understand. (Alison, Gloucester, 2000).

Leanne's presence has given Alison the opportunity to learn that being in relationship with Leanne is an ordinary, positive, and valuable aspect of her life.

My aim in this chapter is therefore:

1. to make visible, through the experience of the research participants, barriers within services and the community to the building of positive relationships between non/disabled people perceived as having learning difficulties and;
2. to outline the effect the difficulties encountered in establishing mutually valued relationships has upon the disabled child/young person and their family.

The identification of ways in which services maintain the status quo paves the way for planning service provision that supports positive family relationships whilst simultaneously creating opportunities for the building of mutually respectful relationships between non/disabled people outside the immediate family. The starting point for this exploration lies within the education system – young disabled participants having identified school/college as central to their opportunities for making friends.

Education

As school is the main opportunity children and young people have for making friends outside of the family, it is not surprising that a strong link was made between making friends and education. For example, James (aged 14) has never been to segregated school – throughout his primary years he was either at his local mainstream school or, when that placement broke down, was withdrawn from school. Never having been a full-time pupil, he 'stood out' from the rest of the children in his class and was at a distinct disadvantage when it

came to making friends. In addition to this, because he was unable to show academic progress and his social skills were seen as 'poor', James remained in reception class for four years. Being perceived as 'emotionally immature' James was given little opportunity to develop friendships as his classmates were constantly changing. In this way both he and his classmates learned that, rather than belonging by right, his presence was conditional on his social behaviour and academic performance. As both these areas were strongly affected by the consequence of his impairments, James and his friends were being taught the lesson that impairment is a legitimate reason for treating individuals differently thus strengthening the illusion of a divide between non/disabled people.

Having gone through this experience, the junior school would only accept James as a 'visitor' –one step down from being a part-time pupil. Over this time, James clearly indicated that he wanted to go to school, to be with other children the same age - this became particularly marked when his younger sister started attending the same school on a full time basis.

As James approached the age for going to secondary school, his mother began negotiations with the LEA once again. Their local mainstream secondary school, where the majority of young people he 'knew' were going, was extremely unwelcoming and did not have a good track record as far as young people with complex impairments were concerned. His mother approached another school nearby which was happy to 'give it a go'. James has attended this school (with support worker) on a full time basis over the past 3 years. In spite of the fact both he and school are happy with the placement, James has no 'real friends' at

school, nor does he receive an 'education' as his impairments prevent him from learning in a 'conventional' fashion and teachers have been unable to fully adapt the curriculum in a manner that engages him. Although James is welcomed into the school, he is unable to be fully included because of the wider issues of an education system geared towards 'fitting into the norm' (Crozier, 2001). Consequently, James is an accepted presence but visibly 'set apart' from the majority.

Similarly, Andrew's experience within his mainstream primary school was that of being treated differently because he could not conform to 'normal' developmental or social expectations. In the early years of Andrew's education he loved to paint alongside the rest of the children in his class. In looking at artwork in the classroom one morning, his mother noticed that none of Andrew's paintings were on display. Asking about this, she was told, 'It is impossible to know what Andrew's scribbles are – a tree doesn't look like a tree, a house doesn't look like a house' (Marjorie, London, 2001). On this basis the class teacher decided that his artwork did not merit being displayed alongside that of the rest of the class. The message silently given to Andrew and his classmates was that his work was not 'good enough', was 'too different'. This incident was one of many – Andrew was not put into groups with the other children (his mother was told that there was no need for this, as 'he belongs to all groups'); he was not included in the school Christmas performance; nor was he included in the daily class 'news' session where the children told each other about events at home. The way in which Andrew was treated in class compounded

institutional and structural barriers to his inclusion, giving Andrew and his classmates the clear message that his presence was tolerated rather than welcomed. As such, he and his classmates were learning that he did not belong by right. It is hardly surprising that when it came to children picking teams for games or PE sessions, Andrew was always the last to be picked – the 'least able' seemed to equate with the 'least popular', the 'least desirable'.

Andrew's experience was not unusual – other participants attending local mainstream schools reported being constantly left out, made to feel different, socially isolated and sometimes physically bullied. This experience of being seen as 'different' in school had a major effect on their time out of school. Both Katherine and Jonny spoke about the few non-disabled friends they had suffering abuse from the larger group. Katherine knew she had a 'real friend' when that person stood up for her against the majority group. Being without friends at school means that there is no one apart from family with whom to go to the swimming pool, go into town, the park, the bowling alley etc. after school and at weekends. As such activities are simply part of the experience of childhood (Corker, Davies and Priestley, 2000) exclusion from relationship has an effect on everyone. As one young participant said, 'If my brother weren't in school, his friends would be one friend short every day' (Sam, Sheffield, 2000). A further barrier to developing friendships was described by young people requiring 'one to one' support. The presence of a support worker not only inhibited friendships, but also on occasion caused resentment as other young people wanted time without adults who they saw to be in a supervisory role.

James' mother made the additional observation that James had become very dependent on adults to 'amuse him' and has therefore had little opportunity to find out how to relate to his peers. Similarly, his peers are given little opportunity to find a way of being with James and assume that they need the presence of an adult to facilitate the relationship.

A common observation from non-disabled young people in mainstream schools was that staff treat disabled pupils differently. For example one young non-disabled woman (Joey, Sheffield, 2002) commented on the way in which she felt under pressure from her form teacher to 'include' her classmate Rosemary in her circle of friends because she was disabled, rather than allowing a friendship based on preference, or common interest to develop. Similarly, Jenny described how her disabled classmate was allowed to behave in ways that would have meant certain detention for non-disabled students. Such incidents lead to resentment from the non-disabled majority, and feed the illusion of a divide between non/disabled people, as the disabled young person is placed in the position of 'other'.

Whilst some young people did have positive relationships with their peers in school, they were unable to spend time with them out of school. This was something commonly reported by young people attending 'resourced units' within mainstream schools. Just as young people attending segregated school had to travel out of their community to get to school, so too did those attending resourced units. Because school friends usually lived some distance away

young people attending resourced units were unlikely to spend time with their friends after school and so missed out on opportunities to explore and develop friendships.

Disabled participants attending segregated schools, generally went to school outside of their community and consequently lived some distance from their friends. The only times these young people were likely to see each other were in segregated settings, either at after school clubs, in holiday schemes or in specialist youth clubs. The isolation of only children (such as Owen) attending special schools was particularly pronounced. One side effect of attending school outside of the community was that young disabled people were not familiar figures in the local shops or parks resulting in their partial (Owen and Andrew) or complete (Leanne) invisibility within their communities. Such invisibility makes it harder for relationships to develop as there are limited opportunities for non-disabled children/young people to enjoy being in relationship with disabled children/young people with cognitive impairments and thereby to learn that we all have the same needs for belonging and relationship:

Leanne is happiest when all of us, including Chloe, are at home. If we have friends round. She just likes the company of other people, people talking to her, not about her but talking to her. I don't know if Mum told you, but we had some of Chloe's friends down and she loved it. One of them came up to her and held her hand when he was talking to her and she loved that. She likes Chloe's boyfriend Joe as well, she's got a big soft spot for him...she just likes people to have a conversation with her, likes to be around people (Alison, Gloucester, 2001)

Alison's observations about her sister demonstrate how, in spite of severe impairments, Leanne is happiest when she is participating in mutually valued, respectful relationships. Issues affecting young people who are perceived to have the most complex and severe impairments, focus attention on the detail of issues affecting all disabled children/young people. The experience Leanne had at school when several of her classmates died highlights the way in which it was generally assumed that relationships were not an important aspect of her life.

Several years ago, while Leanne was a pupil at a segregated school for young people perceived as being 'the most severely disabled' five of her (eight) classmates died over a period of six months. Following the fifth death, Leanne was extremely ill – refusing to eat and becoming very lethargic. Desperately worried, Jean took Leanne to hospital and watched her daughter deteriorate further. Thinking that her daughter was dying, Jean asked for her to come home where she held her constantly over a period of 5 -7 days. Slowly, Leanne 'came round', her will to live returned and she began to eat again. During the course of this crisis neither the medical professionals nor the school acknowledged the impact the deaths might have had on Leanne. As far as her mother was aware, at no point did teachers speak directly to Leanne about the death of her classmates. Her mother was not directly informed by the school at the time of the deaths, so she was unable to talk with her daughter about the loss of her friends or any fears she might have about her own death. The teachers were given emotional support to meet the difficulties they experienced as a result of

this unusually high mortality rate but neither young people nor their parents were included.

This extreme example brings to light the commonly held belief that disabled children/young people (particularly those with learning difficulties and communication impairments) do not have the same need for, or ability to sustain relationships as non-disabled children/young people. This effectively provides a licence for services to run on the assumption that relationships are not central to the well being of disabled children/young people:

That his psychological health depended on him having opportunities for interaction with a range of people became clear when, after leaving school, he was without any provision at all for nine months due to the refusal of our local authority to pay any attention to his clearly stated choice. The autistic stereotype of social withdrawal did not seem to apply – Owen was deteriorating daily as a result of his isolation (Helen, London, 2002).

Sadly, Owen's experience of his relationship needs being ignored was not unusual. Andrew was in a mainstream school until the time came for his class to move to secondary school. On the basis that he was unable to keep up with his peers academically, the school (backed by the LEA) refused to give Andrew a place. This resulted in a severing of the relationships formed over the early school years, with Andrew (and his mother) becoming increasingly isolated within their community. Similarly, during the course of a workshop within a residential respite care unit, it emerged that one of the residents was missing two young people who had recently 'moved on'. Although staff had known that there was a friendship between two of the young people, the other relationship had not been recognised. Indeed, as we talked about the incident, staff said

that although they always talked to young people about leaving, they never considered it was necessary to address the effect that a person's leaving had on the young people remaining in the unit. Such an omission is another reflection of the way in which the relationship needs of young disabled people are seen as secondary to those of service providers.

Of the six families participating in the research, only one family used residential respite care. Unlike Leanne, whose health has slowly deteriorated over the years, Louise had never been expected to live long – indeed the fact that she survived until her fifth birthday surprised both her parents and the medical professionals. From an early age Louise had stayed in a children's hospice, two local social services residential respite care units and latterly a health authority respite care centre. Similar to the experiences of participants within the education system, Louise's need for relationship was not prioritised within any of the units. The following section, whilst concentrating on Louise's experience of 'respite care', touches on issues emerging from the other participants in relationship to support outside of the educational setting.

Relationship and 'respite care'

Louise demanded round the clock medical attention. Towards the end of her life she was on oxygen full-time; was tube fed twice during the day and was on an overnight feed (requiring low level supervision); required frequent suctioning because of difficulties with breathing; and occasionally required medication to be given rectally. Louise and her family lived in a small, two bed-roomed

bungalow. Because their daughter was not expected to live long, Sarah and Alan chose not to send her to school, opting instead to use residential respite care in order to 'have a break'. There is no doubt that Louise, Sarah and Alan lived under a great deal of stress as a result of both impairment and disablement. Whilst Louise's impairment meant that her life was hanging on a thread for five years and she required constant nursing care, living in a disabling world meant that the family:

- a) lived in accommodation unsuitable to their needs;
- b) had to make 'special arrangements' to go out as the rules governing mobility allowance would not allow for the family to have a car until Louise's fifth birthday (as Louise required medical machinery at all times, going out became impossible unless they could borrow a car or have someone else drive them);
- c) were isolated within their community;
- d) accepted residential 'respite care' which they were not happy about, as it gave them the opportunity to catch up on much needed sleep;
- e) had great difficulties in doing the 'ordinary' jobs such as shopping, cooking, and cleaning;
- f) were forced to change their work patterns – with Alan working very unsocial hours and as much overtime as possible whilst Sarah gave up work.

Knowing from the very early days that their daughter's prognosis was poor allowed Sarah and Alan to explore the possibility of support from a children's

hospice. In spite of the fact that there was a hospice within 10 miles of where they lived, they were outside the catchment area and so had to travel a 300 miles round trip to their 'nearest' hospice. The fourteen nights a year respite the hospice could offer neither gave Louise the opportunity to settle there or to build meaningful relationships, nor did it give Sarah and Alan sufficient time to 'recharge their batteries':

When she used to go down to L., the hospice down in L.. which was for her respite care, she sometimes used to come back sicker than what she was when we dropped her off because they would not listen to what we would tell them to do with her. She used to go there for 14 nights a year, and we would split that up. But we used to find that we went down with her and there was an emergency and they needed the bed, then after Alan had spent a whole day driving we would have to go and pick her up again and it would be 16 hours of driving. So we gave up. (Sarah, Barnsley, 2000).

After some time, in order to try and fill the gaps, Louise also visited (on a weekly basis) a local children's respite care unit. During one visit she stopped breathing (as she did from time to time) and after that the family were told. 'We don't want Louise any more, she's too 'medical'. If we allow her in, then all the other 'medical' children will want to come in' (Sarah, Barnsley, 2000). Louise was then offered a place, one night a week, in an adult respite care unit from 8 o'clock on Saturday evening until 8 am on Sunday morning. Whilst the family found the staff on the unit welcoming, and Louise was given a room on her own, the placement was unsuitable because she was the only child there:

She's happy, but there is not enough stimulation for a child her age in the rooms. That's the only problem, so we have to send as many

things as possible when she goes up. Like her books with noises on, her teddies, things like that... (Sarah, Barnsley, 2000).

Several months before she died, Louise was offered a place in a health authority respite care unit some 20 miles from her home which she was happy to go to, and which her parents found gave them more flexibility. In spite of the fact that qualified nurses staffed the unit however, there were frequent occasions when Sarah and Alan were telephoned during the night to say that their daughter was in medical crisis. When they arrived, they would find Louise sleeping quite peacefully with the (minor) crisis over. Both Sarah and Alan felt that the staff were reluctant to take full responsibility for Louise because of her poor prognosis.

Throughout this time, Sarah's preference in terms of support was that of Louise going to stay with a local family on a regular basis giving her the opportunity to form a relationship with one or two people, whilst also giving her a break from the monotony of being at home. Because of Louise's medical needs this preferred option was never explored. In spite of the fact that Louise was known to have a shortened life expectancy, in none of the respite care units were Louise's emotional needs, including her need for relationship, given priority. Whilst it was very difficult/impossible to know how much Louise understood it was not difficult to see that she did have preferences in terms of 'favourite people' and that she felt happiest being held by a 'favourite person'. Clearly able to state her need for relationship in this way, given her poor prognosis and the level of physical suffering she had to endure, whilst acknowledging her need for competent medical care, it seems cruel to think of providing services prioritising anything other than being in mutually valued, respectful relationship.

None of the other participating families chose to use residential respite care provision on the grounds that they wanted their disabled child to have an ordinary experience and, whilst they would have welcomed support of their choosing in the community, did not want to 'send their child away'. Marjorie was very cautious about asking for any social services support as Andrew had been 'received into care' for three days when he was very young; neither Elsie or Jean requested support from their local social services; Helen was considering applying for direct payments; and Linda had negotiated a small package from social services whereby James has a support worker (for three hours every fortnight) to visit him at home and take him out. The following section looks briefly at these different experiences.

Looking for ordinary experience

During his early years, Andrew hardly slept at all meaning that his mother Marjorie who is a single parent had very little sleep. At this time Andrew was being given the diagnosis of autism and Marjorie was worried that she might have caused it and struggling to come to terms with what she might have to 'cope with'. In those early years of Andrew's life, Marjorie had not yet heard about the social model of disability and was confused about the love she had for her son running alongside the fear and distaste of impairment she had grown up with and saw all around her. In keeping with all the parent participants, Marjorie looks back on those early days and realises how much she has had to change in order to become a 'radical' parent having no option but to fight for ordinariness in her son's life. Marjorie can understand why she felt under so

much pressure during the early days, but as a result of that early (and very short) reception into care, she does not dare approach social services for further support in case her son is taken into care again. The fact that Marjorie is black, a practising Buddhist, and has (having fought for a mainstream education for her son who is perceived to be 'severely disabled') a reputation as a 'demanding, difficult parent' who can 'lose it big time' (Marjorie, London, 2002) gives her grounds to be fearful. Although Marjorie does not want her son to go into residential care, she would appreciate some support for him to be able to lead an active life in their local community. Andrew enjoys being at home playing with his game boy and watching videos, but he also loves to be out travelling on buses and trains, going to museums, spending time in arcades, hanging out with other young people his own age, spending time away from his mother (Andrew is now 15).

