

**‘Trying Transitions’: Researching the Identity
Development of Severely Learning Disabled
Adolescents; A Psychosocial, Observational Study**

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Abstract

At the heart of this project is the wish to forge a better understanding of the lives and subjective experiences of severely learning disabled people in adolescence. The thesis adopts an approach that starts with the subjective, lived experience of the young people and the study explores the social and emotional worlds which the young people inhabit. This takes shape as a psychosocial investigation of identity development in the young people concerned with the study.

Observation, informed by psychoanalytic theory and practice, is the chosen methodology. The observer reflexively explores the relationships and emotions involved in the everyday lives of the young people concerned, within the social context of their families, enabling themes to emerge from which case studies are constructed. Relational maps are formed for each young person by bringing together the idea of ‘becoming a subject’ with the unconscious defensive structures employed by parents in stressful caring situations. These are considered in relation to broader social factors: social class, culture and ethnicity.

Implications of the findings for policy and practice are described, highlighting technical and attitudinal issues. Relationship based practice and networking skills are indicated, to emphasise the nexus of care which is required by each young person and their family. This ensures that the stressful aspects of dependency are acknowledged rather than denied within contemporary discourse which idealises independence. Finally, infant observation methodology as both research tool and as an aid to practice is thought about;

its important contribution in helping to uncover the subjective experience of other vulnerable and 'hard to reach' groups stated.

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‘Trying Transitions’: Researching the Identity Development of Severely Learning Disabled Adolescents; A Psychosocial, Observational Study

Introduction

The best way in which to introduce this research study is by accounting for why it came about in the first place. As a young Community Services Volunteer, just starting my career in social work, I was introduced to a young girl ‘Angela’ who had autistic spectrum disorder. The plan was for me to get to know Angela and her family so that I could take the eleven year old out to give the parents a little time off. Although she was exuberant and great fun, Angela could also be a handful. While escorting her to a play scheme one holiday she swung a heavy plastic bottle of squash at plate glass window in front of me, smashing it to pieces in dramatic fashion. I was left feeling ashamed at my inability to stop her and in awe of her parents who somehow managed to contain and manage her behaviour in the home setting, day-in and day-out. Angela’s mother later described to me her frustration at the seeming lack of interest professionals took in her family. No-one ever stayed long enough in the home, she complained, to gain a full understanding of her daughter or the rest of the family and how they coped.

Later on, after I had qualified as a social worker, I came to understand the bureaucratic pressures which take practitioners away from spending time with the families they are allocated to work with and which limit their opportunities to gain an in-depth appreciation of issues which affect families; the presence of learning disability in a child being a frequent focus in my experience. On the other hand I also came to wonder whether the bureaucracy and ever-growing paperwork was protecting us as professionals by enabling us to have some distance from the difficult and trying situations that the families we worked with were facing. Encountering situations where parents were neglecting or harming their learning disabled child seemed to bring some of these issues

to the surface as it was so difficult to understand how a parent could harm their vulnerable and disabled child.

The knowledge and skills offered to social workers in training however did not appear to provide answers to these questions. For practitioners working with disabled children, young people and their families, the available literature tended to dwell upon themes of oppression and disadvantage facing disabled people in society and therefore by extension learning disabled children. This 'values led' approach, while important in helping us to understand the influence of wider social pressures on the children we were working with was however weak when applied to the situations which most perplexed us in practice; those concerning the emotions of families living with learning disabilities.

Through my own studies and a developing interest in the more 'therapeutic' and at that time unfashionable variety of social casework, I became interested in understanding the role of unconscious processes in the families I was working with. In particular I wanted to know how parents of severely learning disabled adolescents adjusted to the needs of the growing and developing young person in their midst and what happened when this went wrong. What also seemed to be missing was a focus on the experience of the young people themselves. Social workers purport to put the child or young person central to their work, in line with the 'welfare principle' which lies at the core of the Children Act (1989) the key legislation under which we practice. Yet I could find very little research or writing which attempted to describe or capture the experiences of severely learning disabled young people and adolescents in particular. This study therefore arises from a set of questions and issues which perplexed me about an area of practice in which I had been involved for some time and about which I thought more ought to be known.

The method of researching made use of in this study is one which was first developed to assist psychotherapists in training; that of infant observation. As will be explained, this allowed me to make contact with a small number of severely learning disabled young people and their families to arrange regular observation visits over periods of six months. While the data which resulted from these observations focuses primarily on the emotional

dynamics that I experienced, in the broad sweep of the families' lives which I encountered a great deal of additional information was also gathered. This made it possible to construct case studies around each of the young people researched and their families; case studies which are psychosocial in their range.

What emerges from the data is an account of the young people in the study which revolves around their developing adolescent identities and subjectivities. These identities, which are as various and distinctive as of any other members of their communities, are impacted upon by features such as the young person's gender, culture and social class. Cutting across these however is the impact of the particular nature of the cognitive impairments experienced by the young person and underlying these features is also the developing adolescent bodily experience of puberty and the incumbent changes encountered within and without the individual. The lives led by the young people who were studied were characterised by the intensity and significance of the key relationships in their lives, particularly between the young people and their parent-carers and also with their siblings. The tensions evident in the families had some commonalities between them, but also some differences and these have been teased out in the data analysis and subsequent reflections on these. Always the theme of transition re-emerges, as families struggle with change and the movement towards a notion of independence in adulthood for the severely learning disabled young person, while dealing with the everyday reality of continuing dependence and the responsibilities and feelings this brings out.

Chapter One

Researching Severely Learning Disabled Adolescents in Transition: Shaping a Psychosocial Approach

1. Introduction: Considering learning disability, social work and the need for a multi-disciplinary, psychosocial approach

At the heart of this project is the wish to forge a better understanding of the lives and subjective experiences of severely learning disabled people in adolescence. The knowledge acquired is intended to assist in the development of social work practice and social policy with service users whose perspectives, in my view, are often poorly represented in the literature and guidance available to social care professionals. As a practitioner working in this area, I often found that the literature was disappointing; rarely did the young learning disabled people's lives that I encountered seem to be described or considered in ways that I felt reflected their subjectivity or complexity. Social constructionist accounts of learning disabled young people's lives, intended for social workers to read, lead to a one dimensional approach, without successfully engaging in thinking across disciplinary, theoretical and experiential divides (Middleton 1996; 1999). One explanation for this is that writing about learning disability (and disability more generally) often emerges from a rights perspective; one which aims to liberate disabled people, parents and carers from the effects of social discrimination and disadvantage (Read et al 2006). While rights-led approaches are important, a cost is attached as the more intimate, subjective aspects of disabled people's experience may remain neglected and unaccounted for (Morris 1992; Beart 2005; Shakespeare 2006).

Severely learning disabled young people's subjective experiences are particularly at risk of neglect as it is often difficult for outsiders, whether they are researchers or practitioners, to get to know the young people concerned well enough to appreciate their

perspectives. For this group of young people, lives are led in close relationship with those around them who love them, care for them, educate them and socialise with them; such that it is often difficult to know how they themselves might be feeling about their own lives without their experiences being filtered and interpreted by those others around them. This piece of work will adopt a different approach. Starting with the subjective, lived experience of the young people, the study will explore the social and emotional worlds which the young people inhabit. This will take shape as a psychosocial investigation of identity development in the young people concerned with the study. For social workers whose profession ‘intervenes at the points where people interact with their environments’ (International Association of Schools of Social Work & International Federation of Social Workers, 2002¹) the information acquired in this research context will be of relevance in the drive to improve practice.

a. Why so little research in this area?

There have been few attempts by researchers to describe and account for identity development in severely learning disabled young people (Watson et al, 1999, is one exception where disabled children are researched as a wider group); themes explored in the literature pointing up two possible explanations for this. These debates revolve around the difficulty of communicating with people with severe cognitive impairments and the resulting problem of how to explore their experiences of life and second to issues relating to rights and discriminatory attitudes. These are briefly discussed here (though in more detail later) as they point up boundaries and blocks to thinking which I argue are holding back this area of research into important areas of learning disabled people’s subjective experiences.

¹ The international definition of social work: ‘a profession which promotes social change, problem solving in human relationships & the empowerment & liberation of people to enhance well-being. Utilising theories of human behaviour & social systems, social work intervenes at the points where people interact with their environments. Principles of human rights & social justice are fundamental to social work’. International Association of Schools of Social Work & International Federation of Social Workers (2002)

Turning firstly to the subject of communication, the problems faced by researchers (Stalker & Connors 2003) seem to mirror those to be found in the domain of social work practice. Social workers are required (DH 2000), and are often seen as failing in the attempt, to ascertain the wishes and views of the disabled children they are working with; part of the process of shaping accurate assessments of need with those young people. The problem that professionals have in uncovering the experiences and needs of young people with severe learning disabilities in particular, is often attributed to those professionals' deficiencies in acquiring the right communication techniques and skills (Morris 2002; DH 2000; Stalker & Connors 2003). Clearly, effective communication skills form part of the essential toolkit for practitioners as well as for researchers working in this area. It will be proposed here however, that more than just technical skills are required for professionals to come to an understanding of the complexity of severely learning disabled young people's lives. There is a need to understand the emotional dynamics of life too.

Discriminatory assumptions have been cited as a second obstacle to research being carried out with disabled children. Priestly (1998:220) suggests that 'disabled children continue to be constructed within a unitary identity that is largely degendered, asexual, culturally unspecific and classless' and that they are seen as 'passive and dependent' (ibid:207). In this argument, Priestly seems to be suggesting that researchers see severely learning disabled children and young people as 'objects of concern' rather than as living, breathing young people, albeit with different, but equally complex life experiences and relationships to those making up the rest of the community. The reasons for this 'objectification' of severely learning disabled children and adolescents, may well be partly to do with discriminatory attitudes, but also I would suggest, they relate to those other problematic adjectives mentioned by Priestly; that disabled children are seen as 'passive and dependent'.

While Priestly and other proponents of a primarily rights-based approach to disability (Barton, 1996; Oliver and Barnes 1998; Middleton 1996; 1999) set about blaming the rest of society for its discriminatory attitudes, it is proposed here that real issues *are* raised for

the young learning disabled people themselves by their impairments and their dependency and for those around them who care for them. Questions about how learning disabled adolescents, their parents and carers and the professionals who work with those young people feel about passivity and dependence and their opposites, personal agency and independence, may indeed be very central concerns of the adolescent phase of development. This highlights a key concern of this research, the idea of 'transition'². A paradox arises when trying to hold together this notion of development towards an idealised notion of 'independence', alongside the reality of considering the dependent state in which most of the young people in this category live and will live into the future, with their parents and carers.

It is important therefore to include how blocks to communication and discriminatory attitudes impact upon research, but this project will go a step further to reflect also on troubling, unconscious emotions which seem at times connected to the experience of learning disability. These emotions, which can encompass powerful feelings of ambivalence, may in themselves impact upon and limit the willingness of researchers to investigate this area. One exceptionally honest account is that of Goode (1984) who describes some of the fears he experienced on meeting a severely learning and physically disabled man with untreated hydrocephalus. His description of a research visit to an old-fashioned hospital setting in America is reminiscent of a horror film:

The room was empty, without objects on the walls or toys. It was brightly lit. I walked toward the bed and peeked over the edge and was as intensely horrified as I have ever been in my life at what I saw.' (ibid: 230)

Goode goes on to make sense of this experience, learning to see the man concerned in his full humanity and to understand how his nurse had grown to see him as her 'special

²'Transition' encapsulates the notion of the birth of the independent adult subject who emerges from a state of childhood dependence; a process mirrored by the policy and practice frame provided under United Kingdom legislation for those working with learning disabled young people and their families. (Tisdall 2001; Dee, 2000; DH 2000; DfES 2001).

favourite' (ibid: 230). His description does say more however, about just how difficult people can find it to cope with real difference, impairment and disfigurement.

These themes hint at unconscious and perhaps difficult to own feelings that psychoanalytic psychotherapists have described in their accounts of work carried out with learning disabled young people themselves, their parents and other family members as well as with professionals (Sinason 1992; Miller 1998; Simpson 2005). Consideration of these emotions suggests that there may be more in this area than rights-led approaches could uncover, if the ordinary lives of severely learning disabled young people are to be better understood. These themes and areas of knowledge will be returned to later in this chapter as they provide an additional perspective from which to consider subjective, lived experience.

b. Preliminary thoughts on researching identity, multidisciplinary and on methodology

The second chapter will address methodological issues in depth, but some initial points need to be made here to explain the structure of this opening chapter. These points relate to theories of identity, to the idea of multidisciplinary in research and finally to the themes of subjectivity and reflexivity.

Identity has been thought about from many different theory perspectives, though usually with some notion present of the interior, personal components of which it comprises as well as elements which relate to the social field³. Hall (1996 in du Gay et al 2000: 20) when considering 'the rudimentary levels of psychic identity and the drives' and 'the

³ du Gay et al (2000: 2-4) suggest there are three ways of understanding 'identity': first, the 'subject-of-language' approach which stresses 'the reiterative power of discourse to produce that which it also names and regulates' which suggests that identities are dislocated because they are defined by difference; second, the psychoanalytic view, which is critical of the first, more philosophically driven view of identity and which prioritises the place of feelings, unconscious defences and intersubjectivity in the shaping of identity and; the third, 'genealogical' approach', which presents a 'thinner' conception of 'human material' than psychoanalysis and which looks at how individuals acquire 'limited and specific forms of personhood...in their passage through social institutions'. While this study will draw on all of these theory perspectives on identity, the psychoanalytic view will be emphasised, because it is argued that emotion has been insufficiently integrated into studies of identity and experience of severely learning disabled young people.

level of the discursive formation and practices which constitute the social field' suggests that 'the term identity...arises precisely at the point of intersection between them'. In order to explore young people's identity development therefore, it would seem necessary to consider both inner, psychic development and outer, social worlds. Hall cautions however against the expectation that it will be possible 'ever to be able to square up these two constituents as equivalents' (ibid: 20). It is hoped instead, that a creative exploration of these different perspectives will enable a rich and complex understanding of the lives of those researched to emerge.