James too, loves to be out in his neighbourhood – walking in the park, sitting in cafes, chatting to people on the street, travelling on buses etc. His mother, Linda, is constantly requesting support from social services to enable James to do these things. She has recently been told however that, because her family is coping well and there is no danger of James coming into care, the support James has three hours a fortnight is to be withdrawn. James and his support worker have developed a close, positive relationship over the past two years and enjoy going out together. This time with his support worker is the only time James has away from his family (apart from time with support workers at school). James is keen to have the same experiences as all other young people

of his age – he loves being with his mother, but wants to have teenage adventures without her.

The experience of both these young men with their local social services demonstrates the limitations of conventional family support. Based on child protection rather than giving opportunities for building relationships that might allow for ordinariness and adventures, families have to fit into existing service provision or 'go it alone'. While one family does not ask for support in case her son is taken into care, the other family is not eligible for support as they are managing too well.

In a recent attempt to build relationships within the community and visit different leisure venues Owen and his mother decided to contact social services to find out about direct payments. Preliminary enquiries have revealed that, whilst there is a system set up in their London Borough for direct payments for people with physical impairments, there is no similar system for people with learning difficulties and/or communication impairment (in spite of recent legislation supporting direct payments for people with learning difficulties). The absence of such support in the community in the present puts Owen at risk of entering residential care at some point in the future when his mother is no longer able to look after him. Owen's extreme vulnerability is the result of having few meaningful relationships within the community. In order to explore the difference being in relationship can make, I now turn to a comparison of the experience of Owen and Ben who, although they are perceived as having similar impairments, have remarkably different lives.

Similar impairments, different experience

In spite of being perceived to have similar impairments, Ben and Owen have had completely different experiences both in and out of school. Ben has always attended mainstream school (on a part-time basis as the LEA would not provide him with full-time support) whilst Owen has been to segregated schools for autistic young people and is now at an autism specific day centre. As a result of their communication impairments both Owen and Ben were labelled as having 'severe'/'profound' learning difficulties before they were five years old. Both young men happened to 'come across' Facilitated Communication (F.C.) in their teens so, whilst they had spent their early childhood having no recognised means of communication, both have been able to demonstrate a keen intelligence from the age of 13/14. In fact, Owen has recently been accepted on a distance-learning course at Aberdeen University, whilst Ben has taken several GCSEs and plans to go on to Sixth Form College to take A Levels. Recognised by his current maths teacher as a 'talented mathematician', he hopes to study maths at university.

What's the problem?

A frequent theme from both families was the way in which the young men were frequently 'judged' by their appearance or behaviour:

Ben is constantly being judged by his cover. It may be hard for many to marry the 'hyperactive' young man who happens to dribble to the one who reads well and has an above average IQ (Elsie, Sheffield, 2001).

Similarly Owen describes the way in which his impulsive behaviour (flapping his arms and jumping up and down when he is excited) 'puts people off'. Because of the way people respond to such behaviour they do not believe, when he communicates with the support of his mother that he is able to speak so intelligently. At a recent meeting with social workers about his future, Owen stated clearly that he wanted to go to spend some time in a mainstream setting and wanted to take steps towards fulfilling his ambition to be a monk. Whilst the social workers listened to all he had to say, they did not incorporate any of his wishes in the service provision they subsequently offered him (an autism specific day centre from which people generally go on to live in residential accommodation). When his mother challenged the social workers on their plans and asked how her son's wishes fitted in to them, they responded by saying that they did not believe Owen was doing the communicating. Indeed, it does challenge our usual perceptions to see Owen communicating - just as with Ben, it is difficult to marry the large young man who cannot stay still very long, makes 'strange noises' and lurches down the street with the young man who expresses himself so articulately. Helen and Elsie both recognise the challenge their sons present to our accepted norms of appearance and behaviour:

Helen (O's mother): ...Anne Emerson taught school how to do facilitated communication. School learnt. Then Owen went into the leaver's class and it's clear that they do not want to do it and when I go into school they discourage me from doing it. School says that head of class was untrained. Owen wrote a letter to school saying how unhappy he is about it. School said the standard of the letter was much higher than communication produced at school. We showed them a video we have of Owen communicating at home, but it didn't make any difference. They didn't believe Owen could communicate (Helen, Sheffield, 2001).

Elsie: It was the same with an IQ test Ben was given when he moved from Junior to Secondary school. The secondary school wanted to

know where he was academically. Ben did a test and we took the results into school. The headmaster said, 'Gosh, that's high (128)! How did they do it?' Even intelligent people cannot but doubt that people with communication impairment have good intellect (Elsie, Sheffield, 2001).

It was through developing a relationship with Ben and watching him in school that the headmaster saw for himself that Ben was indeed, highly intelligent. Having been convinced, he is now one of Ben's strongest advocates. It is because Ben has many such relationships that his experience stands in contrast to Owens. Both young men have recently had 'big' birthdays – 18 (Ben) and 21 (Owen). As testimony to their different experiences, the contrast between their celebrations could not have been greater. Whilst Owen had a tea party for some of his old school friends (all were young men with autism attending with their mothers for support), Ben had an all day party in a pub to which he invited his many friends (disabled and non-disabled) of all ages.

Why the difference?

As part of this project, Ben and Owen chose to meet with each other (neither young man having had a conversation with anyone else using the same form of communication). During their discussion together, one of Owen's first questions to Ben was about his success in accessing a mainstream education:

Owen: I want to know how you managed to get into a mainstream school when I am not regarded as mainstream material.

Ben: Mum, wise gobby, she had help.

Elsie: Who from?

Ben: John (support worker), part of establishment.

Elsie: I think he's right. John was a science teacher and so was listened to in schools. (Elsie and Ben, Sheffield, 2001).

Whilst Ben is undoubtedly right that his participation in the mainstream is due to both the fact that his mother is outspoken and his support worker used to be a science teacher, several other factors have contributed to his 'success':

1. Elsie is a member of a local parents support group whose common interest is that of securing mainstream provision for their disabled sons/daughters.
2. Ben's LEA has been willing to reach a compromise in providing a 'part-time education' rather than insisting that he attend a segregated school on a full-time basis.
3. Elsie was prepared to educate Ben at home when he was not at school.
4. Elsie has lived in the same community all her life with the consequence that both she and her son are very well known locally (both happen to have outgoing personalities).
5. Elsie has actively included other people from the community in Ben's life from an early age. This means that she is well supported by people who value Ben when she has to fight with her Local Education Authority (LEA).
6. Ben's support worker is confident in facilitating his communication, thereby allowing others to see it is something beyond the imaginings of a 'fanciful' mother who is unable to accept her son's level of impairment.
7. Elsie has refused to accept any 'label' to describe her son and thereby has contributed to his strong sense of self – in other words, his identity is not totalised by impairment.

In contrast to this, Owen and his parents are isolated, having few contacts in their local community. A major barrier to the development of Owen's confidence lies in the fact that his father refuses to acknowledge his communication instead insisting on teaching Owen to speak. In spite of years of trying, Owen is unable to use speech and consequently feels that he fails miserably in his daily task. Both Owen's parents feel anxious about the way in which his behaviour is perceived and tend to stay at home with him or only go out to 'safe', tried and tested venues. As a result, Owen gets very anxious when he goes out – sometimes now choosing to stay at home. On a recent occasion, having met a new person Owen communicated:

I was a bit worried that she would find me awful and very gratified to find that she was not put off by my autism. It think it will be easier to go there next time now that I know that she is OK with me. I wish everyone was the same, and then my life would be much happier (Owen, London, 2002).

It is difficult to imagine the effect that constantly being rebuffed, misunderstood and/or shunned away from must have on Owen's self confidence. During the course of the research Owen, Helen and I went to the pub together. (Who says doing a PhD is all hard work?) The publican was friendly and, in spite of hesitant looks from some of the other customers, we all quickly picked up that Owen was welcome there and we settled down happily. Having watched the way in which Owen was communicating with the support of his mother, the publican came and sat with us and started chatting with Owen (ignoring both Helen and myself). Afterwards Owen told me that it was the first occasion in his life (he is 21 years old) that he had had an 'ordinary' conversation with a stranger (they

talked about football, their families etc). Even having been there and having talked with Owen at length about his experience, I am unable to fully comprehend the effects of being denied access to such relationships for 21 years other than to glimpse at the fact that it is a particularly cruel – if inevitable – consequence of disabled people being considered as 'other'. The emotional pressures on Owen to 'become normal' are immense, yet his impairments (alongside the internalised oppression demonstrated in his extreme lack of self confidence) mean that he is unlikely ever to satisfy society's demands.

A recent interview at Aberdeen University provides an example of ways in which opportunities for expansion are opened up when normative demands are lifted. Having heard of Owen's interest in studying theology, a lecturer at Aberdeen University invited him to attend an interview at the university to explore possible options. During the course of the interview, bursting with excitement and nerves Owen stood on a revolving chair and twirled around, making loud noises. Unperturbed, the two lecturers sat smiling and waited for him to calm down before carrying on with the interview. On this occasion, in spite of his unconventional behaviour and the fact that he has no formal education, the university has 'gone against the norm' and offered him a place with meeting the required academic standard the only demand being made. In doing this, the lecturers have paved the way for Owen to have an ordinary experience – in spite of the fact that 'out of the ordinary' arrangements have to be made.

Back to Ben

In stark contrast to Owen, in spite of having a support worker with him at all times and attending school on a part time basis, Ben does have friends at school and in the community:

Ben: Good friends? 7 or 8 good friends at school. Nathan, good friend, go swimming. Chris not fazed.

Elsie: Why not fazed?

Ben: Does not bother him.

Elsie: What does not bother him?

Ben: Me. Chris...

Elsie: He's right, Chris does not mind that Ben touches him, sprawls all over him.

(Elsie and Ben, Sheffield, 2001).

Recently, for the first time, Ben has started going out socially with a group of friends from school. On the first occasion Elsie gave them a lift to a bowling alley, and then went to sit (out of sight) in the bar while the young men had a very ordinary time together. Elsie's anxieties were challenged by the young men who did not feel the need to call on her support – effectively making her redundant (an ordinary parental experience).

Having looked at the contrast in experience between Ben and Owen, it is interesting to consider the difference in experience between Ben and James. Although they have both had a similar mainstream educational experience, while Ben has a strong network of friends, James remains isolated, and therefore vulnerable, outside of his immediate family.

Why the difference of experience this time?

The fact that both Ben and James have been in mainstream school suggests that they might have had a similar opportunity to develop friendships with people of their own age. Yet their position in the community is markedly different – whereas Ben has friends of all ages and a strong community presence, James is known by many but has few solid relationships outside his family and education support workers. A likely explanation for this difference in experience lies within the perceptions others have of their impairments. Whilst both young men are described as having communication impairments, Ben has been able to 'prove' his intelligence and, although he does not communicate in a conventional way, with support is able to join in 'ordinary' conversations. Although James uses a wide range of communicative methods, including speech, he is less able to conform to conventional codes of behaviour (including engaging with conversations going on around him) and whilst obviously 'intelligent', is unable (due to his impairment) to prove his intellectual competence.

Joining in the conversation

The experience of Sally, a young woman with a visual impairment, provides an understanding of the ways in which being able to join in general conversations affects the building of friendships. Sally has been at mainstream school all her life and has many friends and an active social life. In spite of this, she finds that there are occasions during the school day when she is excluded in subtle ways. Sally told of the time when all her friends had been reading and talking about

Harry Potter in the playground. Unable to read the book, as it was not in large print, Sally was excluded from all such conversations and therefore was left out of the general excitement. By the time Sally had got hold of a large print copy several months later, Harry Potter was no longer *the* topic of conversation. Although her experience is different to that of James in as much as the solution to her exclusion in this instance is easy to identify and put in place, it nevertheless makes visible the extent to which not being able to 'join in' conversations has on friendships.

For children and young people with a communication impairment, this is a (generally unrecognised) barrier they constantly face within their relationships. There is no doubt that a relationship with someone who is unable to access speech or language is very different to the majority of relationships within which we take language and/or speech for granted. Such a difference does not necessarily mean, as is generally assumed, that the relationship is worth less. The majority of family members participating were both comfortable and confident with the different ways in which their disabled child/brother/sister communicated their needs and their preferences. In these instances, whatever communication was present and worked was accepted as the norm. Outside the immediate family, however, different methods of communication are less easily tolerated and frequently seen as a problem simply because they deviate from the norm.

Back to difference in experience

The differences of experience between James, Owen, Andrew and Ben indicate that an ability to conform to the social norm eases the way into valued relationships and social acceptance. All four young men find it extremely difficult, due to the effects of impairment, to adhere to conventional codes of behaviour. The discovery of a method of communication allowing Owen and Ben to express themselves through language and to prove a keen intelligence provides a window of opportunity holding the possibility of social acceptance. James and Andrew on the other hand have not been able to prove their intelligence in this way and consequently have less tangible attributes with which to convince others that they are valuable members of their communities. For example, James can display great sensitivity and care through his ability to 'read' other people's emotions, whilst Andrew's apparent deep acceptance of himself allows others to feel very much at ease in his company. Such qualities generally go unnoticed in a culture that refuses to see beyond the surface. Until difference can be seen to be 'the norm' (Williams, 1997) it is unlikely that young disabled people with learning difficulties and communication impairments will be truly valued beyond close family and friends. In addition to this, we can see through their experience, how even close family relationships are put at risk by the pressure to conform to the norm.

Even further on the margins

Whilst James, Andrew, Owen and Ben are excluded from the centre of the mainstream, they are at least visible in the margins. Walking to the local shops

with James can take some time as he stops to chat to the many people who know him; Owen's local health food store was delighted to hear that he had a place at Aberdeen University; Andrew is a well-known figure at his local station, and Ben's community take great pride in his achievements. The experience of Louise (who sadly died during the course of the project) and Leanne was markedly different. In many ways the large, close family network enjoyed by Louise ensured that she and her family, whilst not being visibly present in the community, had an experience of belonging. The pride of her extended family ensured that the wider community was aware of her existence – helping to provide a protective cushion of sorts against poor service provision. Leanne, on the other hand, who does not have the same large extended family has no such protective cushion and is thrown into a greater emotional dependence on her mother and two sisters.

The lack of attention given to the emotional well being of disabled children/young people outside the family environment, inevitably affects their time within the family and their family relationships. It can make families reluctant to use services, just as it can give young disabled people an unhappy experience in services provided. Both these factors impact on the family as a whole. The following section explores the effect the social exclusion of a disabled child has on parents and siblings.

The effect on the family

The invisibility of the barriers to building positive relationships running alongside the general lack of recognition of the relationship needs of young disabled people within the entire range of service provision (education, social, health and leisure services) has an effect on the entire family. For example, young children start bringing friends home from school at an early age – this means that while adults need to be present, children play on their own freeing adults to carry out necessary domestic tasks. Such friendships frequently lead to mutual childcare 'swaps' allowing parents to work, go out and/or have time alone in the house etc. These informal networks – rooted in friendships made by children - are invaluable for both children and adults in that they provide an ease of access to relationships in the wider community. Such friendships naturally help children to loosen their dependency within the family. Disabled children and their families generally have a different experience because of both the effects of impairment and disablement. Whilst impairment might mean that young people are physically dependent on their parents for longer than usual, the lack of friends means that young disabled people are emotionally dependent on their parents when other young people are experimenting with relationships and developing bonds outside the family. This is particularly marked when the young person is chronically ill and/or uses a specialised form of communication or depends on someone who knows them very well to 'read' their communication. For example, the fact that James has no friends to invite to his house means that he requires more adult attention at home and wants to play with his sister and her friends. Understandably, and in typical sisterly fashion, Elizabeth is not always

happy to share her friends in this way. Having no friends, means that James is always at home unless his mother makes 'special arrangements'.

Photographs of Leanne's life bear testimony to the fact that her ill health is taking its toll on her body. A major fear for her family is that she will have an early death. This (largely unspoken) fear greatly impacts on the services the family is prepared to engage with. In addition to this, Leanne's ill health and the fact that being in a wheelchair for any length of time is extremely uncomfortable for her, means that it is difficult for her to be 'out and about' in the same way as Owen, Ben or James. In addition to the practical consequences of Leanne's impairment, the experience of 'living with the threat of death' casts a shadow over the family that professionals have been largely unwilling to engage with. The silence surrounding their emotional reality further isolates Leanne and her family.

Brothers and sisters

For siblings, the social isolation of their disabled brother/sister can produce conflicting emotions as they frequently see someone they are close to being ostracised from their school and community. A recurring theme from the small number of siblings involved in this project was the way in which, although their closest friends might grow used to their disabled brother/sister they felt that none of their friends really understood either the love they had for their brother/sister or the practical difficulties they faced.

...but some of my friends, they are like, why can't you come out and I explain to them how much hassle it is getting out of the house but...(Alison, Gloucester, 2000).

This gap between siblings and their friends meant that they had no one outside the family who they felt could really understand their experience. Chloe and Alison told how, during their teenage years when they were becoming aware of the hostility surrounding impairment, they would get into strong arguments at school when they heard others talking about disabled people in a derogatory way. Although Alison told how she was pleasantly surprised at the way in which her close friends supported her in such conversations, Chloe had the experience of her friends staying very quiet. This led to feelings of 'not being understood' (Chloe, Gloucester, 2000). Chloe also told how teachers would treat her differently when they discovered she had a disabled brother with one teacher effectively offering her counselling based on the assumption that she 'had problems at home'. Whilst this did not necessarily impinge on Chloe's relationships with her friends, it did make her feel that no one outside her family understood her close bond with her brother.

On occasion, the fact of being the brother/sister of a disabled child led to stigmatisation – both Jonny and Katherine spoke about their younger sisters being bullied simply because they were their sisters. The mixture of the effects of impairment and disablement meant that it was difficult for Alison's mother to carry out the ordinary teenage parenting task of ferrying Alison to and from her friends for evenings out, as Leanne could not be left on her own, her mother did not want her going into 'respite provision', and it was uncomfortable for her to be

moved from sofa, to chair, to car seat. This meant that there were occasions that Alison missed out on nights out with her friends.

Parents

Just as non/disabled brothers and sisters attending the same school reported stigmatising treatment, so too did parents feel that they were treated differently from parents of non-disabled children. This was especially marked when parents had both a non-disabled and disabled child in the same school. Linda talked of her experience of the early years with James and Elizabeth – whilst Elizabeth was seen as a pleasure to have in class, James had been seen as a problem. Whenever she went into school to collect James, she had to steel herself for negative comments and complaints, whereas picking Katherine up from her classroom meant having chats with other mothers and young children – she was fully part of the school network.

The fact that disabled children are not part of a social network most non-disabled children/young people take for granted, means that the usual parenting patterns are changed. For example, children not being invited out to tea, teenagers not going out, mean that there are fewer opportunities for developing natural childcare networks. For Helen whose only child, Owen, had always attended special schools, it meant that she did not have the opportunity to meet other families at the school gates and develop her social networks in this way. This lack of community networks so easily taken for granted, means that it is more difficult to go out socially or go to work. For parents with more than one

child, it can make it difficult to undertake parental responsibilities with their other children which involve them going out (such as going to events at school in the evening, being the 'taxi driver' etc).

The effect of struggling for the right to be present

Parents choosing to negotiate a presence in the mainstream (whether in education or the wider community) for their son/daughter had to spend much time and effort to a) secure a place and b) to ensure its continuation. This inevitably affected their family life.

Over the past two years, Andrew's mother Marjorie has given up her job and her life has been dominated by preparing evidence for appeal tribunal in order to secure a mainstream education for her son. During that time, she has watched her son's contacts in the community – made through his presence at a mainstream school through his infant and junior years – diminish to the point of having no friends. Although Marjorie has maintained a good support network around herself during this period, she has nevertheless felt very much on her own and has had her emotional strength tested to the limit. Over this time, Marjorie has not wanted to ask for 'respite care' as, having once needed emergency respite she is fearful that a second request will be perceived as an 'inability to cope' and mean that she will be seen to be failing to fulfil her parenting responsibilities. During this period, Andrew has both spent some time at home being 'home educated' and some time at a segregated school. Both these options have had an impact on Marjorie's life. During the period that Andrew was being home educated, Marjorie co-ordinated his 'programme' and

arranged for volunteers to come in and spend time with Andrew or take him out. Over the period that Andrew was at segregated school, Marjorie took him across the borough to and from school every day as she did not want him to spend long periods of time on the transport provided. At the same time, her relationship with the school was delicate as she was seen to be 'confrontational' in that she wanted something else for her son. The emotional cost of this time was great for Marjorie and meant that she had to stop work and give herself to the full time job of trying to secure an education for her son. It is worth bearing in mind that Marjorie had already fought to get Andrew into a mainstream infant/junior school and faces more such struggles in the future. As with all the parents involved, the subject of 'what is going to happen after school' loomed large for Marjorie.

Ben's mother Elsie has similarly given up her career in order that she had the time to a) look after her son when he was young and b) fight for a mainstream education and b) be able to be at home for Ben when the LEA agreed to part-time mainstream education. Elsie, a trained nursery nurse, presently works one day a week at MacDonald's in order to bring in a 'bit of extra money' and to keep 'outside contacts'. Whilst the experience of spending the early years of child rearing at home is common to many mothers, Elsie has been unable to return to work due to the difficulties of both accessing and maintaining an education that both she and her son are happy with. Had she not taken the decision to fight for her son in this way, it is likely that he would be in a school for young people perceived as having severe learning difficulties and communication impairments with a future of a day centre place and eventual residential care. Instead, Ben

has plans to go to university. Whilst his mother has no regrets about the decisions she has taken to give up her career and do all she can to enable Ben to be present in the mainstream, her own life has been greatly affected, and made extraordinary, by the fact of both her son's impairments and a disabling world which does not automatically welcome her son or give him the same opportunities that non-disabled young people can take for granted.

Whilst James' and Leanne's' mother have continued working, they too have made compromises. Jean, a trained optician, has never picked up her career but instead has found work in school administration which allows her to fit in with her daughter's daily timetable and be at home during school holidays. James's mother too, feels fortunate that her work as a college lecturer allows her to have 'time off' during the school holidays. Although she has continued with her career throughout James' school career, she has worked part-time to ease the stress on the family and spends much of her salary paying for child-minders and support workers.

Louise's mother chose to give up her career in order to stay at home with her daughter who was very ill and had a poor prognosis. Whilst her position was extreme, this decision is in keeping with 'ordinary' parenting whereby parents are expected (and generally want to) look after their children when they are ill. The experience of Louise and her family throw into sharp focus issues of both housing, support in the home and the ability to earn 'good money'.

All the parents involved in the project had many relationships with professionals. Although on occasions, there was mention of a supportive relationship, on the whole parents spoke of professionals as adding stress to their lives in that they always seemed to be arguing with them and seldom managed to secure the services they felt were right for their disabled son/daughter. The next sections goes on therefore, to look at the relationship parents had with professionals.

Parents and professionals

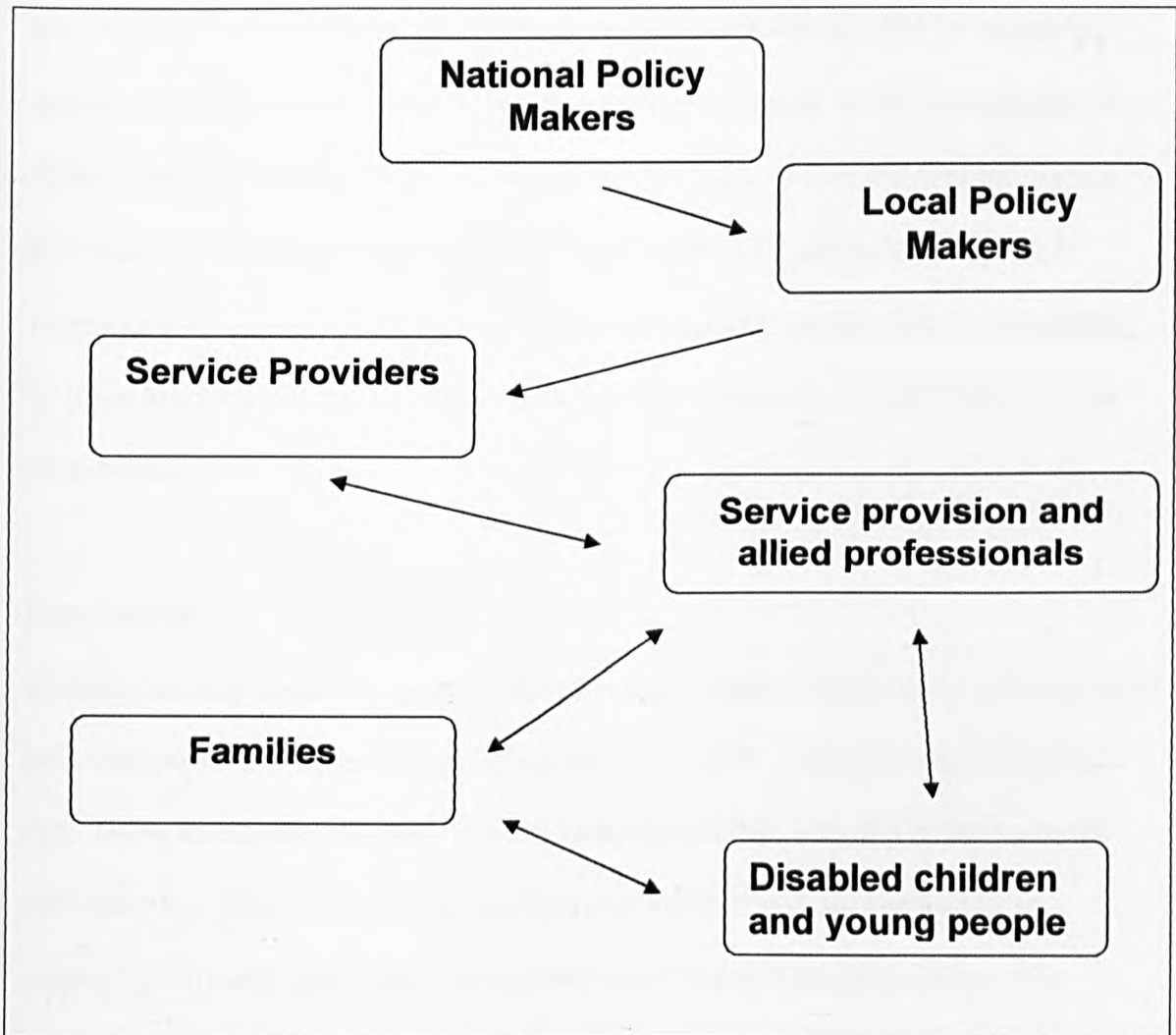
During the course of the project, whilst parents talked at length about their relationships with professionals being characterised by struggle, it was common to hear professionals (for example social workers, teachers, youth workers, and support workers) talk of the 'problem' of parents. What was generally meant by this was that parents were perceived as being over-protective, unwilling to 'let go' of their disabled son/daughter without outside factors such as lack of support allowing for ordinariness in the lives of parents being taken into account. For example, in order for Helen to feel able that 'she can let Owen go' she has to know that support workers can:

- a) facilitate and understand Owen's communication;
- b) be sensitive and responsive to Owen's changing emotions;
- c) be able to keep Owen safe when out;
- d) enjoy being with Owen, and know that Owen enjoys being with him/her;
- e) successfully negotiate their way through meetings with other people so that both Owen and others learn that it is fun to be in relationship.

For Helen to begin to 'let go', such issues need to be acknowledged rather than ignored; her expert knowledge of her son needs to be taken into account when planning for services, and support packages that both she and Owen feel comfortable with put in place. Instead, Helen has the recent experience of professionals ignoring the wishes of her son and once again having to 'battle for resources' not necessarily of their choosing.

The common experience of parent participants exerting time and energy in negotiating unsatisfactory care and/or education support packages, in the context of a culture claiming to promote 'partnership' between parents and professionals, meant that it took parents some time to understand their relationship with professionals. Underlying the conflict between parents and professionals over access to service provision, are different attitudes towards the young disabled person. Even when individual professionals valued the disabled child/young person just as they were, the service provision they acted as gatekeepers to typically reflect the view that disabled children/young people are inherently deficit. Whilst the parents involved in this research were all looking for services that valued their sons/daughters, professionals could offer little support as they were institutionally allied to services supporting the status quo. Neither the professionals in frequent contact with families, nor the families had significant access to service providers or policy makers.

Figure 2: Making connections



As the above diagram of relationships between participating families and services illustrates it is clear that even where the connections between disabled young people, their families and service provision in both the statutory and the voluntary sector were strong (even if full of struggle), the only links between disabled teenagers, their families and policy makers and service providers were via service provision. In this way, parents had few opportunities to directly communicate with 'the people at the top' who control the nature of service provision. In light of Alison's statement that people do not understand the

issues because they are not in close relationship with a disabled person, this gap in relationship and communication provides a starting point for engaging with strategies to move towards service provision based on an acceptance of difference as the norm. Placing mutually enjoyable, respectful relationship at the heart of service provision creates opportunities for radical change as it presents a fundamental challenge to the widespread belief that to be disabled, to have learning difficulties and communication impairment is somehow to be 'sub-human'.

Conclusion

Present service provision, even with the move towards mainstream schools and services within the community (Education Act, 2001; Disability Discrimination Act, 1995) does little to challenge the assumption that young disabled people with learning difficulties and communication impairment are incapable of engaging in meaningful relationship and contributing towards society. The experience of families however, indicates that relationship is a powerful way of combating the strongly held cultural beliefs that disabled young people with learning difficulties and communication impairment are incapable of forming mutually beneficial relationships. In addition to this, a prevailing anxiety about people whose communication, development and behaviour deviates from the 'acceptable norm', makes non-disabled people very reluctant to enter into an equal relationship with disabled people perceived as having learning difficulties. Whilst families have such an opportunity, their enforced isolation and lack of power within the system, means that they have limited opportunities to influence

the development of service provision. In order to create possibilities for radical change, the following chapter outlines a starting point for the development of services supporting and enabling young disabled people with learning difficulties to be valued as they are.

Chapter Nine

Service Provision

Do you do what you say or do you make empty promises and run away as soon as things get difficult? (Etherington, cited in O'Brien and O'Brien, 1994, p. 209)

Introduction

A major source of frustration for participants was the fact that service provision purporting to support disabled children/young people and their families failed to live up to the rhetoric of policy (for example the Quality Protects Initiative) or legislation (for example, the Disability Discrimination Act, 1995; Valuing People, 2001). In many cases the gap between the promises of inclusion, rights, participation, and choice for disabled young people; consultation and partnership for their parents; and the daily experience of exclusion, resulted in a lack of trust and a sense of dissatisfaction between families and service providers (Goodey, 1991; Murray and Penman, 1996; 2000). A comparison between the language of legislation – 'Rights, Independence, Choice and Inclusion' (Valuing People, 2001, p. 3) - and the words of a young man perceived as having learning difficulties bears testimony to the chasm existing between the rhetoric and daily experience:

I want to say that I am very badly impaired and that I am not able to live without a great deal of support. ...I am aware that I am a curiosity for many people who will not have seen someone as weird as me, but I believe that we should be given the same opportunities as others. ...I also think it is important that people realise that disabled people have something to contribute to their community, and it is high time that their abilities are appreciated for what they are. We wearily allow ourselves to be herded into institutions by people who have no idea of our misery, and how lucky they are not to be handicapped (Personal correspondence from a participant, July 2002).