The question then arises of how such a wide range of psychosocial, identity related themes might be researched. Contemporary approaches tend to emphasise the notion of multidisciplinary (for example, Marks 1999 on disability; Edwards et al 2006 on childhood sibling identities). This study is going to take a multidisciplinary approach and later in this chapter a wide range of ideas from sociological to psychoanalytic perspectives will be discussed and reviewed to this end. The form of multidisciplinary made use of here is going to take a step further by making use of academic knowledge woven together with that developed during clinical and practice experience. My own experience as a field social worker, practising with disabled children and their families, necessarily colours my interest and leads me in this direction.

The plan to investigate the lives of young people with severe cognitive impairments, as intended here, therefore also raises questions about the methods to be employed; how do you carry out research with people to understand their experience if you and they cannot communicate verbally? Traditional approaches to psychosocial research tend to take for granted the content of written or verbal responses in shaping and forming the outcomes of the investigation (Hollway 2004) and arguably this is where attempts to research severely learning disabled young people's lives have come unstuck in the past (Stalker and Connors 2003). If people cannot communicate their response clearly, how does the researcher come to an understanding of the subject's world? In this area, research approaches which go beyond the spoken word to consider subjectivity and the emotions come to the fore.

In their research on the experience of crime, Hollway and Jefferson (2000) set out a way of conducting psychosocial research which does not take the initial, surface, verbal response of respondents as the final ‘truth’ behind the phenomena they are researching. Instead they set up the notion of the ‘defended subject’; someone who like all of us presents, when interviewed, a narrative of their experience which is coloured by social, historical and environmental context, but also a narrative shaped by unconscious processes, including defence mechanisms. They consider the need for reflexivity in research methodology by emphasising the existence of the ‘double hermeneutic’; that both the researched and the researcher’s subjectivities should be taken into account, providing the very substance of the material to be researched (Hollway, 2004; Hollway and Jefferson, 2000; and Briggs, 2005).

Researching severely learning disabled young people will require a method which is capable of going beyond traditional verbal methods of enquiry to place the young person’s subjective experience at the fore. The skills required to carry out the research will therefore be ‘practice near’ (Marsh and Fisher 2005) in nature and they may provide information about new directions for researching the needs of ‘hard to reach’ respondents and service users for the future.

c. A multidisciplinary approach: describing the fields of knowledge covered in this chapter

Before mapping-out a method for this research in more detail, the next stage is to define the multidisciplinary areas of knowledge which have informed the design of the project. These have been divided into three main areas; first, themes which emerge from sociology (primarily from social constructionism) and social policy and which move on to a concern with understandings of the self and identity in the late modern world. The second perspective is concerned with intra-psychic and interpersonal concerns, derived chiefly from the Kleinian object relations tradition and from attachment theory. The

third and final area looks at theories of adolescent process, relating these to the notion of transition.

2. The Sociological Domain: the social construction of disability, identity and the family

a. The Social Construction of Disability

i. The social model of disability

‘In our view, it is society which disables...Disability is something imposed on top of our impairments, by the way in which we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society’. (Union of Physically Impaired Against Segregation/Disability Alliance, 1976 (in Priestley 2001:xviii))

Derived from the work of political activists and academics in the United Kingdom from the 1960’s on, the social model of disability was developed as a tool with which both to conceptualise and to contribute towards ending, the oppressive experiences of disabled people⁴. Simply put, the model suggests that if attitudes and physical environments can change, then many of the physical, mental and sensory impairments experienced by disabled people become inconsequential and disability can be seen as a social construction. Drawing on the work of disability academics (Hunt, 1966; Finkelstein, 1980; Oliver, 1990) Marks (1999:79) summarises the principles involved by suggesting

...that many restrictions imposed on disabled people are not a natural or inevitable consequence of their impairment, but are a product of a social environment which fails to take account of certain people.

⁴ The eugenics movement of the early twentieth century had an enduring and devastating impact on learning disabled people’s lives, with emotional echoes continuing to the present day. Harris (2006) describes how sterilization was widespread in North America, parts of South America and Scandinavia. In Sweden 62,000 people were sterilised in a forty year period some as recently as 1976. 70,000 learning disabled people and those with neurological conditions were killed in Nazi death camps; 10,000 of these gassed in a major hospital for people with learning disabilities in Hesse-Nassau.

By establishing the notion of disability as a social construct, the 'medical model' of disability is heavily challenged and critiqued by authors. One account of a history of three phases of significance to disabled people (Finkelstein 1980 in Marks 1999) sets out the idea that the category 'disabled' came into being in a true sense, only during the industrial revolution in Britain. Before this, in feudal times, production took place on a local scale in small, home-based units, so that people with impairments remained integrated within society, able to contribute economically to their communities (though cruelty could still feature, as evidenced by the existence of 'freak shows' for example). With industrialisation, work became more organised and urban in nature and the separation of people with impairments commenced along with their classification as 'deviant' and morally degraded (Poor Law Reforms 1834 described in McClimens 2005:31). Medicine and its allied professions are seen as participating in the control and management of people with impairments, by assisting in processes which led to the incarceration of disabled people within the workhouse and the establishment of the principle of 'less eligibility' which set benefits below the level of the poorest working labourer (McClimens *ibid*).

In critiquing the medical model, disability theorists have interrogated the notion of 'normalcy' itself as a construct:

One of the tasks for a developing consciousness of disability issues is the attempt, then, to reverse the hegemony of the normal and to institute alternative ways of thinking about the abnormal. (Davis 1997).

Marks (1999) leads on from here to question the idea that there is such a clear-cut difference between able and disabled bodies, by showing that impairment is a universal experience for human beings (*ibid*: 114). This can be thought about in terms of the life course, as many are living longer with impairment rates rising with age, so in a sense 'able bodied people' might better be described as 'Contingently Able Bodied' (*ibid*:18). Technological developments (for example mobile phones and other communication aids)

are themselves blurring the distinction between the body and prosthetics which are made use of to assist and to become part of the body in question.

As will be described in greater detail later, Sinason's work (1986;1992) can also be seen to contribute to the notion that there is no simple distinction between those with impairments and those without, when she writes about the experience of learning disability in those she has worked with. In formulating the idea of 'secondary handicap' she shows that some learning disabled people present as appearing to be more 'handicapped' than they really have. Being treated badly by others and then internalising this negative identity can lead to this position. She also suggests that learning disabled people may be emotionally intelligent in ways often ignored by those around them, thus breaking up and questioning any simple definition of what constitutes intelligence.