The institutions referred to here are segregated schools and day centres, the misery is that of social exclusion and, perhaps most painful to hear is the experience of living with the constant experience of 'being a curiosity' for others whilst having an internal sense of 'being weird'. Such heartfelt words evidence the immensity of the distance to be travelled in order that the experience of disabled children and young people meets the fine rhetoric of legislation and policy.

Parents, too, experience a gap between the services they are told are on offer (moving from residential respite care to 'community based inclusion') and the experience of having little/no support in the community. For example, Sue contacted her local social services prior to the summer holidays to find out what support they could offer her sixteen year old daughter who has complex impairments and high support needs. In addition to the one night a week care that Mary has at a respite care centre, Sue was told that her daughter could have a place at a 'play centre' for three days over the entire summer holidays. As Sue works part-time (nights, in order to look after Mary in the daytime), and as Mary requires twenty-four hour supervision, this support offered over a six-week period does not reflect an experience of 'community based inclusion'. In addition to this, the experience does not look promising for Mary as three days, spread throughout the entire holiday period, does not allow for her to be supported by someone who has time to get to know her idiosyncratic (and charming) communication. The lack of care going into such provision leaves Sue feeling alone, frustrated, and cynical about services offering 'inclusion'.

The frustration and cynicism generated by the gap also affects professionals working directly with disabled children and young people (O'Brien, 2002). A frequent theme to emerge from a wide range of professionals during the course of this project was that they did not have the time, resources, or support to work in the ways in which they would like to work. In many cases it was evident that professionals were not valued by the organisations they worked for - indeed a senior manager within social services said she often felt isolated and powerless at high level policy meetings because no-one wanted to hear about, far less prioritise, 'disability services' (Sheila, Sheffield, 2002). Such a finding is consistent with Goffman's (1990) argument that when a group of people are devalued to the extent of disabled people with learning difficulties, then those in close contact are inevitably 'tainted' by the same stigma.

Confusion between the rhetoric of inclusion and exclusionary practice can be seen in services that purport to be rights based but are in fact needs led (Morris, 1998 (a); Oliver and Sapey, 1983; Ramcharan et al, 1997;), and in projects claiming practice running along the lines of the social model of disability whilst encouraging the attainment of normative goals and expectations (Stalker et al, 1999). There is, therefore, an articulation of fashionable ideas such as inclusion, empowerment, and participation without a subsequent shift in understanding the full implications for services seeking to reflect such values (Rioux, 1994; Young and Quibell, 2000).

My aim in this chapter is then, to explore these gaps by looking at some of the key concepts lying behind legislation and policy initiatives – concepts such as human rights, citizenship, inclusion, participation and autonomy - and, with these concepts in mind, to look at the experience participants have of service provision. In keeping with the theme of relationship running through the thesis, the main thrust of the chapter lies in the argument that it is only within respectful relationship that such concepts can become meaningful in the lives of young disabled people and their families. The starting point for this exploration lies in exploring the concept of 'human rights' and what 'translation into practice' (bridging the gap) might look like, as it is the rhetoric of the United Nations Convention on the Rights of the Child (1988) that underlies present legislation and policy.

Human rights or rights for humanity?

Current legislation and policy initiatives of relevance to disabled children and their families are underpinned by International Human Rights Conventions. For example, the Children's Act (1989) promotes the human rights highlighted in the United Nations Convention on the Rights of the Child (1988), whilst Valuing People (2001) aims to pave the way to the fulfilment of the obligations enshrined in the Human Rights Act (1998). Following on from the Universal Declaration of Human Rights in 1948, the Convention on the Rights of the Child states that human rights are not owned by a few to be given to others as they lie within the individual. Elaborating this point Fitzgerald (1994) identifies our essential humanity as an intrinsic dignity lying within, similar to 'a spark of light within each person', which unprotected is in danger of being extinguished. This is

similar to the argument put forward by Raymond Williams (1967) when he argues that equality of worth (see Chapter 2) is something lying within that has to be uncovered, nurtured and 'allowed to flower'.

During the course of this project it has been commonplace to hear families refer to a 'spark' within their disabled son or daughter, their brother or sister. It is the presence of this spark that signals relationships of mutual respect, signifying recognition of a 'dignity within':

Leanne will be in a situation sometimes where she's not herself, she loses her spark...(Jean, Gloucester, 2001)

To the families involved these sparks can, in a very simple way, be indicators as to whether their disabled family member is being valued; of whether they are being treated as a human being or as a member of some kind of sub-species. Having given value to an individual, the spark signifies moments of meaning and significance, moments of being alive. In respect of the young people engaged in this project 'finding the spark' was the key to ensuring that they were being treated with dignity, and, in the rhetoric of policy and legislation, that their 'human rights' were being acknowledged and met. Whilst the rhetoric of human rights - generally understood as the right we all have to life and inherent dignity - abounds in legislation, policy papers and service manifestos, the overwhelming experience of participants was that service provision rarely looked to protect and/or nurture the spark within.

A recent research project exploring evidence of the social model of disability within day and residential services for adults with learning difficulties who do not use language based communication, found that good practice was dependent on the nature of the relationship between the disabled person and their support worker. Within relationships where the disabled person was respected for who they were a positive and mutually enjoyable relationship was allowed to emerge:

Danny and Gary are facing each other in the water. They hold each others faces between their hands. They are both smiling. Danny moves his hands to Gary's shoulders and starts to bounce up and down. Gary does the same – bouncing in time to Danny with his hands on Danny's shoulders. Danny throws back his head and laughs. (Coles, 2001, p. 508)

In this instance Danny is given a safe space' (within relationship) where he can ' be himself. Significantly, Gary (Danny's support worker) tells how it is extremely difficult for this to happen within the confines of the day centre as he feels under pressure to insist on Danny conforming to the norms of behaviour and of maintaining a traditional professional/client relationship that does not prioritise having fun together. In contrast to this, young disabled people and their families are more likely to prioritise 'having fun' as the basis for any successful service provision arguing that it is only when this is in place that learning within education, for example, or community involvement in leisure settings can begin (Todd and Higgins, 1998; Murray, 2002; Heslop, Mallett, Simons and Ward, 2001).

Defining human rights as lying within, with respect being nurtured or denied through relationship, places a spotlight on the nature of the relationships existing within service provision:

'The way people touch me is my way of knowing that they care about me. Some people are gentle and take time, and others hurry with everything. It's the difference between just being a body needing washed or a real person. I can feel their attitude right away in the way they touch me.' (Marquis and Jackson, 2000, p. 416).

Through such an example, it is possible to understand that respecting the 'human rights' of others does not lie outside our power or influence as individuals but rather is something that we can nurture or undermine in all our relationships – personal and/or professional. Viewed in this way, human rights can be encouraged through policies and/or legislation, but can only ever be put into place through respectful relationship (Telesford, 1998; Vernon and Qureshi, 2000; Heenan, 2002). In this sense, service providers have an obligation to recognise and transform the philosophical and structural underpinnings of current service provision (Kemp, 2000) whilst workers have the responsibility of establishing and maintaining respectful relationships with those whom they seek to serve (Marquis and Jackson, 2000; Lovett, 1996). Making a distinction between the different roles and responsibilities of service providers and workers allows for the occasions on which professionals treat a young disabled person respectfully but are constrained by the system within which they operate to become visible. Whilst recognising the limitations of service provision, the young disabled participants and their families welcomed the presence of valued relationships within services they consider inadequate, as such treatment adds

relational richness to their lives (For further examples of this see accounts given by Todd and Higgins, 1998; Carpenter, 1997).

The practical difficulties of resolving tensions between legislation, policy, service provision and the nurturing of the 'spark within' can be seen in the recent debate surrounding manual lifting and handling. Enshrined in the overall context of social inclusion and the Disability Discrimination Act (1995) the tensions surrounding lifting and handling hinge on the safety of staff and the 'quality of life' of disabled people receiving the service (College of Occupational Therapists, 2002). Based on UK legislation (Manual Handling Operations Regulations, 1992) and European Guidelines (Commission Of European Communities, 1989) there has been considerable confusion on the state of play with the result that differences of interpretation have led to wide regional variations of implementation and practice. Such confusion has meant that the interests of disabled people have been dealt with in an 'arbitrary and insensitive way' whilst simultaneously 'inhibiting good professional practice' seeking to enable disabled people to exercise control and autonomy over their lives (College of Occupational Therapists, 2002; Disability Rights Commission, 2002).

Within this project, Louise's care whilst in hospital was detrimentally affected by the unnecessarily rigid application of EC guidelines. Identified as a 'three man lift', she was unable to be bathed because there was no sling and hoist available to safely or comfortably lift her, nor were there sufficient staffing levels to enable her to have the attention of three nurses for the required period of time. In

contrast to this, when Louise was at home one adult (usually her mother, father or grandmother) lifted her into the bath taking ordinary precautions. Indeed there was no alternative as the bathroom was too small to accommodate more than one adult and would certainly not have accommodated a hoist. There were discussions taking place about the possibility of having a ceiling hoist throughout the bungalow but these were extremely slow moving and in fact, Louise died before they reached any resolution. Similarly, a residential respite care unit reported how local policy instructions on manual handling had adversely affected their practice, as they now have to take hoists with them if they are going out in the mini-bus. Having on one occasion attempted a picnic in this way, they are now less likely to go out as they found that moving children/young people in hoists over slightly bumpy ground placed the young people at risk. In such an instance the power wielded by support workers, however much it is thought to be 'in the best interests of' young disabled people, serves to disempower them. By prioritising special needs in this way, young disabled people are denied choice and stripped of their autonomy. Unable to resist, there is no choice but to comply.

From human rights to civil rights

Having identified ways in which the rhetoric of human rights might meet with the daily experience of disabled children and their families within the complete range of service provision, I now go on to look at the closely associated concept of civil rights arguing that, unlike human rights which have to be nurtured rather than given, these can be granted or denied through our social organisation

(Ramcharan et al, 1997). The fact that gaining access to a mainstream education does not necessarily mean that young disabled people are fully accepted or have the same experience as their non-disabled peers (see the experience of James outlined in the previous chapter) provides a pointer to the intersection of human rights and civil rights. Having gained access to the mainstream through acknowledgement of citizenship, the treatment within reflects the degree to which human rights (previously defined as the nurturing of the 'spark') are understood and respected. The fact that young disabled people within the mainstream report being 'set apart' in gross and subtle ways from their non-disabled peers (Murray, 2002) indicates the lack of attention given to their basic human rights within service settings.

The consequences of differential treatment within a mainstream educational setting are both far-reaching and multi-faceted. As James' experience in the previous chapter demonstrates, the social isolation commonly experienced within school is not only hurtful, but also has a detrimental effect on the opportunities for being in valued social relationships out of school. This lack of respect for human rights then impinges once again on civil rights as the high level of social isolation experienced by young disabled people perceived as having learning difficulties and communication impairments, means that they are placed on the margins of the cultural, educational, and social experiences of their non-disabled peers (Hendey and Pascall, 2002).

Although disabled people are not alone in having rhetoric provide a thin veneer of gloss over the harsh reality of inequality (Phillips, 1997), disabled people with learning difficulties face particular challenges in being viewed as citizens because of the assumption of individual competence underlying notions of citizenship (Young and Quibell, 2000; Rioux, 1994) running alongside the widespread assumption that having learning difficulties means being 'incompetent'. The general reluctance to engage with the reality of physical vulnerability (Frank, 1995) means that there has been little public exploration of what the fulfilment of civil rights of disabled people with cognitive and/or communication impairments might 'look like' (see Chapter 4). In looking at the issue of citizenship and disabled people with learning difficulties, Rioux (1994) argues that present understandings lying behind our ideas of formal equality (everyone being treated alike) and equality of opportunity (enabling access) present formidable barriers to disabled people with learning difficulties being viewed as citizens as they are given the often impossible task of having to conform to the norm (for example gaining employment, moving away from parents, becoming a householder etc).

As the experience of childhood lays the foundation for adulthood, the following section explores ways in which current service provision, in contrast to the rhetoric of legislation and policy, gives disabled children with learning difficulties, amongst other groups of disempowered children/young people, the unmistakable message that 'citizenship', and consequently a civic identity, is not within their grasp.

Building a civic identity

In keeping with the account of Souza (1997), young disabled people identified their educational experience as crucial to their sense of self-worth and to their social standing within the wider community. Likewise, parents struggling to access a mainstream education for their disabled child saw the reluctance or refusal of local education authorities and mainstream schools to accept their child, as 'proof' of their lack of civic status (For accounts of similar struggles see Brandon, 1998; MacKeith, 2000; Clarke, 2000).

For young disabled people who have been separated from the majority through placements in segregated schools, the difficulties in developing a 'civic identity' are even greater:

If you get placed in a mental hospital or a special school, or an Adult Training Centre, if you haven't got the money to be able to move about freely, if you need others to support you in doing the things you want to do and there is nobody there, and if you need help with transport, then you are denied access to anywhere but the environment of the place where you're put. This means that the opportunities for friendships, for real employment and for long-term relationships are severely limited (Souza, 1997, p.4).

An afternoon spent with several young women with learning difficulties and support workers from a project seeking to encourage independence, provided painful evidence of the extreme lack of confidence and self-worth of the young women present. During the entire afternoon, although the young women competently used speech to communicate, they only did so with support workers – choosing not to engage with each other. The passivity extended

beyond the conversation to the activities – the young women only getting involved when encouraged to do so by a support worker. Underlying the passivity of the young women was a deep sense of lack of self-worth, to the extent that it appeared to be extremely difficult for one or two of them to say what they wanted, what their preferences were. At the same time, again in spite of the fact that the young women were extremely capable, the support workers did everything for them in practical terms – preparing the food, washing up etc. thus confirming (albeit unconsciously) the sense the young women had of 'not being competent'. A visit to a different group of teenagers (male and female) taking part in a holiday scheme for young people with learning difficulties provided further evidence of this same deep seated insecurity and lack of self-confidence. In spite of the fact that the support workers rarely stayed longer than 'one season', the young disabled participants were desperate for their approval and friendship – often choosing to relate to the support workers rather than with each other. Within both groups, relationships between the young people were marked by relationships being 'held together' by the support workers rather than existing independently. On occasion, there was evidence that not only were relationships between young people dependent on the presence of support workers, but also the young people (particularly the young women) appeared to gain their self-worth through relationship with support workers rather than recognising their own intrinsic value. Describing the same dynamic as it affects the support relationships of young people with physical impairments, Skar and Tamm (2001), tell how the young people lacked opportunities to control the small decision-making processes shaping their

everyday life. Whilst such decisions may seem small and insignificant, they are a vital means of demonstrating to the young people that they have the ability to make choices and therefore to construct a civic identity.

In the same way that being present within a mainstream school does not automatically give young disabled people the same experience as their non-disabled peers, Bayley (1997) highlights the way in which having employment or gaining householder status does not necessarily lead to a sense of living a fulfilling life as exclusion from relationship leads to an overwhelming sense of 'not belonging'. This experience of 'not belonging' inevitably threatens any sense of 'civic identity' or experience of citizenship for, as Giddens argues:

...Inclusion refers in its broadest sense to citizenship, to the civil and political rights and obligations that all members of society should have...it also refers to opportunities and to involvement in public space (Giddens, 1998, pp. 102-103).