Hughes (1999, in Twigg 2006:58) argues that the creation of the category 'disabled' involved more than just economically determined division of labour, between the 'normal' and 'abnormal' within society, as Marxist-influenced social model advocates such as Finkelstein have suggested. There is a notion based on the work of Foucault (1977) of the 'gaze' under which disabled people are held by the professionals and by wider society: 'Observation is not neutral. The gaze is socially constitutive. Eyes are instruments of power' (Twigg 2006:58) and this power has been used to control and to further 'disable' those with impairments. The process of 'returning the gaze' in order to take control back of disabled bodies is one which disabled artists and filmmakers are actively involved (for example, Liz Crow's film 'Nectar', 2006, which describes one man's experience of deafness). It will be argued in this research that it is possible to go beyond the use of gaze in such a powerful manner and to use observation instead as a reflexive tool; a methodology which enables the researcher and the subject to share in uncovering meaning (Hollway and Jefferson 2000). This perspective has particular resonance within the social work field where observation skills have been taught to help sensitise trainees to the emotional lives of service users, who are often in vulnerable

situations (Le Riche and Tanner 1998). The meaning of observation as a research tool which may be of use in this project therefore requires further consideration and debate⁵.

ii. The Social Model of Disability critiqued

Twigg (2006) is critical of adherents to the social model of disability who, she suggests, by rejecting the medical profession's focus on impairment have also downplayed 'the body' leading to an under-theorising of the 'body' in disability studies. Olsen and Clarke (2003) in their exploration of the experiences of disabled parents also address this area, drawing on Hughes and Paterson's (1997) critique of the social model and its separation of impairment and disability. For these authors, the social model is as guilty as the medical model of objectifying and denigrating the bodies of disabled people:

Indeed there is a powerful convergence between biomedicine and the social model of disability with respect to the body. Both treat it as a pre-social, inert, physical object, as discrete, palpable and separate from the self. The definitional separation of impairment and disability which is now a semantic convention for the social model follows the traditional, Cartesian, western meta-narrative of human constitution. The definition of impairment proposed by the social model of disability recapitulates the biomedical 'faulty machine' model of the body'.
(Hughes & Paterson, 1997: 329).

Critiques of the social model have then moved on somewhat from an economically determined view which gave primacy to issues such as employment and independence (Marks *ibid*:87) and the tendency to stand for the concerns of 'white, Western, male wheelchair users'. Morris (1992) has long developed this line of thinking as she adopts a feminist approach to considering the experience of disability. She suggests that the social model of disability runs the risk of 'adding women in' (1992:160) rather than itself providing a way of incorporating subjectivity and individual experience into its discourse. Marks (1999) extends Morris's perspective by observing that the social model has tended

⁵ The issue of making use of observation as a research tool will be looked at further in chapter two.

to ignore the differences that disabled people experience as a consequence of their gender, sexuality, race or culture and any other aspect of their individual identities. Through its preoccupation with physical disability, those with other forms of disability such as emotional distress, communicational difficulties or learning disabilities, may be left out of the picture by the social model. More recently, Shakespeare (2006) has also broken ranks with social model adherents, commenting on disability, emotions and their relationship to care and dependency; about which more will be said later.

Discussing social constructionism more generally, Craib (1998) is critical, pointing out that the approach fails to understand the workings of the emotions. Sociological studies he describes ‘do not present any conception of emotions, or of the psyche, as something which has a degree of autonomy from the social and from society itself’ (ibid:107). It is possible to see this confusion within disability studies, when angry, underlying feelings about the experience of disability get caught up in academic discourse (for example in the ‘blaming’ discussions outlined below on families in Priestly, 1998 and Middleton, 1999). Emotions, Craib argues, ‘are best seen as having a life of their own which is framed and deployed by the social’ (ibid: 107). Craib’s views on the significance of emotions are echoed by the present study, but it is proposed here that they do not have to be seen as autonomous and necessarily disconnected from the social. By use of a reflexive methodology in which the twin subjectivities of researcher and researched are central to the study, it may be possible that a more coherent exploration of the psychosocial world of the respondents can be made.

b. The Social Model of Disability: views of the family

While adopting a social constructionist perspective on disability, some academics have dwelt upon the damaging potential of the family in reproducing and enacting oppressive social attitudes towards their disabled children. Priestly (1998:213) for example, suggests that family itself can be a disabling force:

...disabled children are even more subject to unequal power relationships with their primary 'care' givers than disabled adults. Where relationships of enforced dependency are played out within relationships of parental influence, the agency of disabled children may be doubly constrained.

Middleton explores similarly ambivalent perspectives towards parents and families as she adopts an 'anti-oppressive' approach to social work with disabled children and their families (1996; 1999). Doubt is expressed as to whether non-disabled parents of disabled children are able to empathise with their child's situation sufficiently to 'get over' their shame and embarrassment arising from the disability or to help children acquire the necessary coping strategies:

Non-disabled parents of disabled children cannot easily act as role models. Unlike black parents, for example, they are unable to share their own personal coping mechanisms for dealing with teasing, bullying and other forms of oppressive behaviour. There has yet to be any real debate in this country about the needs of non-disabled parents raising children with impairments. (Middleton 1999:127).

A more balanced picture of parents of disabled young people is put forward by Pascall and Hendey (2004). While on the one hand they suggest that: 'Families can be damaging places' (ibid: 175) they also describe the important role played by 'exceptional parents' who support their physically disabled sons and daughters in the move towards successfully living independently from them. Even after moving to independent living,

...they acknowledged their parents' continuing role in moral and practical support. They described the ways that parents continued to protect them against needs and risks long after they were established. (Pascall & Hendey 2004:172)

Pascall and Hendey therefore view the circumstances of families of disabled young people in a way which acknowledges the ambivalence involved in caring relationships; that it is possible both to love and to feel resentment towards those who are very

dependent upon us. These authors are also able to show how structural advantages enjoyed by some families, enable them to support their disabled offspring in their wish to live more independent lives (a finding mirrored in studies of the non-disabled community, Jones 2006). A more complex, textured picture therefore begins to emerge of the identity development of disabled young people; development which may be viewed in terms of the young person's significant relationships and with the wider society in which they are living, rather than based only on rights.

c. The 'ideal' of independence and the 'problem' of dependency

Earlier, Shakespeare's (2006) critique of the social model of disability was highlighted for showing how the model fails to consider the complexities of disabled identities. Addressing the nature of relationships of care between disabled people and members of their close social networks, Shakespeare is particularly critical of adherents of the social model, who pursue the 'ethics of rights' as their aim, rather than thinking about other dimensions of disabled people's lives, namely the 'ethics of care'⁶. Separating the emotions of care from its physical aspects in a manner which some elements of the independent living movement see as an aim, is not possible for every disabled person and for many, the reality of long-term dependency therefore needs to be thought about:

...I believe not only that dependency is inextricable from human existence, but also that many disabled people have needs which will inevitably generate forms of ongoing dependency which exceed typical time-limited dependencies.

(Shakespeare 2006: 136)

⁶ Irwin (2001) and Rummery (2002) have looked at the idea of there being a moral shift in social policy towards disabled people in recent times, with a move from social rights entitlement to welfare (as accessed by assessment under NHSCCA, 1990) to civil rights and entitlement (evidenced most recently through 'personalisation' and individually held budgets, DH 2008). Whereas Irwin (2001) sees this as disrupting prejudiced attitudes that independence and work are 'good' while dependence and welfare claiming are 'bad' Shakespeare (2006) has shown that many groups of disabled people, such as those with severe learning disabilities, are not able to benefit from the choices being made available by social policy. Thus the inter-dependency of disabled and non-disabled people in care relationships ('ethics of care') needs to be given greater consideration than simply the 'ethics of rights'.

Shakespeare's introduction of the subject of disabled people's dependency needs enables a 'bracketing' or a putting to one side of rights perspectives, hinting as it does that emotions and relationships are important to consider in the 'ethics of care'. Often this area is explored in the literature from the perspective of parent and sibling carers and the physical and financial burden of care they face in providing for the needs of their disabled family member (Read 2006; Beresford 1995). This literature has been of great importance in influencing government policy aimed at improving the life experiences of disabled children and their families (DfES & HMT 2007), however it has not dwelt on the emotions of caring as this study aims to. Here the intention is to contextualise the notion of 'burden' by considering the identity needs of the severely disabled adolescent centrally, as well as those of other family members. Before the inter-personal and intra-personal aspects of learning disability are addressed later in this chapter, the broader sociological topic of identity formation and the family in late modern society will now be touched on.

d. Identity, families and disabled children in late modern society.

Sociologists writing about identity in the context of late modern society have tended to dwell upon the notion of flux and change facing individuals (Giddens 1991; 1992; Beck 1992). Individuals are described as seeking 'pure relationships' where personal intimacy needs might be met while trust is no longer 'anchored in criteria outside the relationship itself- such as criteria of kinship, social duty or traditional obligation' (Giddens 1992: 6).

Family studies writers (Jamieson 1998; Morgan 1996; Smart and Neale 1999) are critical of Giddens' inattention to the influence of factors such as class, ethnicity and religion. The arrival of children also impacts upon parental relationships. As relationships between the parental couple are characterised by their fragility in the context of the search for individual identity in the modern world, relationships with children are sometimes all that is left once the couple fractures and thus children become 'the focus of new hopes' (Beck & Beck-Gernsheim, in Smart and Neale:73). This is a theme echoed by Parton (2006) who seeks to account for the anxiety and intensity of feeling that surrounds the welfare of

children in modern society. In families where the particular features of long term dependency are in evidence with the presence of children with severe learning disabilities, the identities of family members might therefore be expected to be subject to these social processes which act both to unify and separate individuals.

Several themes raised by Giddens (1991) are important to consider in relation to the families in this study. First, he suggests that in late modernity, many aspects of real life and nature have been sequestered: 'nature literally ceases to exist as naturally occurring events become more and more pulled into systems determined by socialised influences.' (1991:166) Giddens shows how the body has become 'emancipated' (ibid:218), losing its mystique, opening its boundaries and becoming subject to improvement as with other aspects of the self. How then does the real, 'natural' appearance of impairment, both intellectual and perhaps physical too, impact on both the learning disabled young person in this study and on their parents? It was described earlier how commentators such as Twigg (2006) have indicated that the body is underplayed in sociological studies of disability. Are parent-carers directing the 'project of the self' in relation to their children, leading ever the search for improvement, cure and mastery over their child's impairment or are they contradicting or distancing themselves from this process?

Allied to this point is the subject of expertise. Giddens gives significance to the acquisition of expertise in the reflexive project of the self: a project which is 'generally oriented towards continual internal improvement or effectiveness' (ibid:31). He suggests that in modernity for the first time people are not disengaged from expert knowledge as they were in pre-modernity. While Beck (1992) suggests Giddens downplays the role of class in gaining access to expertise, families with severely learning disabled children may be likely to have a particular relationship to the notion of expertise. Do parents feel pressure to be experts on their children given the individualising tendencies of late modern society, the winding-down of institutional care for disabled people and the emphasis on the family as the 'right' location for care?

A third dimension to late modernity discussed by Giddens (1991) is the idea that life politics hold sway. Personal choice and autonomy are seen as key determinants as individuals steer their own life course. Social policy might be seen to be trying to meet infinite variations in the desires and wishes both of parent carers and young learning disabled people if this is the case. Surely this then raises the problem of how these desires can be met by existing welfare structures which may struggle to meet basic need in times of finite resources?

These themes require further exploration in this project, but one other area of research will be touched on before the subject of the family is moved on from; sibling relationships and disabled children.

e. Sibling identities and relationships with disabled children

Sanders' (2004) comprehensive review of the literature on sibling relationships indicates that research tends to focus on the negative aspects for non-disabled siblings' identities of having a disabled brother or sister. Themes uncovered by researchers include feelings of anger and guilt experienced by siblings caused by being ignored and unappreciated by parents, and children (particularly older girls) being placed into caring roles before they are ready (citing Seligman 1983). Sanders (2004) describes a review by Clausen (1984) which suggests that the risk for the non-disabled sibling is made more severe when the family is small in size, the non-disabled sibling is younger than the disabled child, the child's disability is severe and is not well understood by the non-disabled sibling.

Interaction between disabled children and the siblings is said to be more instrumental in nature (to do with helping, caring and teaching) while that between non-disabled siblings is often more expressive (citing McHale and Harris 1992). Sanders (2004) describes the work of McHale et al (1986) which shows that mothers of disabled children who have non-disabled siblings tend to see siblings relationships as positive, while their non-disabled children actually rate their family relationships as less cohesive than do children who have a non-disabled sibling.

To balance these negative findings, there are studies which emphasise positive outcomes for siblings of disabled children. Stainton and Besser (1998) are cited and they show that such experiences can lead to family unity, closeness and tolerance and greater understanding. One of the main mediating experiences seems to be the non-disabled child's feelings of fairness at differential treatment within the family. If siblings can understand that 'fairness does not mean being treated exactly the same' (Sanders: 134) then the experience of having a disabled brother or sister may be managed positively.

Mitchell's work on siblings (2003) is a helpful addition to this review as she emphasises the intensity of sibling relationships and the significance they have for human development. Mitchell stresses how important it is for children that parents manage both the hierarchy inherent in sibling relationships ('seriality') and the need for fairness; to be unique, yet part of a sibling group. Clearly her perspective echoes the findings of the research on siblings of disabled children described above.

3. Intrapersonal and interpersonal experience; relationships, the emotions and learning disability

a. Why dwell on relationships? Attachment theory and Kleinian object relations

It has already been said that sociological and rights-driven approaches to disability focus usefully on conceptualisations of disabled people as self-determining and with full status as members of the community (as illustrated by the shift from social rights to civil rights of entitlement). Emphasising themes of independence and rights has however led to the downplaying of the lived, subjective experiences of learning disabled young people whose lives are often led in dependent relationships with carers and families. Rights perspectives also do not often factor-in the experience of families and carers in their analyses and sometimes as shown, they resort to blaming families for 'damaging' the disabled member. In this study, additional approaches which include ideas about relationship and emotion are going to be incorporated; including attachment theory and Kleinian object relations.