The picture presented then is that of inclusion (being perceived as full participation) leading to citizenship. Highlighting the close relationship between civil rights, human rights and inclusion, the Inclusion Charter (CSIE, 1989) presents the move towards inclusive education as a human rights issue holding the potential to make real the claims of equality and citizenship for all. In the present climate then, it is the movement towards 'inclusive' service provision that offers the possibility of a 'turn around' in the experience of disabled children/young people. However, as the following section demonstrates, there is

a great deal of confusion about the meaning of inclusion and, once again, the daily experience of exclusion belies the rhetoric of inclusion.

What is inclusion?

Over the last few years, when talking with different groups of people (disabled young people, parents, professionals) about the family experience of living with impairment in a disabling world, I have asked them about their own experiences of inclusion/exclusion and how that made them feel. Without exception, all groups have described both experiences in remarkably similar language:

Figure 3: The experience of exclusion and inclusion

Exclusion	Inclusion
Useless, unwanted, depressed, lonely, isolated	Warm, secure, anything is possible
Sad, angry, frustrated	Important, self-worth, loved, respected
Isolated, unhappy, unconfident, unfair	Happy, fulfilled
Hurt, dismayed, confused, betrayed	Valued, needed, loved, safe
Unsure of myself	Able, creative, healthy, alive
Frightened, can't take anything in	Relaxed, involved, warm, comfortable
Different, stressed, afraid, unloved, ridiculed	Safe, calm, hopeful, light hearted
Insecure, low self-esteem, inadequate	Involved, wanted, able to contribute
Embarrassed, anxious, depressed	Valued, strong, confident, human

As the above table shows, while this exercise demonstrates a common understanding about the experiences of inclusion and exclusion it also shows how, in the complexity surrounding issues of providing services, we forget just how simple, ordinary, and human, 'inclusion' actually is. In order to demonstrate

this point, the following section explores the wide variety of understandings of 'inclusive practice'.

Differences of interpretation

The variety of definitions of 'inclusion' serves to demonstrate high levels of confusion surrounding the way in which the concept of inclusion is translated into practice. Whilst young disabled participants talked about belonging within relationship as an essential pre-requisite of 'inclusion', services claiming to be 'inclusive' defined the term somewhat differently as:

- giving disabled young people a choice; or
- disabled young people participating, as a group or individually, in mainstream facilities; or
- offering a service to non-disabled siblings; or
- providing one-to-one support for young disabled people to take part in activities of their choice in the community; or
- providing visits from a segregated setting to the mainstream.

Whilst young disabled participants welcomed such initiatives, they did not necessarily consider them 'inclusive'. Rather, young disabled people pointed to a definition of inclusion as something that takes place when physical accessibility meets with a welcoming attitude. In this sense, inclusion is not confined to one particular place but is seen as a natural process through which all of us go to the places we want to go to, be with the people we want to be with. Such a definition carries within it the potential for the breakdown of all

exclusive barriers – impairment, age, gender, race, ethnicity, class, and religion
– in all situations.

How do we include?

A major tension within services as they presently stand is how to 'include' someone who cannot participate in conventional ways and therefore, conform to the norm. For example, the difficulties experienced by Andrew in his early years at a mainstream school (see previous chapter) arose primarily from the fact that he could not participate in the same ways as the other children in his class. At a basic level, the fact that Andrew is unable to take part in conversations using language is a barrier to his inclusion – on one occasion a teacher questioned Andrew's presence in the mainstream on the basis that, in spite of her best efforts to teach him, 'he never says good morning to me'. The fact that Andrew was unable to participate in lessons in a conventional way provided further 'evidence' that he should not be in the school, that he needed 'stimulation' rather than 'education'. It is hard to see how Andrew will ever be welcomed into the mainstream, other than on the odd occasion when he comes across someone who happens to like him and is prepared to 'champion his cause', whilst participation in the 'doing' sense is viewed as the litmus test for success. Due to his impairment, there are many occasions that Andrew is happy to be present but cannot participate. The following section explores the oppressive results of our present demands for 'participation', arguing that a 'different approach' opens the doors to all.

Participation

Aligning themselves to the view put forward by Triangle (2001) that communication is a 'two way street', the Trent Children's Task force places the onus on professionals to develop better ways of communicating with disabled children and young people 'so as to let them participate in decision making' (Trent Children's Task Force, 2001). Reflecting the perception of participants that the rhetoric of policy seldom meets with experience of the practice, social work practitioners in the region revealed that disabled children are rarely invited to participate in their own reviews, far less being part of any wider decision making process affecting the direction of services (Social Workers Training Session, Sheffield, 2002).

For disabled young people such as Leanne or Andrew (neither of whom are able to communicate through language or intentionally through any physical means such as pointing, signing etc.) it is difficult to see how they can be regarded as participating (and therefore being able to 'give back') in events, social gatherings, public occasions etc. whilst participation is defined as 'taking part' in an activity. For example, whilst Leanne loves to sit in the kitchen whilst her mother is cooking, she cannot take any part in the actual activity. Similarly with Andrew, although he loves to be out in open spaces with other young people, he is unable to follow the rules of a game of football (or even to successfully kick the ball). Whilst both Leanne and Andrew like to be present in the kitchen and on the playing field, neither is able to 'join in'. As the widely accepted definition of participation lies within joining in through 'doing something' rather than the

relationship focus on 'being present', Leanne and Andrew are seldom seen as active participants.

As Souza (1997) describes in her description of her educational experience, the most accepted way of getting round this perceived problem is to 'pretend' that someone is participating by an adult doing the work for them. For example, Andrew would, on occasion come home with a painting, with his name on it, that his mother knew could not possibly be his own work. Such pretence demonstrates a deep-seated reluctance to face the consequences of impairment and is bound to have serious consequences for young disabled people as it provides a constant reinforcement of the message that 'they are not good enough' (French, 1997).

A change of focus however, allows for a different approach. For example, if participation is placed within the realms of relationship as a positive interaction between people, a door is opened allowing for disabled people presently perceived as being 'unable to participate' to have their presence both acknowledged and valued. A practical example of the gains to be made by such a definition is seen in Jordan and Goodey's (1996) report of the benefits to all children in the London Borough of Newham when the education authority adopted an inclusive education policy. In adapting to changes within the classroom to accommodate disabled children alongside their non-disabled peers, the educational achievements of all children improved whilst there was also evidence of a greater than usual tolerance towards difference from pupils. On an individual level, Joe Jenkinson (1996) describes how his younger

brother's presence means that his classmates are 'one friend better off all day, every day'.

An advantage to be gained by all in this wider definition of participation lies in the fact that the positive or negative influence we exert on each other through relationship is made visible (for further discussion on the impact this has on our families, communities and wider society see Zohar and Marshall, 1994).

Frequent in accounts from families are the benefits brought to the quality of relationship within the family, through the presence of a disabled child/young person with learning difficulties and communication impairments (Sheffield Star, 2002; Murray and Penman, 1996; 2002; Circles Video, 2001). Such benefits include 'bringing the family closer together' (Morris, 2001) , 'making us look out for each other more' (Alison, Gloucester, 2001) 'teaching me about humility' (Whinnett, 2000) and 'learning how to listen' (Lovett, 1998). The effect of these benefits, so often reported by those in close relationship with people perceived as having 'severe' cognitive impairments, permeating upwards through the layers of society can surely be defined as positive participation that serves to enhance our individual and collective lives. In this sense participation can be seen to be a dynamic, creative energy emerging from valued, mutually enhancing relationship. As Souza (1997) describes, it is within relationship and through friendship that we participate in each others lives, that we influence and support each other. Whilst such participation often takes the form of 'doing something' it always demands our presence and through our very presence we inevitably influence the dynamics of relationship.

Throwing out the baby with the bath water

In putting forward an argument for the widening of our understanding of participation, I do not argue that our conventional understanding is useless and/or undesirable. There are clearly occasions when it is appropriate (and even radical) to aim for participation in the usual sense of 'taking part in'. For example, having been denied access to a mainstream education, in applying to go to university Owen is asking to be able to participate in a degree course with no exceptions being made for the standard of academic work. It is important to Owen, who has such a low level of self-esteem as the result of 21 years of having his identity totalised by impairment, to be given the opportunity to prove he has the ability to participate on the same basis as the other students on the course. Accepting all forms of participation as valid, valuable and essential to the whole, is only possible when individuals are valued just as they are. From this starting point, participation in a wide variety of forms is acknowledged, valued and welcomed.

Recent television coverage of a Commonwealth Games award ceremony (BBC, 30th July, 2002) provided a delightful cameo recognising the value and necessity of different people in different roles (athletes, volunteers, local dignitaries, officials, spectators etc) all of whom were needed to make the event a success. As the athletes stepped onto the podium, young people - disabled (some with learning difficulties) and non-disabled - stepped forward holding a cushion on which the medal was placed whilst the person presenting the prize gave the medal to the winners. From the smiles on the faces, it appeared that everyone

was happy and proud, at that particular moment in time, to be in their ascribed roles.

Having outlined a definition of participation allowing for different contributions to be recognised, acknowledged and valued, and having argued that such an understanding is needed as a baseline for 'inclusive provision', I now go on to look at associated areas of autonomy and choice.

Autonomy and choice

It was the common experience of being asked but not listened to that led one of the young participants to define meaningful consultation as 'asking, listening and acting' (Ben, Sheffield, 2002). In order to offer services that reflect the common understanding of inclusion (see table on page 224), the process of asking, listening and acting has to be ongoing, with a concentration on evaluating outcomes based on the quality and nature of relationships in the lives of disabled people with learning difficulties. Such outcomes, described by Rioux (1994) and Bach (1994) as 'social well-being', focus any evaluation firmly in the experience of the disabled person with learning difficulties. In this way, the process takes on a spiral movement upwards, giving the experience of being valued citizens central to the process of change, instead of the present experience of going round in circles – changing the name of the game without enabling radical practice change (Roulstone, 2000). The purpose of this section of the thesis is to explore the challenging question of how the autonomy of disabled children and young people can be respected in service provision. The manager of a residential respite care centre articulated a difficulty faced by

many professionals in transforming the rhetoric of 'autonomy and choice' into a meaningful experience for young disabled people they work with:

We try hard to give the young people choice but the fact is that some of them would not choose to be here, they are only here because their families need the break, need to sleep or whatever. One of the young people coming here has to be persuaded out of the transport van every time he comes. He cries and screams and doesn't want to be here, but we have to have him. We do our best to make him happy, to give him a good time. He settles down, but we know that really he would rather be at home. (Joanna, Sheffield, 2002).

In this instance, the fact that the young man has no other options but to go to the unit clearly leaves him having been denied choice. Such inflexibility, lack of control and little choice, or as Wareing and Newell (2002) say, 'the choice between no choice', results from service delivery driven by cost efficiency and service accountability (Pearson, 2000; Kemp, 2002) rather than being allowed to evolve through a process of 'asking, listening and acting'. Similarly, parents describe how the choices they have to make about services for their disabled child, frequently lie 'between a rock and a hard place' (McDonnell, 2000).

The experience Owen had on leaving school serves to demonstrate the interplay between choice and autonomy. Having spent his entire education within segregated schools, it was assumed that the natural 'follow on' would be the local day centre. During the period of assessment, Owen clearly stated to professionals that he wanted to further his education within the mainstream. His wishes were completely ignored (indeed when his mother rang up to find out why they had not been included his method of communication was questioned)

and he was given a place at the local day centre. At this point, Owen and his mother decided that whereas getting what he really wanted might be 'too much to ask for' there was a choice to be made between going to the day centre and staying at home. As Owen wanted to 'get out of the house', he decided to accept a day centre place but wanted to find one he was happy with, rather than taking the first one on offer. Having found such a day centre, the family then had to fight for the local authority to agree to funding. This was a protracted process that, although eventually successful, has served to make Owen and his parents very anxious about his presence there and reluctant to explore alternatives in case the hard fought for provision is taken away. In spite of the fact that Owen is happy there, he remains isolated and fearful for his future. The majority of people at the day centre go for about 10 years (early 30s) and then go into a variety of residential establishments when their parents can no longer 'manage at home'. Through this experience, it becomes clear that although Owen has technically 'chosen' his day centre, he has had to forego what he would really like due to the lack of alternatives. Whilst this has an effect on the way in which he spends his time, it has also had an effect on his self-confidence, thus making it more difficult for him to exercise choice. Mosley (1994) makes a connection between self-advocacy and self-esteem, arguing that the two are interlinked to the extent that one is not possible without the other with the result that every act of disempowerment (lack of regard for autonomy) makes it harder for individuals to say what they would like. In this way, Owen has been given the opportunity to make a choice but, because that choice is presented within limited boundaries, he is unable to exercise personal

autonomy. In exploring aspects of personal autonomy, it is important to point out that exercising personal autonomy does not always mean 'getting what we want' – rather it means that our requests/opinions are acknowledged, taken seriously and responded to respectfully.

Concentrating on the detail of people's lives in this way, it is evident that it is the daily experience that either belies or gives weight to the claims of the rhetoric. Whilst it is impossible for workers within services to 'change the system', it is within their power (and is arguably their duty (Tronto, 1993)) to build respectful relationships through which disabled people with learning difficulties and their families have the experience of being valued (leading to empowerment) rather than being treated disrespectfully (colluding with institutionalised disempowerment). For example, during a four hour visit to the 'home quarters' of a residential school, the staff frequently spoke in negative terms about the young people in their presence, made numerous comments about how long they 'had to go' on shift and how much they were looking forward to 'getting out of this place'. At the same time, creating opportunities for giving the young people choice, a great deal of effort was put into finding out what the young people wanted for tea, whether they wanted a drink or not. The resulting 'mixed messages' for the young people provide a 'living' example of the gap between the rhetoric of choice, autonomy and disrespectful practice.

The difference practice makes

Andrew's experience of a change in support worker (from one who was extremely negative about him and questioned whether he should be at the school, to one who enjoyed his company and never doubted that he should be anywhere else) at mainstream school provides an example of the difference respectful practice can make on an individual level. In this instance, although nothing else changed (and indeed the placement remained problematic) Andrew's experience was 'turned around' because his new support worker enjoyed being with him and was happy to 'let him be as he was', on occasion taking criticism from other members of staff for doing so. The process of the way in which we influence each other through our actions (in demonstration of the interdependent nature of the human experience) became evident as the positive attitudes of the new support worker allowed some teaching staff to show their positivity and in his final year at the school, Andrew only took part in classes in which he and his support worker were welcomed. This 'solution', although by no means ideal, meant that Andrew's social well-being within the school was restored and the messages sent out to teachers and pupils alike was that his presence was 'OK'. Such examples provide much needed inspiration that, whilst it is a huge task to change systems entrenched in deep seated cultural beliefs such as those outlined in this thesis, it is possible for respectful relationship to take place within such oppressive systems (for *glimpses* of positive relationships within the oppressive and unwieldy regime of the old 'mental handicap hospitals' see Oswin, 1984) so challenging the belief of the status quo that disabled people with learning difficulties are 'not quite human'.

In arguing for change to come from within services through respectful relationship I put forward an argument encompassing a moral and ethical standpoint in addition to the social and political:

As a type of activity, care requires a moral disposition and a type of moral conduct. We can express some of these qualities in the form of a universal moral principle, such as: one should care for those around one or in one's society. Nevertheless, in order for these qualities to become a part of moral conduct, people must engage in both private and public practices that teach them, and reinforce their senses of, these moral concerns. In order to be created and sustained, then, an ethic of care relies upon a political commitment to value care and to reshape institutions to reflect that changed value (Tronto, 1993 p. 179).