Before introducing these, it is worth adding that psychoanalytic concepts have been rejected by many disability academics⁷. While it may be true that psychoanalysts have ‘pathologised’ disability in the past (just as occurred in wider social institutions and professional groups) it is a shame to throw the baby out with the bathwater by rejecting everything psychoanalytic thinking has to offer. For one thing, feelings of blame are often located around the subject of disability, as I have explained previously (Hingley-Jones, 2005) and psychoanalytic thinking provides a way of understanding this. Psychoanalytic therapists can in fact be seen to have actively engaged with the struggles faced by learning disabled people in modern society, by adding an understanding of interpersonal relationships and emotional development, thereby seeing disabled people as fully human, participating members of society. It would seem to make sense then, to bring together rights based and relationship based ideas of disability in forging a psychosocial approach.

i. Attachment theory and Kleinian object relations

Psychoanalytic and attachment perspectives see relationships in terms both of an individual’s external world, as well as within the internal world of the psyche. For attachment theorists, some of whose perspectives on disability are described later, patterns of early attachment between parent-carer and infant provide an internal working model which shapes the child’s expectations of, and shaping of, relationships through life (with secure, insecure and disorganised attachment styles resulting) (Howe 1995; 2006).

The Kleinian object relations approach also sees the significance of both the internal and external world of relationships (Klein 1952); the personality beginning to take shape from the earliest stages of life. Young infants are described as splitting the parent into good and bad objects as the anxiety of bearing intense feelings of love and hate are impossible

⁷ Davis (1997:20) for example sees Freud’s ideas as ‘producing a eugenics of the mind’ as he suggests that psychoanalysis is preoccupied by defining normalcy in relation to sexuality and function ‘then contrasting them with the perverse, abnormal, pathological, and even criminal’. Writers on the experience of parents of disabled people have also pointed out that psychoanalysis has not always been experienced in a sympathetic manner, for example Kysar (1968) on theories of autism causation and ‘parent blaming’.

to tolerate; a splitting process which is mirrored within the child's psyche. Feelings of love and hate are therefore projected into the mother, whose ability to experience 'reverie' (Bion 1962) and to contain these feelings should enable her to 'introject' the feelings back into the child in a 'digested', manageable form. This phase of the child's development ('paranoid schizoid position') assisted by adequate experiences of parental containment, gradually gives way to a stage when the infant becomes more able to integrate good and bad parts of the mother in their view of her and within their own psyche ('depressive position') thus lessening the need to adopt the defence mechanisms of projection and splitting. Movement between the two positions is seen as continuing throughout life. This is an important point, as parents too vary in their ability to contain and tolerate anxiety, partly through their own experience of being parented. Psychoanalytically informed clinicians and writers have contributed formulations, as will be described, of how the emergence of learning disability can impact on parent-child relationships in important ways.

ii. Some ways in which psychoanalytic thinkers have considered learning disability

Three sets of ideas of relevance to this study will be described initially: Dartington et al (1981) who examine the emotional dynamics of institutional care and societal attitudes towards disability; Valerie Sinason (1986) on 'secondary handicap' and trauma; and Miller (1998) and others on the issue of separation. These writers are influenced by Kleinian object relations thinking, their ideas shaped by clinical and institutional encounters with learning disabled adults and young people. Once these ideas have been described, consideration will be given to the impact of learning disability upon early infant-parent relating (the 'normative' operation of which is described above) and the development of inter-subjectivity. Simpson's (2005) description of the role of defence mechanisms and Howe's (2006) review of attachment and disability will then be described, as these present contrasting views on the emotional consequences of disability and learning disability in particular.

iii. Psychoanalytic studies of institutions and their defences

Psychoanalytically-informed studies of institutions in the 1960's and seventies took in the emotional dynamics of disabled residents' living circumstances (Miller & Gwynne 1972). In a later book which dwelt on the move of residents to smaller, community-based care settings, Dartington, Miller and Gwynne (1981) remembered how unpalatable their analyses had seemed to some. The authors focused on the extreme ambivalence towards disabled people which they identified in those institutions, in individuals around the disabled person and in wider society. Society found it difficult to accept those 'damaged' members they suggested and so placed them at social distance from the rest of the community, in large institutions: 'the implicit task of the institution is to cater for the 'socially dead' in the interval in between social and physical death' (ibid:14). Dartington et al (1981:14) said that 'segregation protects the general public from being confronted by the damage and the feelings it evokes'. Two further defence mechanisms are also identified: the 'warehousing model' and the 'horticultural model'.

The 'warehousing model' they suggested, evolves from a 'humanitarian defence', where learning disabled people are cared for to prolong life, or to 'postpone their physical death for as long as possible' (1981:14). This value-base emerges from the medical and nursing professions and it goes with 'the hope and expectation...that damage can be repaired'. The structures and defences of the hospital are then transferred into the residential setting in this 'warehouse' model of care: 'the "good" inmate is one who accepts the staff's diagnosis of his needs and the treatment they prescribe and administer' (1981:15). Boredom, frustration and distress are likely outcomes of such regimes.

Dartington et al (1981) propose the 'humanitarian defence' as a reversal of the first model. This is 'anti-medical' in approach, stressing that the learning disabled person is 'really normal' and that they have 'the same rights as every one else for autonomy, self-development, and self-fulfilment' (1981:15). This is termed the 'horticultural model' of residential institutions, in which development of the individual's potential is seen as central. Dartington et al describe this as a defence however, as the model suggests

‘unrealistic fantasies of rehabilitation’ and also, it proposes ‘independence’ as an ideal, in a manner which is unrealistic for anyone, but especially for those with physical disabilities (1981:15). In this way, dependence is seen as a weakness, not something to think further about. These authors proposed a model of residential care, in which residents are seen ‘*both as damaged and as people, both as dependent and as independent*’ (1981:16). This ‘both/ and’ perspective is one which the authors attempted to put into practice in work with two new small community care projects.

Given that this study is going to look at the lives of severely learning disabled teenagers within their own homes, it will be interesting to explore whether or not these models applied originally to institutional settings, have any relevance to contemporary family structures which have largely taken-back care responsibilities from the institutions. Is the social constructionist, rights-led approach to disability with its idealisation of independence, actually very much in line with the horticultural model and if so how do the young people and their families experience this kind of thinking?⁸

iv. Valerie Sinason: Learning Disability and Trauma

Sinason describes two underlying principles of the Workshop on Psychotherapy for Subnormal Patients at the Tavistock Clinic, started in the 1970’s, which helped to shape her thinking. Firstly, ‘no handicap in itself meant that a patient could not make use of therapy. There could be emotional intelligence left intact and rich regardless of how crippled performance intelligence was.’ (Sinason 1992:6). Secondly, learning disability was seen as ‘a fluid state that people moved in and out of throughout the day’ (1992:7). The premise was established by this thinking that even severely learning disabled people have complex emotional worlds that might be understood by others. Also, it was suggested that like non-disabled people, learning disabled people’s mental states could shift and change. Sinason (1992) provides many examples in her clinical work of people

⁸ This question links with the earlier discussion on the features of late modernity and their impact on families with severely cognitively impaired young people.

who might appear at one moment out of touch, and the next, more acutely aware of their own inner world and of relationships with those around them.