Recognising care as a central concern of human life and consequently placing it within a political context, necessarily questions the structure of societal values. It is only with this in place that the central argument in this thesis will be given fertile ground on which to grow. Whilst there is undoubtedly a need for structural change, such change has to be placed within an ethical context of integrity of practice (Stalker, 2003; Lloyd, 2003). The importance of taking an ethical position on an individual as well as a collective level lies in the question of the potential abuse of power (Brechin, Barton and Stein, 2003). An important aspect of looking at services for disabled people with learning difficulties and communication impairments is the acknowledgement that within services, as in individual relationships, people with learning difficulties are vulnerable to an abuse of power (O'Brien and O'Brien, 1997). Whilst legislation and policy has a part to play in setting boundaries, abuse of power is not something that can be entirely avoided through legislation, but rather depends on each of us taking a

committed personal responsibility to working in a way that allows for disabled children/young people and their families to live with dignity (Tregaskis, 2004).

The gap between policy and practice calls on all of us then, in whatever role we happen to be in, to question the moral and ethical basis of our own practice. In this sense we are all implicated in the process of change – each of us carrying the potential to ‘make a difference’ to the ‘bigger picture’. With this in mind I embark on the final section of this chapter, exploring some of the demands ethical practice places on us both as individuals and as a collective.

Putting the words into action

It is one thing to talk about ideas for change on paper, it is quite another to translate those ideas into strategies that services can begin to work with. During the course of extensive networking over the last year, I have received telephone calls from managers in social and leisure services asking for ideas about ‘strategic change’. Such questions are extremely challenging, coming as they do from people who want to ‘make a difference’ but feel trapped in a cumbersome system. The final section of this chapter is then an attempt to contribute to a dialogue (see for example, O’Brien and O’Brien, 1997; Evers et al, 1997; Lewis, Gerwitz & Clarke, 2000) seeking for strategic change that is both possible within services as they presently stand, whilst simultaneously challenging the underlying basis of those services. Whilst agreeing with Shakespeare that ‘social policy cannot go on tinkering with prevailing arrangements based on a discourse of care which is individualising and

excluding' (Shakespeare, 2000, p.63), past experience indicates that social change, whereby systems and institutions adopt a radically different basis for their practice, is unlikely to be rapid.

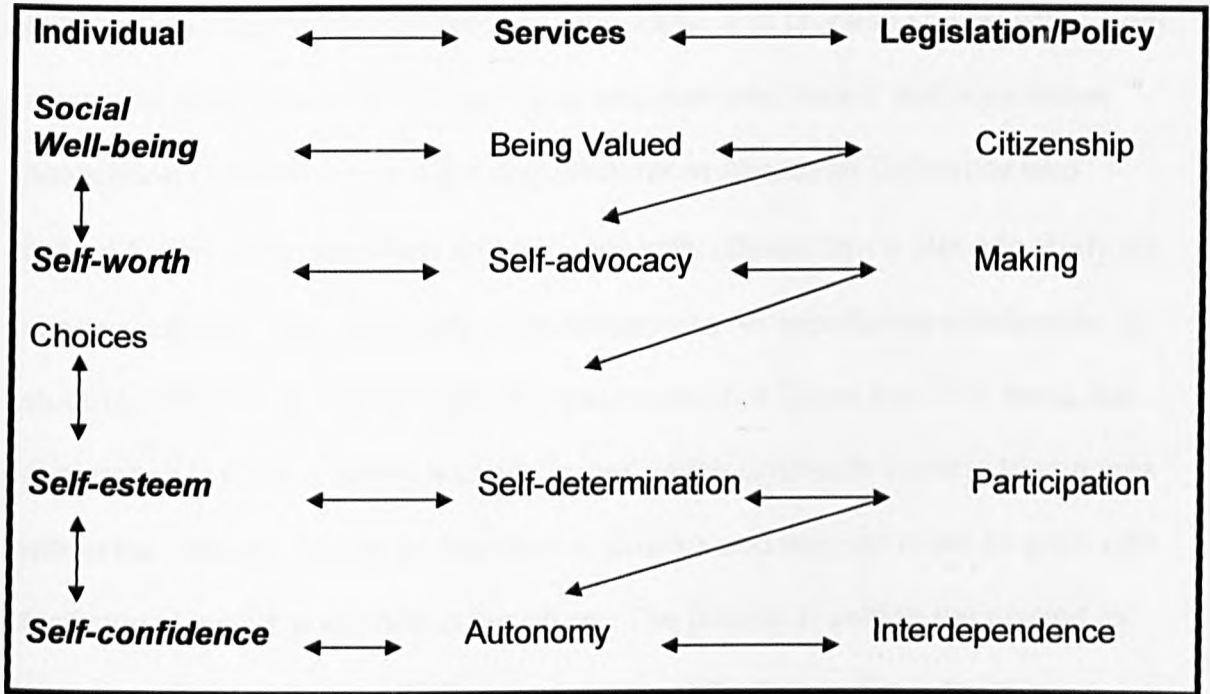
The implications of respectful relationship being recognised as the means through which individuals live fulfilling lives, demands a new approach to practice development (Bayley, 1997 (a) and (b)) as the initiative for change inevitably has to come from the 'bottom up' rather than being directed from above. Such an approach is consistent with Zohar and Marshall's (1994) vision of a quantum society based on diversity and equality in recognition of the interdependent nature of the universe. Whilst it is impossible to predict the outcome of such radical change, it is possible to envisage Leanne, James and Andrew (for example) being able to play a valued part in the shaping of services (and therefore wider society) emerging upwards from within mutually respected relationship in a way which is impossible for them to do at present in their role as passive recipients of services. Working upwards and outwards in this way would, I argue, support the rhetoric of legislation and policy through the practice of the 'ethics of listening' (Frank, 1995) and in so doing, facilitate service provision aiming to 'nurture the spark within'.

Looking for change that works

Throughout this thesis, I have argued that the major barrier to the acceptance of difference as an ordinary part of the human experience lies within the deep-seated belief that there is a fundamental difference between self and other (see

Chapter 1). Whilst there is talk about consultation and partnership between service 'providers' and 'users' the gap lying between them is that created by the division between self and other. For example, in the present drive for multi-agency working, service users or clients are invited in for consultation rather than being seen as 'part of the team'. The result of such a system can only be that of resources 'being handed down from above' with many opportunities for abuse of power to take place along the way (Lloyd, 2003). Service delivery that radically differs from this would respond to the social well-being of disabled children and their families (Grant, 2003). A focus on social well-being as the desired outcome of service provision allows for all barriers (social, economic, physical, environmental, psychological) to be questioned whilst also demanding that immediate resolution is made to any instances of 'lack of well-being' with the result that the short term problems are addressed in a way that inevitably leads to radical structural change so meeting the demand of Zohar and Marshall (1994) that the impetus for change is 'bottom up' rather than 'top down'.

Figure 4: Services based on outcome of 'social well-being'



As the above diagram shows, the focus on achieving an outcome of 'social well-being' holds the potential to:

1. place the disabled child/young person (and their family) at the centre of their own lives and therefore to direct policy initiatives;
2. provide the opportunity for both immediate (based on the practice of respectful relationship) and long term change (allowing respectful relationship to lead the way in creating structural change);
3. bridge the gap between legislation, policy and daily experience; and
4. allow for services to evolve through a constant process of re-evaluation on the part of everyone involved, with respectful relationship firmly at the centre.

One example of the way in which such a process works is to be found in Owen's forthcoming attendance at Aberdeen University. The process started with Owen saying he would like to be a monk; this ambition was 'heard' and researcher networking contacts led to a theology lecturer at Aberdeen University who invited Owen for an interview and subsequently offered him a place to study his chosen subject. The University of Aberdeen has no experience whatsoever of students with the degree or type of impairments that Owen has. For them, the experience is to be a 'steep learning curve' which is already leading to changes within the chosen module as the course director and lecturer come to grips with facilitating Owen's presence in the group. The priority in setting the ground for the placement has been moving slowly and positively in order to build up confidence (for Owen, his mother and the University). It is not just Aberdeen University who will be affected by the placement – the day centre that Owen presently attends has agreed to support Owen in his studies; Owen's mother is gaining confidence that other people will be able to 'look after' her son and so is gaining confidence to 'let go'; and Owen's request for direct payments (to provide support over the next few years) is the first his local authority have had from someone perceived as having learning difficulties and is therefore causing 'ripples' through the structures of social services. In this way, each small step, grounded as it is in 'going at Owen's pace' provides him with much needed encouragement and has the potential to herald major organisational change in several different institutions. Whilst this example is small and does not hold the potential to 'change the world', it nevertheless provides an exemplar of 'good practice' that is challenging present structures. Thus, although Owen is

powerless within the system, he is finding his own power (self-respect) and therefore has opportunities to make responsible decisions regarding his life. As a result of his impairment, Owen is unable to 'journey alone' but requires 'round the clock' support, thus providing others with an opportunity to fully explore an essential aspect of our common human experience.

Chapter Ten

Conclusions

A human being is a part of the whole, called by us the 'Universe', a part limited in time and space. He experiences himself, his thoughts and his feelings as something separated from the rest – a kind of optical delusion of consciousness. This delusion is a kind of prison for us, restricting us to our personal desires and to affection for a few persons nearest to us. Our task must be to free ourselves from this prison by widening our circle of compassion to embrace all living creatures and the whole of nature in its beauty. Nobody is able to achieve this completely, but the striving for such achievement is in itself a part of the liberation and a foundation for inner security. (Einstein, cited in H. Eves, 1977).

A developing framework

The central concern of this thesis has been to explore the conditions necessary to build support services enabling disabled children and their families access to the ordinary opportunities and life experiences so easily taken for granted by their non-disabled counterparts. In the early days of doing fieldwork I found myself confronted by a picture of chaos as families identified a broad collection of practical issues needing to be addressed in order to facilitate ordinariness in their lives (Beresford, 1994) indicating the need to engage with an equally wide range of theoretical questions. As the work developed it became increasingly evident that although different bodies of literature contribute valuable parts to the necessary theoretical framework, the extraordinary experience of disabled families is nowhere explored *in its entirety*. Adding this to the corresponding discovery that there is no one theoretical perspective underlying the provision of family support (Connors and Stalker, 2003) helped me realise that the work I needed to do was around explaining and developing theory that did not further pathologise disabled

children and their families. For this reason the thesis is primarily a comparative exploration of literature around disabled family experience, augmented by a small amount of fieldwork that served to inform and guide the developing theoretical framework.

The search for a suitable theoretical framework has been challenging and it was only when I stumbled across the literature of quantum physics that I found the breakthrough I had been looking for. To my dismay, however, having found a 'home' that allowed me to make sense of my own experience and consequently that of participating families, I immediately found myself on the outside of all prevailing schools of thought. I turned once again to the writings of the new science and took comfort in the words of Margaret Wheatley:

This is a strange world and one that promises to get stranger. Niels Bohr, who engaged with Heisenberg in those long, night time conversations that ended in despair, once said that great ideas, when they appear, seem muddled and strange. They are only half understood by their discoverer and remain a mystery to everyone else. But if an idea does not seem bizarre, he counselled, there is no hope for it (in Wilber 1985, 20). So we must live with the strange and the bizarre, directed to unseen lands by faint glimmers of hope. Every moment of this journey requires that we be comfortable with uncertainty and appreciative of chaos' role. Every moment requires that we stay together. After all is said and done, we have the gift of each other. We have each other's curiosity, wisdom, and courage. And we have Life, whose great ordering powers, if we choose to work with them, will make us even more curious, wise, and courageous. (Wheatley, 1999, p. 175).

In such a context, it is the unearthing of issues rather than stating of definitive findings that is of prime importance. However, with this caveat in mind, it has been

possible to identify three key features of a theoretical framework that would support ordinariness in the lives of disabled families:

1. The need to engage with the paradoxical nature of impairment;
2. Recognition of the family experience of disablement;
3. The need for a commonly understood and frequently articulated ethical code of practice, informed by the interdependent nature of our human experience, to underlie service provision.

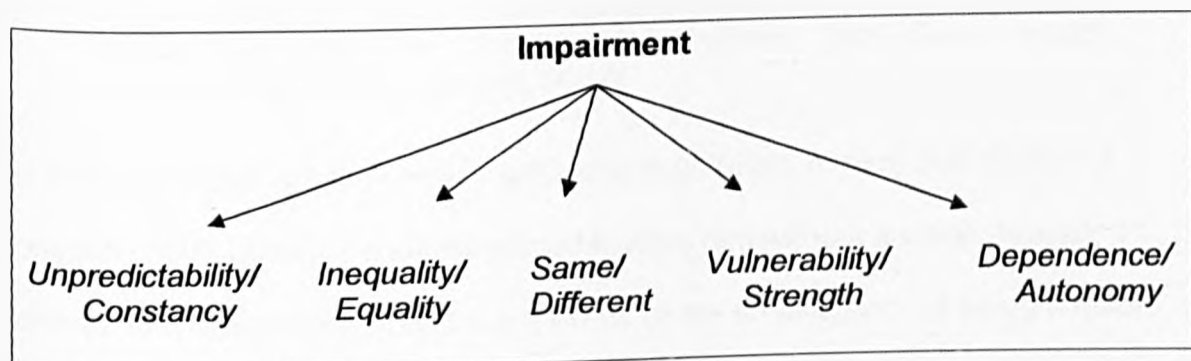
Combining the experience of participating families with the literature drawn from the range of disciplines explored in previous chapters, the first section of this concluding chapter looks at these key factors.

Engaging with paradox

A shift in discussion from relationships, structures, organisations and societies grounded in duality (either/or) to a perspective embracing plurality (both/and) provides an invaluable opportunity to engage with the paradoxical nature of all our human experience (hooks, 2000; Zohar and Marshall, 1994). In terms of disablement the advantages of such engagement is immediately apparent as we move from the constricting emphasis on *cure* and being *made to fit* a largely unquestioned norm to the liberating position of accepting each and everyone of us *just as we are*. As I described in earlier chapters, the acceptance of impairment as part of our human experience presents a challenge to a society intent on chasing the goal of physical and intellectual perfection. Acknowledgement of the ordinariness of impairment allows for engagement with its paradoxical nature and

the subsequent questioning of assumptions lying at the heart of our social organisation – for example, how can we be the same (equal) but different (unequal)?; how can we be autonomous when we are dependent on others for survival?; how can we be strong when we are so vulnerable? As the table below indicates the apparent contradictions inherent in dealing with the paradoxical nature of impairment leaves nothing (and therefore no-one) out.

Figure 5: The paradoxical nature of impairment



Although seldom articulated, the apparently contradictory issues such as unpredictability/constancy; inequality/equality; same/different; vulnerability/strength; and dependence and autonomy lie at the heart of the daily experience of disabled children and their families. An example of the way in which an embrace of paradox holds the potential to affect our daily experience is evident when we look at the way in which Owen's communication is viewed:

Owen: *I was taught by my speech therapist to do facilitated communication at school and I did it with everyone and then I went into the leavers class and they didn't want to do it with me but they said that I wouldn't co-operate and I was so angry that I refused to communicate with anyone including the speech therapist because she backed up the staff.*

Helen: *Shall I add something?*

Owen: *Yes*

Helen: *Anne Emerson taught school how to do facilitated communication. School learnt. Then Owen went into the leaver's class and it's clear that they do not want to do it and when I go into school they discourage me from doing it. School says that head of class was untrained. Owen wrote a letter to school saying how unhappy he is about it. School said that the standard of the letter was much higher than communication produced at school. We showed them a video we have of Owen communicating at home, but it didn't make any difference. They didn't believe that Owen could communicate (Helen, London, 2002).*

As with other participants, Owen's particular impairment means that his actual communication often goes unrecognised leaving him without a voice. In stark contrast to this, acceptance of the possibility of the co-existence of being capable and having a severe cognitive impairment leads to an array of different possibilities. In Owen's case it allows for the recognition of a communication impairment *and* an ability to be extremely articulate:

I want to say that I am very badly impaired and that I am not able to live without a great deal of support. ...I am aware that I am a curiosity for many people who will not have seen someone as weird as me, but I believe that we should be given the same opportunities as others. ...I also think it is important that people realise that disabled people have something to contribute to their community, and it is high time that their abilities are appreciated for what they are. We wearily allow ourselves to be herded into institutions by people who have no idea of our misery, and how lucky they are not to have an impairment. (Owen, personal correspondence 2002).

Appreciation of the wisdom in Owen's words leaves us with no doubt that he is a valuable member of our society from whom the rest of us have much to learn.

Indeed it is possible to go further and contemplate the possibility that the understanding gained from the experience of living with impairment informs Owen's wisdom. Such reflection makes it possible to move from the view of disabled people (especially those with cognitive impairments) being a burden to others, to the recognition of the unique contribution people with cognitive impairments have to offer the *whole* of our society.

As outlined in Chapter 3, the family experience of living with impairment and disablement provides fertile ground for an exploration of paradox as we are confronted with not only issues of impairment and disablement facing disabled children, but also the way in which they impact upon non-disabled family members. As a microcosm of larger society, families offer a range of responses to the dual experience of impairment and disablement. Whilst some parents view their disabled child positively, others remain deeply ambivalent. Such responses hold the power to alternatively weaken or strengthen the status quo. Positioned as a link between the individual and community, those families that view their disabled child positively are ideally placed to take a lead role in the process of the deconstruction of discriminatory cultural values, attitudes and practice.

The ambivalence attributed to parents of disabled children through the gaze of a medical model of disability provides a veneer masking the paradoxical nature of the family experience. This has resulted in the harmful misinterpretation of parental attitudes towards their disabled children that threatens the building of positive family relationships (Mason, 1995) whilst also providing the justification

for support services based on a deficit model – ‘the need to provide a break’.

However, the occasional glimpses we have of family life suggest that families have not always found their disabled children ‘burdensome’:

There was no place for my child. I was on my own. It was up to me and I hadn't a clue. But I had made my mind up about one thing. I was going to love my baby whether she liked it or not.

Wrapping Melanie up was the easy part. The screams, the stiffening out, anyone would have thought I was murdering her, it was just a battle of wills then as no way was I going to give up. I did this every day. Melanie never really gave up the battle. She wouldn't let me hold her hand or touch her but she did accept me holding her in my arms to love her (Lakin, 2000, p. 45).

The growing number of parental accounts towards the end of the same century tells a similar story – many parents love their disabled child (Dyer, 1996; Carpenter; Murray and Penman 1996; 2000) in spite of simultaneously struggling with a desire to make everything OK for their child:

I am not happy because (...) I believe the hardest thing is having a son with a problem I know that I can never solve. (But on the other hand) I am at peace, I am content with my son because with the limitations he has I have learned to know him, to love him and to understand a new way of living (cited in Larson, 1998, p. 870).

Closely related to the confusing emotions of loving a child just as they are and wanting to erase impairment is the tension surrounding the extra work arising as a result of the consequences of impairment. The body of literature looking at the family experience of having a child with a cognitive impairment conveys a clear sense of love parents have for their disabled children and the fact that impairment makes their lives harder (Todd and Shearn, 1996;1997; Dunst and Trivette, 1988;

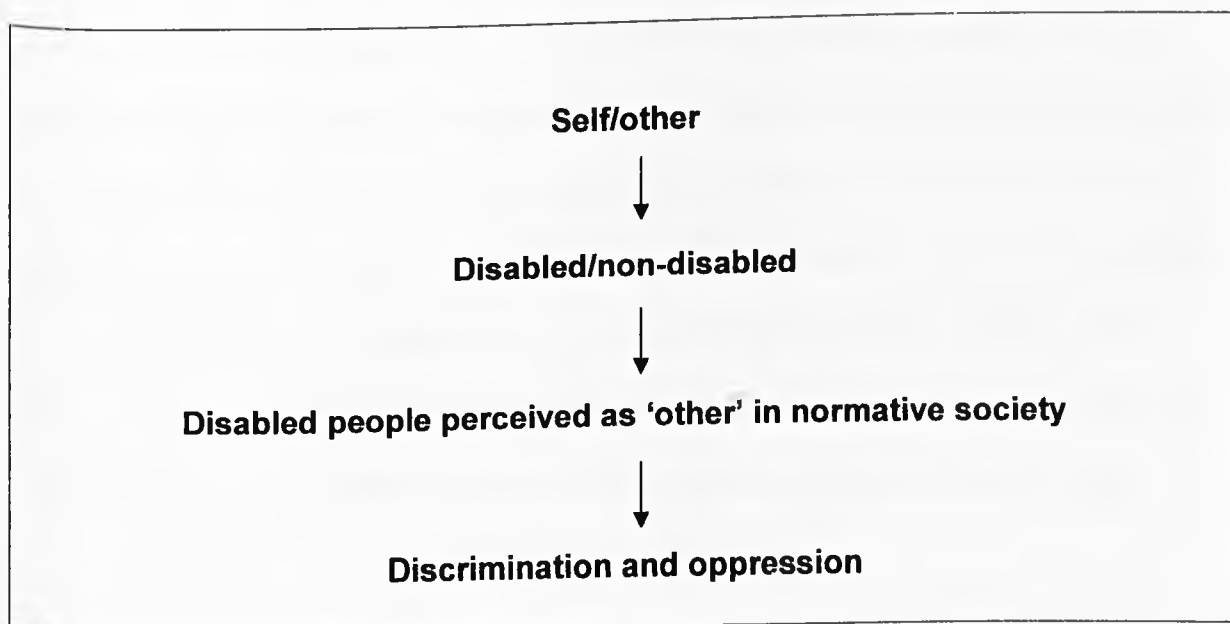
Grant (2003); Grant and Whittell, 2000). Unfortunately, and in spite of an engagement with paradox, the absence of a social model analysis within this body of literature means that the reader is left with a sense of ambiguity as to why families' lives are so hard – is it impairment or is it disablement? The fact that impairment usually brings extra work and responsibilities that typically extend beyond the expected years of parenting (Todd and Shearn, 1996) gives a measure of truth to the medical model understanding that to have a child with an impairment creates extra work. Without the distinction of impairment and disablement afforded by the social model it is all too easy to go along with the assumption offered by our prevailing culture that to live alongside someone with an impairment is an unwelcome burden. Making a clear distinction between the two, however, allows us to clear the wood from the trees as we recognize the burdens through a disabling world imposes on parents. Adopting the distinction between impairment and disablement offered by the social model at the same time as engaging with paradox allows apparently contradictory aspects of parenting to be there without conflict – *'it is hard work **and** we love our children'*.

Family experience of living with impairment and disablement

Throughout this thesis I have provided examples of the way in which all members of families within which there is a disabled child suffer from the effects of disablement (Murray and Penman, 1996, 2000). Whilst disabled children experience exclusion from mainstream schools and leisure opportunities (Morris, 1998 (a) and (b); Murray, 2000), the lack of employment opportunities and the restricted social lives that parents of disabled children typically experience (Shearn

and Todd, 2000; Stalker, 2003) are the direct result of a disabling world. For both parents and disabled children, exclusion from the mainstream leads to a differential experience from their peers and consequently social isolation (Murray and Penman, 1996; 2000). Whilst siblings of disabled children have an easier route of access to the mainstream and therefore are less likely to experience the extreme experiences of social isolation, they too suffer the effects of living in a disabling world (Closs, 1999; Connors and Stalker, 2003). I argued in Chapter 4 that although the social model of disability makes a crucial distinction between impairment and disablement, the fact that it is based on the binary assumption of a divide between disabled/non-disabled, mind/body, and physical/intellectual means that, as it presently stands, it cannot accommodate paradox (Corker, 1999). For this reason, even if the social model were to embrace both the disabling experience of people with cognitive impairments and the family experience of disablement, it is still not able to provide the necessary theoretical base from which to base services enabling ordinariness.

Figure 6: Disabling world constructed by binary divisions



As long as we regard others as fundamentally different from ourselves – a position shored up by a binary model supporting a distinction between self and other - we allow for the possibility that we are intrinsically different. It is on this basis that, over the centuries, difference on the grounds of gender, ethnicity, class, age, impairment etc has been the reason for affording lesser and greater value to individuals (Shakespeare, 1994). Because adherence to a binary distinction does not allow for difference to be recognised as part of the human experience, while it can improve the status and experience of disabled people within our present society, I have argued that it cannot facilitate ordinariness. It is only when difference is placed in the context of commonality that we can move towards practice reflecting the fundamental conviction that we are all of equal value (Philipps, 1999; Taylor, 1992).

As we saw in Chapter 3, a detailed examination of the position of parents within the social model reveals that their particular experience of disablement goes unrecognised with the result that they are assigned the role of ally to their disabled child. Being given the role of ally not only detracts from their ordinary parenting role but also positions them firmly on the side of non-disabled people. In many ways this leaves parents of disabled children 'homeless'. Excluded from the ranks of disabled people they also find themselves excluded from the main body of non-disabled parents. Although cultural attitudes militate against the forming of positive bonds between non-disabled parents and their disabled children (Mason, 1995), the fact is that many parents do not bond with their children and not all parents are skilled at the job of parenting. Placing the particular experience of parenting a

disabled child within the wider context of parenting allows for the 'ordinary' fact that some parents do not bond with their children.

It is those families where non-disabled parents are fortunate enough to both bond with their disabled children and understand the distinction between impairment and disablement that there is so much to learn about the process of inclusion. Within such families, disabled children/young people and their families identify respectful relationships as the starting point for building support services based on human rights and principles of empowerment (Carpenter, 1997; Todd and Higgins, 1998; Murray and Penman, 1996, 2000). Careful observation of the dynamics between family members with and without a disabling impairment allows us to see that the process of inclusion is ongoing and lies within relationship. Taking this to our wider social organisation allows for the recognition of inclusion as a process embedded within respectful relationship, supported by policies based on a human rights perspective and operationalised through a range of creative strategies encouraging flexibility and sustainability. In this way, families living alongside impairment are crucially situated to move forward the agenda for inclusion because they hold the potential to provide disabled children with the positive experience of being valued and belonging (Shearn and Todd, 2000) and, in doing this, to challenge the status quo through examples of positive relationships between disabled and non-disabled people.

Ethics and Interdependency

I have argued that embracing the reality of physical vulnerability offers the possibility of enhancing our social organisation generally as it leads us directly to the reality of our interdependency as human beings. For this reason then, has the exploration led to much bigger questions than initially assumed - questions of a perennial nature and universal relevance. Rooting such questions in the daily experience of disabled children and their families, whilst providing an example of the way in which they have the potential to contribute to the whole, has also ensured that the exploration provides the invaluable opportunity of exploring something both tangible (daily experience) and intangible (interconnectedness) at the same time. Basing the exploration within one paradox in this way has allowed for the emergence of paradox as a central theme – for example, self/other; autonomy/interdependence; individual/collective; disabled/non-disabled; adult/child; ordinary/extraordinary; male/female; black/white; and life/death. It is impossible to know the implications an engagement with the interdependent nature of human beings would have on the provision of human services as it is so far removed from the present basis of service provision (perceived need and unequal status). However, with interdependency as a starting point, services would necessarily be based in a morality 'that envisions each of us in the other' (Williams, 1997 p. 14). The implications of such a practice are radical and have the potential to generate profound change based as they are in the concepts of selflessness and co-operation. In contrast to a 'morality' based on 'duties' and 'rights', imbued with the 'shoulds' and 'should nots' that religions preach and

politicians teach, a morality based on caring one for the other as equals would evolve through the dynamic power of mutually enhancing relationship based on listening as 'a moral act' (Frank, 1995). In this way young disabled people with complex impairments and high support needs such as Leanne and Andrew, could be centrally positioned in the development and running of support services.

Inevitably, services grounded in the application of ethical principles challenge ideas of dependency/autonomy, thus leading to new concepts of citizenship (Tronto, 1993) based on the 'observable facts' (Williams, 1967) rather than ideas of how things *should* be. As with the development of this research, and in keeping with the definition of 'inclusion' as a process through which we can all go to the places we choose to go to with the people we choose to be with (Murray, 2002), an ethical approach means that the process is necessarily seen as being of equal importance to the end result. Indeed any failure in the process to meet the stated goal of respect for human rights (Valuing People, 2001) means that such rights have been disrespected and violated to a greater or lesser degree, so introducing a 'gap' between rhetoric and experience. Placing the focus on the process in this way in both research and service provision, allows for:

- a) constant evaluation of outcome as it affects the individual, rather than individuals having to fit into systems aiming to 'fit people into a prescribed norm';
- b) inclusion of *all*, rather than those that happen to 'fit';

- c) concentration on bridging the gap lying between rhetoric and experience;
- d) evolution of support services based on what works at any particular time, in any particular circumstances; and therefore
- e) flexibility of service provision.

Power

In proposing a radical shift in terms of moral discussions, perhaps the most important discussion, one that is played out in the lives of families in a variety of ways and is constantly an issue in the provision of services, is that of power. As I explored in Chapter 5, embracing the paradox of self and other leads naturally to a different perspective on power as the movement from one person towards another ceases to be that of insisting on superiority instead becoming one of acceptance of diversity in the context of equality of being. Within relationships based on mutual respect, the ethical principles of respectful listening within the context of 'existing for the other' (Frank, 1995), power ceases to be used to dominate and coerce but instead is recognised as a powerful force that is both life affirming and creative (Arendt, 1958). Such power, emerging within and through relationship provides the opportunity to act with strength, ability and a sense of accomplishment (Hartsock, cited in hooks, 2000) in the interests of the whole. Owen's writings serve to demonstrate the way in which relationships based on respectful listening produce a 'power' that does not belong to an individual but rather are the result of a process between people:

People have forgotten the importance of simple qualities such as kindness and self-sacrifice for those weaker than themselves, and that there is a moral superiority in a person who perceives such needs, and is prepared to put themselves out to help an impaired fellow member of the human race. I am waiting to find such people and then I will take off and soar like a bird (cited in Murray, 2002).

Although the powerful words come from Owen alone, he depends on his mother to facilitate his communication (and indeed is rendered powerless without her) and on others to get the words out to a wider audience so allowing them to have greater effect. The fact that since Owen's writings have been published, many people have contacted me to say how powerful they find his expression to be and to find out if he has written more, is testimony to the process of creative power emerging through respectful relationship. Whilst there is a body of literature looking at ethical research methodology and respectful research practice with disabled children and young people with learning difficulties, there is a noticeable gap of a similar emphasis with regards to service provision and/or professional practice.

Methodological reflections

As with all research projects, a retrospective look at methodology allows light to be cast on the strengths and weaknesses of the approach. In order to maintain an open stance of listening and learning the methodological approach has necessarily been flexible and exploratory. I knew from the outset that I was stepping into a chaotic arena as my lived experience had taught me that the issues were complex, multi-faceted and characterised by paradox. I also knew that the opaque tenacity of services based upon medical model thinking masks the nature of the issues. At the beginning of the project I envisaged that, in order to

surface the daily experience, the work would be of a very practical nature and would involve an exploration of the experience through in-depth work with a number of families. However, an initial review of the literature engaging with the family experience showed me that the complexity of the issues facing families of disabled children are well recorded (Morris, 1995; 1998; 1998 (a) and (b); 2001; Beresford, 1994; 1996; Grant and Whittell, 2003; Goodey, 1991). No doubt my position as a parent researcher might have brought a different slant to the question, but this was did not seem enough. Indeed, it was my role as a bereaved parent that motivated me to move beyond an extension of existing works to produce something that had the power to contribute towards substantial change. The question I found myself engaging with was why, when the experience was relatively well documented and policy documents proclaimed the need for inclusion, families remained marginalised. Clearly something was missing. As my reading progressed and I started engaging with a small number of families I realised that a missing piece of the overall picture was a well understood and deliberately chosen theoretical framework on which to base support facilitating ordinariness. Without this, the move from services implicitly based on medical model thinking that pathologised both the child with impairment and his/her family members, was simply not possible. For this reason I prioritised the development of theory over spending time with families. In order to accommodate the wide range of issues arising from the ensuing literature review and to allow a flexible explanatory framework for the way participants negotiate their relationships with the world around them I found it necessary to adopt an anti-foundationalist stance

permitting me to engage with the widest possible range of literature and also equipping me with a selection of appropriate analytical tools.