Sinason's writing is based on innovative clinical work with learning disabled young people and adults who have entered therapy with quite severe difficulties in relating, following abusive and neglectful experiences. Her view is that life for learning disabled people is often traumatic and she recounts many stories of abuse, neglect and their consequences in her work.⁹ Hollins and Sinason (2000) have formulated a set of 'shared psychic organising principles' which they have found many of their learning disabled patients have described and revealed during therapy. These commonly experienced features are the individual and particular effect of the disability itself; the theme of loss; issues to do with sexuality; dependency and fear of death or murder. Later, these themes will be returned to as they are linked to formulations of the common defence mechanisms found in individuals and families with a learning disabled member (Simpson 2005).

v. Learning disability and the need to separate

Other clinicians have begun to consider the issue (which will be returned to when adolescent processes are discussed) of how the learning disabled people they have treated have struggled with the notion of separation or 'becoming a subject' in adolescence and early adulthood (Miller 1998; Hartland-Rowe 2001). Miller (1998) described therapeutic work with one young woman who has Down's syndrome where issues of connection and separateness characterized much of the work; in particular the therapist's understanding of the young woman's pain at separation which put her in touch with feelings of damage and distress associated with her disability. Hartland-Rowe (2001) also considers these ideas of capacity to be separate in work she did within a residential setting for learning disabled adults. For her it seemed some early life experiences had limited the adults'

⁹ This view on trauma is supported by statistics available on the prevalence of abuse of disabled children as a broad category. Margaret Kennedy (2002:150) for example, cites studies which mention high rates of physical abuse and sexual abuse experienced by disabled children, with sometimes as many as 50 or 60% of children reporting abuse. Disabled children are also more likely to be placed into local authority care than non-disabled children. When in the care system, they are then more likely to end up in residential than family-based settings; settings which are themselves more risky than family-based care (Miller 2002).

capacity to have independent life. Without someone to carry and contain their emotional experience, the residents seemed lifeless and cut-off, subject to experience, not active agents able to have some sense of control and influence their lives.

More recently, Miller (2004) looked at personality development and learning disability, suggesting that the origins of some of the difficulties identified lie in relationships between parents and their disabled infant at the earliest stages. Her approach is to describe this in terms of the transference she has experienced in her therapeutic work with learning disabled young people and adults, which she says is often characterised by the sense that the young person has a harsh super-ego which generates poor self-esteem. Miller describes this:

‘...it is this powerfully negative view of themselves that leads learning disabled adolescents to readily take on their societal role as excluded, unwanted outsiders, preferably remaining unseen by others. It may also impede their capacities to develop and to learn because the fundamental sense of self is damaged and is felt to be incapable of healthy cognitive growth’ (ibid: 84).

Miller goes on to describe how sensitive therapeutic work can assist in young people’s emotional development, by reflecting on the idea of the ‘container-contained’ model of Bion (1962).

b. Disability and models of parent-child relationship

Therapeutic practice with learning disabled adults, such as that described, looks at how difficulties in the early relationships between subjects and their parents may set the pattern for relational problems in later life. The following section considers research and theory of early infant development which emphasises the importance of inter-subjectivity between parent and young infant. The impact of disability on inter-subjectivity is then described, as the themes of ‘primary disappointment’ and the role of defence mechanisms

are introduced. After this, attachment perspectives will be added as they offer a different view of the impact of disability.

i. Early infant development

Stern (1998) and Trevarthen et al (1998) have studied the earliest stages of mother-infant relating, showing that the relationship is one contributed to by both parties. Infants can be seen to be born with the capacity to relate and mothers can be seen to unconsciously predict and accommodate to their baby's wish to be active and then to relax and the relationship can be seen as a kind of mutually satisfying dance when it goes well.

It is often suggested that parents experience the arrival of a disabled child as traumatic and that this trauma begins from the moment the parents identify their baby's impairment themselves or a diagnosis is offered by a professional (Rafael-Leff 1993; Bloom 2005). While this is no doubt true in the majority of cases, there remain some exceptions to this idea of impairment as a universally feared and undesired eventuality. For example, a minority of profoundly deaf parents would choose to have a deaf child if there were able to, stating that a child who is not deaf would find it hard to fit into a deaf household (Times on line, December 23rd 2007).

Where a child is disabled, researchers on parent-infant relating suggest that the parent-child relationship will usually still proceed in a manner in which the mother and child remain able to naturally accommodate to each other's needs. On occasion however, perhaps because of the trauma of discovery of the disability, because of the nature of the disability itself, or because of the parent's own difficulties, parents will be less available and responsive to the child. Jones (in Schaffer 1977) has looked at early relating between babies with Down's syndrome and their parents in this light and while he found no major inability to accommodate, there were indications of mothers and babies finding it difficult to get the stimulation/relaxation pattern right at all times. Sometimes the baby responded in a disappointing way, or the mother became dejected. While these observations make only tentative links, some authors have begun to suggest that learning

disabled children may come to experience a greater degree of insecure attachment to their caregivers than non-disabled children (Hollins & Sinason 2000). Recent critique of this perspective will be described later, drawing on Howe (2006), but before this some ideas developed by psychoanalytic thinkers and practitioners will be considered in more depth as these address how early parent-child relationships may be influenced by the infant's disability.

ii. Disability, 'primary disappointment' and the mechanisms of defence

Primary disappointment

One means of looking at this area of dejection and suggested insecure attachment between parent and infant is represented by focusing upon the need for mother and child to 'fall in love' with each other. Louise Emanuel (1997:279) describes the 'primary disappointment' experienced by some parents at the birth of their disabled child. The child may 'introject a disappointed, hostile or even horrified internal object and may feel herself to be monstrous and worthy only of rejection'. Meltzer's ideas of 'aesthetic reciprocity' are introduced to describe aspects of the early mother-infant bond, suggesting that disability can impact upon this area. Reid (1990:50) has addressed this area too, describing 'the beautiful experience of being in mother's mind a loved, beautiful baby' and the idea that 'an important aspect of mother's love should include the capacity to be uncritically appreciative of her baby'. Rafael-Leff (1991 in Bloom 2005:205) suggests that with the birth of a learning disabled child, the loss of the fantasised 'perfect baby' must be mourned before attachment to the living infant can occur.

Simpson (2005) considers parenting and the experience of having a disabled child in the light of his extensive clinical experience of working with learning disabled young people and their parents. These ideas will be described in some depth as they provide a coherent perspective. Following on from the ideas of Rafael-Leff (1993) and others, Simpson (2005:103) describes how all parents have to give up the idea of the imagined and idealised baby of pregnancy at birth and that for parents having a disabled infant, this

grief is 'not dissimilar to losing a child through death'. He suggests that the mourning for the loss of the ideal child, when the real child is learning disabled, is rarely worked through and it is 'often arrested with important consequences' (ibid). Sinason's inclusion of loss as one of the 'shared psychic organising principles' (Hollins & Sinason 2000) exhibited by young learning disabled people themselves, indicates that all members of the family can be affected.