With respect to the small amount of work with families I was constantly looking for different ways of maximising participation. Once again my own experience had a part to play in this insofar as my son was perceived as being 'difficult to include'. Throughout his life, I observed professionals making decisions about him reflecting their perception that, as a result of being unable to communicate through language, he had little to say. Knowing how much he had to offer the world I was interested in exploring these issues further through the involvement of disabled children with cognitive impairments in the research process. Within this particular project, the people I had most difficulty including were those young people who, like my son, were unable to communicate intentionally. I knew that those closest to them were able to read their communication and so the puzzle facing me was how I, someone who did not know them well, could read their responses to the extent that they were able to participate in the research. I wrangled with the inherent difficulties - trying out different ways of involving the children while also questioning my practice. In the end, as far as this project goes, it became evident that meaningful answers to the question, '*What do I like to do best?*' could reliably be found in the body tension of those young people who do not use language to communicate. With the overriding stipulation that the asking of questions and the listening to responses is problematised in an ongoing way, the information gleaned not only informs the research project but also indicates a way in which support services can be based on the preferences of the child with impairment.

Having overcome the challenge of allowing for the voice of every participant to inform the process, the problem then lies in being able to convincingly convey such responses as valid to a wider audience. At this point I am reminded of the experience parents have when they attempt to convey their child's communication to people outside the family setting. It can be difficult at times to suspend the deep seated beliefs engendered by a disabling world and to open our minds to other possibilities.

It goes without saying that because the fieldwork was based work with a small number of families, that its findings cannot be universally applied. Related to the numbers involved, the contrived choice of a 'certain type of family' throws the work open to criticisms of being slanted in a certain direction. However, in terms of the aim to look for a theoretical framework supporting ordinariness, these families are the ones that are 'leading the way', 'breaking boundaries', and by so doing paving the way for future services. All families involved are seeking family support services that value their child; are centred on their needs and entitlements; and allow for ordinariness in their lives. In other words, even this small number of families gave me a springboard from which to explore the issues arising from the literature review. Future work on the same topic, however, would undoubtedly benefit from engagement with both a greater number and a wider range of families.

Due to the exploratory nature of the work; the complexity of the issues; the many different skills required to gather data; and the sensitivity required in working with

families living with difficult issues, the work would have benefited enormously from the sustained input of more than one person. To this end, it would have been helpful to have had an advisory group and to be working alongside other researchers. In light of the fact that the work sought to explore the experience and gain insight into the views of young people it would have been interesting to have engaged young disabled people more fully in the process as researchers. A full exploration of issues connected to the research as an empowering process, was limited through lack of funding.

In keeping with the central theme of paradox running through the thesis, many of the positive aspects of the approach also generated the negatives. The most striking example of this was in the amount of data generated. Although the amount of data generated gave me the opportunity to connect with a complex range of theoretical perspectives, it also made it very difficult to keep 'scope specific'. In this respect, the free flowing nature of the semi-structured interviews with parents might well have benefited from a more directive approach. Similarly, whilst the extensive networking and engagement with different professionals groups undoubtedly brought a breadth to the research and contributed to the development of the theoretical exploration, at times it simply seemed as though I had been too ambitious in scope.

Implications for practice and directions for further research

It is the move towards inclusive service provision, based upon the understanding of disablement afforded by the social model of disability that offers the possibility of a turn around in the extraordinary experience of disabled children/young people

and their families. While the current trend of linking short breaks with mainstream leisure services is to be applauded, it is not until the whole experience of disablement is confronted that disabled families will find themselves able to lead ordinary lives. In other words, It is not until the entire family is recognised as having an extraordinary experience (i.e. disablement) that family support services will be able to deliver packages enabling ordinariness in the lives of those they seek to serve.

Just as the knowledge and expertise of disabled people gained from first hand experience of living with impairment in a disabling world is crucial to the deconstruction of disabling barriers, so too are families placed as key players in the identification of barriers to ordinariness. Whilst the rhetoric of human rights - generally understood as the right we all have to life and inherent dignity - abounds in legislation and policy, the overwhelming experience of participants was that service provision rarely looked to protect and/or nurture the spark within. Young disabled people and their families are more likely to prioritise 'having fun' as the basis for any successful service provision arguing that it is only when this is in place that learning within education, for example, or community involvement in leisure settings can begin (Todd and Higgins, 1998; Murray, 2002; Heslop, Mallett, Simons and Ward, 2001). There is a move amongst some local authorities, for example, Solihull, Dudley and Bolton, to explore ways in which access to mainstream leisure services and respite care can merge. This thesis supports such moves and there is clearly a need to evaluate and monitor such initiatives. At the same time, in other parts of the country, disabled children are rarely invited to

participate in their own reviews, far less being part of any wider decision making process affecting the direction of services (Social Workers Training Session, Sheffield, 2002). Similarly parents describe how the choices they have to make about services for their disabled child, frequently lie 'between a rock and a hard place' (McDonnell, 2000). The starting point for services wishing to make the change between traditional short breaks and/or respite care is through engaging with disabled children and their families within a social model framework.

Distinctive contribution to knowledge

The principal value of this work lies in the introduction of a new approach to looking at the family experience of living with and alongside impairment in a disabling world. It was the discovery of a new world view emerging from quantum physics that provided me with my first glimpse of a new way of perceiving the webs of interconnectedness characterising all aspects of not just our world but the entire universe. Although there are increasing articles and books within disability studies moving away from the binary nature of the social model of disability, as far as I am aware, there is as yet nothing that attempts to encompass our entire human experience and to pull the experience of living with impairment into a theory surrounding the nature of the universe. Similarly, although the theme of interconnectedness is one that is addressed within the literature covering the family experience (new lit) applying the lessons of the new sciences allows for a paradigm shift. With the new physics we enter the world of accepting, rather than fighting against paradox. Each being is noticeable as a separate entity, yet it is simultaneously part of a whole system. In the quantum world, relationship is the key determiner of everything and an acceptance of paradox makes it impossible to

attribute value to things on the basis of difference. Hence neither normal or abnormal is primary – both are absolutely necessary. This view allows for human frailty and human strength to be recognised as inevitabilities of our human experience, with neither one better than the other (Wheatley, 1999). I discovered that it is the acceptance of paradox that provides ground sufficiently fertile and expansive to allow for ordinariness in the lives of families living with and alongside impairment.

Engaging with paradox is extremely challenging precisely because we have to leave behind our preconceived ideas on the inherently separate nature of the universe. Relational aspects are key. It strikes me that the family experience of living with and alongside impairment presents the perfect setting in which to explore the human aspects of this new paradigm. As we have seen, paradox is close to the surface in the lives of families:

I knew her condition was serious and her prognosis poor but, to me, she was my firstborn, beautiful child. Every time I expressed my joy to the staff at the hospital, they said, 'She's denying reality'. I understood the reality of my child's situation but, for me, there was another reality (cited in Kearney and Griffin, 2001, p. 585).

I am not happy because (...) I believe the hardest thing is having a son with a problem I know that I can never solve. (But on the other hand) I am at peace; I am content with my son because with the limitations he has I have learned to know him, to love him and to understand a new way of living (cited in Larson, 1998, p. 870).

Having provided the starting point for a shift in paradigm, there is the need for more work with families exploring the paradoxical nature of the experience and identifying ways in which the lessons learned from this particular (but universal)

experience can assist our struggling social organisations. In this way the experience can truly be brought from the margins to the mainstream as we begin to seek meaningful change based on the nurturing of the spark lying within each and every one of us.

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Appendix 1

The families

The families involved in the project came from a variety of backgrounds, nationalities, age and geographical locations – from city to small town in a rural area. The young disabled people involved spanned the ages of 5 to 21 and had mixed experiences with regards to services. For example, whilst 4 young people attended specialist service provision (school, day centre and specialist 'respite care' centre) 2 of the participants did not use any form of specialist provision – preferring instead to be at home. Whilst all the families involved sought for 'ordinariness' in their lives, all agreed that compromises had to be made. These compromises were different for each family and depended on their background, economic status, personal preference, personality, health and the consequences of impairment. All the disabled young people in the families had cognitive impairments resulting in learning difficulties and/or communication impairments whilst two of the six disabled young people had serious medical conditions and suffered from frequent ill-health.

Marjorie and Andrew Philips

Marjorie and Andrew (aged 13) live on a council estate in London. Andrew attended mainstream school until his transfer to secondary education when, after a year at home during which time his mother took his case to Appeal Tribunal (and lost) Andrew started to attend a segregated special school. Andrew and his mother are now trying to negotiate visits to a mainstream school (agreed by the Tribunal but difficult to put into practice). In his early years, Andrew had friends within his neighbourhood but over the last two years (since he stopped attending mainstream school) his friendships with other young people in the community have dwindled and he is now extremely isolated. Due to the fact that Marjorie finds it difficult to work the lack of money in the household makes it very difficult for Marjorie and Andrew to develop relationships with other family members who live some distance away.

Marjorie and Andrew live on an estate predominantly housing elderly people and families with a disabled child/young person. Whilst both Marjorie and Andrew enjoy the contact with other families going through similar experiences, they would both like to be in a more mixed environment.

Sarah, James, Louise and Zoë Marshall

The Marshalls went through considerable change, upheaval and difficulties during the time of the research in that Zoë was born, Louise died, Sarah and James separated, they all moved house and Sarah went back to work. At the beginning of the research Sarah and James were living together with their daughter Louise (aged 5). Louise did not attend school due to her constant ill-health and the danger of her picking up any additional infection. A home-school teacher visited once a week. Sarah had given up work shortly after Louise was

born and Andrew worked very long hours as a courier (leaving at 5am and finishing work at 6 or 7 pm). He would regularly come home in the middle of the day to rest. The size of their house (a small privately owned bungalow) meant that Sarah could not have visitors at this time (nor could she easily go out as she had no car until Louise reached her fifth birthday). Sarah had stopped work in order to care for Louise – whilst she was very happy to do this, she nevertheless missed adult company. Zoë was born during the course of the project – this was an extremely difficult time for the family as Louise had to go into hospital to be looked after due to the lack of any other provision. Following the birth, when the additional support to the family was withdrawn, it was very difficult for Sarah, Louise and Zoë to go out – special arrangements had to be made with Sarah's mother in order for Zoë to attend clinic appointments. Luckily both Sarah and James had family living close by who were keen to be involved in child care.

Elsie and Ben Meredith

Elsie (another single parent) and Ben live together in a community in which Elsie has lived from a very young age. From early in Ben's life, Elsie has looked for support from others living in that community and the two of them have a strong (informal) circle of support around them. Elsie fought for Ben's right to attend mainstream school from a very early age and, although his attendance at mainstream has always been on a part-time basis, Ben has never attended segregated schooling. He has presently started attending college to do A levels. (During the early years of Ben's life, doctors predicted that Ben had 'severe learning difficulties'). The emphasis in Ben's life has been around education and finding a way in which Ben could communicate. With success in both these areas, Ben's self-confidence and easy presence in the community was marked in comparison to the other participants. Over the last year, Elsie has returned to work (although not the career she was involved in before having Ben) on a part-time basis – her main priority being that of supporting Ben through college and into university.

Jean, Chloe, Alison and Leanne Wilson

The Wilsons lived in a small town in a rural area and once again were a family 'going through changes' during the time of the research. These changes were those of 'growing up' – Chloe had recently left home to go to university, Leanne had left school and started attending a local day centre and Alison was filling the gap left by her older sister in terms of supporting Jean to look after Leanne. The main priority for the Wilsons was to give Leanne as comfortable and pleasant a time as possible – there are severe concerns about her health and indeed photographs of Leanne as a child showed how much her physical condition has deteriorated over the past 10 years. Jean managed to return to work, choosing to make a career change that allowed her to have 'time off' in school holidays so that she could be at home with Leanne. Jean's parents who had lived nearby and who supported her in the task of bringing up three daughters had died leaving her with no family nearby. The girls' father had not been involved in their upbringing in any way.

Linda, James and Elizabeth Smith

The Smith family was the only family involved who used a variety of services – education, health and social services - but had succeeded in 'staying within the mainstream' within both education and social services. This had been done because they were prepared to compromise on both – at one point James had been out of school full-time and the education department had been 'persuaded' to appoint a support worker at home. Similarly social services had taken the unusual step of paying for an agency worker to spend time with James for three hours every fortnight. Linda had succeeded in working throughout – as with Jean this was made possible because her job allowed for time off over school holidays.

Helen, Peter and Owen Lubienski

At the age of 21, Owen was the oldest disabled person involved in the project and having attended a segregated school all his life, now goes to a specialist day centre. Once again the project worked with the family at a time of change – with Owen trying to break out of his isolation by embarking on a university course and exploring different means of being supported in the community. Neither of Owen's parents work – his father having taken early retirement several years ago and his mother having stayed at home in order to 'be there' for her son. Their housing arrangement caused some tension for Owen – their top floor flat is very small and does not allow him any space of his own whilst also demanding that he curb his exuberant nature (he loves to jump up and down).

In addition to these 'principal' families the following young people (disabled and non-disabled) participated in the research:

Katherine**Jonny****Sam****Joey****Jenny****Sally****Sue****Mary**

Appendix 2

Organisations

Centre for Studies of Inclusive Education (CSIE)

Room 2S203 S Block
Frenchay Campus
Coldharbour Lane
Bristol, BS16 1QU

Website: www.inclusion.uwe.ac.uk

CSIE is a national centre giving information and advice about inclusive education and related issues. The Centre, which was set up in 1982, is fully committed to working towards an end to segregated education. Inclusion means all. This commitment is based on human rights principles.

Circles Network

The Dunstan Centre
Pennywell Road
Easton
Bristol BS5 0TJ

Website: www.circlesnetwork.org.uk

Circles Network is a national voluntary organisation based around the key principles of Inclusion and Person Centred Planning approaches. Circles provides personal support for people who are in danger of becoming socially excluded, or who are currently suffering the consequences of prior segregation and discrimination. Circles Network supports families to build 'circles of support' around either the whole family or the disabled family member, thus contributing to the disabled family member being able to remain in the family, and for that family to be fully part of that community.

Disability and Equality in Education

Unit 4Q
Leroy House
436 Essex Road
London N13QP

Website: www.diseed.org.uk

Disability and Equality in Education provides training and resources for schools, colleges and local education authorities around the issue of inclusion for all students within our education system.

Triangle

Unit E1
The Knoll Business Centre
Old Shoreham Road
Hove
East Sussex
BN3 7GS

Website: www.triangle-services.org.uk

Triangle is an independent organisation providing training and consultancy throughout the UK, and outreach support for children and young people in Sussex. We work directly with children and families, we teach and advise parents and professionals, and we provide consultation to individuals, teams and organisations.

Scottish Human Services (SHS)

1a Washington Court
Washington Lane
Edinburgh
EH11 2HA

Website: www.shstrust.org.uk

SHS believe that people of all ages and abilities have the right to the supports and services they require to enable them to participate fully in their communities. At the core of their work is a commitment to inclusion and empowerment. 'We believe that communities are healthier, stronger and better for everyone when they recognise and value diversity. We also believe that people who are at risk of exclusion must be at the heart of the movement for change'.

Parents for Inclusion

Unit 2
70 South Lambeth Road
London SW8 1RL

Website: www.parentsforinclusion.org

A national organisation of parents for parents, working with disabled people to ensure access to mainstream education for disabled children.

Parents with Attitude

PO Box 1727
Sheffield
S11 8WS

Website: www.parentswithattitude.org

Parents with Attitude is an organisation seeking to make visible the family experience of living with the issues of impairment and disablement. To date the organisation has published two books looking at this experience (Murray and Penman, 1996, 2000) and carries out empowerment work with families.