Simpson then looks at the existence of powerful feelings of hatred which learning disabled children can arouse in their parents. While feelings of love and hate are normal for all parents to experience in relation to their offspring, he points out the particular difficulties where learning disability is concerned, suggesting that impairment and disfigurement can arouse unconscious fears and anxieties about monstrosity. He then goes on to look at the concept of 'nameless dread' which Bion used to describe the mother's inability to contain the destructive drives of the infant and the anxiety this arouses (Bion 1962), linking this to the fears aroused in parents of children with impairments. Of course, becoming aware and then working through these feelings of hatred and dread of a vulnerable child with learning disabilities is an extremely difficult process for parents, resulting in a combination of anger, guilt and shame (ibid 105). Again, Hollins and Sinason (2000) pick up on this area in their work, by naming 'fear of death and murder' as well as dependency issues as themes often expressed by learning disabled young people in therapy.

Simpson's perspective is that parents may feel blameworthy, feeling that they have caused the child's disability themselves in some manner, even when this is not the case at all. Living with these emotions which are often in the unconscious realm can result in the experience of depressive anxiety in the parent, as the parent feels that their own internal objects are damaged, mirroring the impairment of the actual child they have produced. Thus the adult's sense of self as a good and containing parent for their child may itself be impaired and there may be a deep sense of shame and a wish to hide the disabled child away from the world. In an earlier work, Simpson (2004:73) describes the state of mind

which can prevail as a 'melancholic state'. Certain defence mechanisms are then likely to be set up to deal with this difficult to bear anxiety.

Projection, denial and idealisation

Three main defences can be identified (Simpson 2005): projection, denial and idealisation. Projection, he puts forward, can be made use of in order to rid the mind of difficult to bear anxieties such as those described and this defence can be expressed between the parental couple or between the disabled child and their siblings in different constellations. Denial is another common defence mechanism made use of, when parents of learning disabled children may deny their child's impairment or see it as a 'gift from god'. Simpson suggests that while campaign groups for learning disabled people are important to provide support to individuals and their families, such groups can have deleterious effects as the moral superiority of disabled people may be implied, denying the difficulties experienced by the person with learning disabled person. Such an argument may be levied against the proponents of the social model of disability which as has already been described, may deny the individual experiences and the physical and emotional pains of living with some forms of impairment.

In considering the third defence mechanism of idealisation, Simpson proposes that parents may turn their unacceptable negative feelings about their learning disabled child into a kind of pure love, or idealisation of their child, who is kept in a dependent state. In this way, the young person's selfhood is denied and their opportunities to learn and to develop in a manner separate from their parent, is not permitted. Simpson highlights the sexuality development of adolescents with learning disabilities as problematic in this regard as at this stage of development, curiosity and experimentation are necessary for the young person to learn about themselves and others and to develop the potential for relationships. He suggests that many learning disabled teenagers have to remain in the 'good', compliant and uncurious mode in order not to challenge their parents' defensive structures. In this way, learning disabled adolescents may have to 'protect their parents from the reality of their disability, which they fear will lead to their parent's psychic

collapse' (ibid 110). Sinason (1992) describes other occasions when the expression of sexuality by learning disabled adolescents and young adults becomes aggressive and socially challenging. In one case, she describes this occurring when a mother infantilised their adult son, treating him as 'Peter Pan' and refusing to allow him to learn to wash and dress himself more independently. Sinason shows that: 'To try and develop sexual and bodily autonomy in such a context is very difficult' (1992:260).

Siblings of learning disabled children too, may be placed in a difficult position by their parents who expect them to be exceptionally well behaved and academically successful, Simpson suggests. In these cases, Simpson (2004) proposes that learning disability may then become a 'refuge from knowledge' within the family.

c. Critiquing notions of learning disability as trauma: the contribution of attachment theory

Howe (2006) recently reviewed available literature on attachment patterns between disabled children and their parents. This forms a useful counterpoint to Simpson's clinically relevant, but rather bleak account of learning disability and its impact on parent-child relationships. Howe starts from the position of questioning whether a child's intrinsic characteristics have a major impact on attachment patterns; patterns which are usually viewed more from the perspective of the caregiver's potential to parent than the child's factors. For many disabled children, Howe suggests, the ability of the child to communicate their mental state may be influenced by particular functional and sensory impairments (ibid:98).

In one example, Howe looks at children with Down's syndrome, who have been found to process information slowly due to their learning difficulties (Anderson 2001, in Howe 2006); but they also use fewer words to describe their internal state (describing how they think or feel for example). Mothers have been found to respond to this by using fewer internal state words themselves when communicating with their child who has Down's syndrome and this leads in turn 'to less coordination and synchrony in parent-child

exchanges' (as Jones, in Schaffer 1977 reported above). Therefore, while people with Down's syndrome do develop a 'theory of mind' concerning others around them, their understanding may be 'simpler and less subtle' (Howe *ibid*:99).

Howe also considers the impact of severe physical disability (including that experienced by children with some forms of cerebral palsy, spina bifida and other developmental difficulties) on communication and social interaction. Not only can such a physical disability (which is accompanied by learning disability in around three quarters of cases) impact on communication and social interaction directly, but he suggests that caregivers' availability may also be impaired by stress caused by their own difficulties in coping with the additional needs of their child.

Looking at the available research which considers the interaction-effects of impairment, environmental factors and the parents' factors in shaping attachment patterns (from secure attachment, through insecure avoidant, insecure ambivalent and disorganised forms) he suggests that:

...there is a growing body of research that supports the broad thesis that children with a wide variety of congenital medical conditions and disabilities are more likely to be classified insecurely attached (*ibid*:100).

Drawing particularly on van IZendoorn et al (1992) however, this position is qualified by the point that disabled children of mothers who had particular problems such as depression, were especially likely to exhibit disorganised insecure attachment behaviours. Disabled children of mothers who did not have such problems were much more likely to display attachment behaviour closer to the 'normal' population.

There are other examples of increased rates of insecure attachments amongst disabled children cited by Howe. For example, Barnett et al (1999 cited in Howe 2006) found that children with neurological problems (including Down's syndrome and autism) showed rates of disorganised, insecure attachment between 20 and 33%, compared with 15% in

the normative population. Most interestingly however, Howe shows that the severity of a child's disability and the appearance of insecure attachment patterns may be correlated, but in an unexpected fashion:

...it also has been observed that the increased severity of a child's disability does not actually predict increased risk of insecurity; indeed, there are some indications that in the case of children with more severe disabilities, rates of security actually increase (ibid:100).

Howe looks at Pianta et al (1999) who have considered how unresolved grief reactions to diagnosis of disability in their child might impact on parental caregiving patterns. They suggest that despite the risk that the child's attachment behaviours (crying or other signals) might trigger an avoidant reaction, most parents, even those with unresolved grief, respond appropriately to their child:

... the immediate physical needs of the children left parents with no illusions or uncertainties about the nature of the caregiving relationship. Mothers developed a strong focus on 'doing-things' and the many practical tasks associated with caring for their children. The authors [Pianta et al 1999] speculate that the need to focus intensely on direct, physical care may, to some extent, override resolution of past losses or traumas (Howe 2006: 102).

This is suggesting that the predictability of some impairments and medical conditions may contribute to the ability of parents to provide reliable care thus reinforcing secure attachment behaviours. This contrasts with children with conditions such as epilepsy which have stressful and unpredictable illness episodes where attachments 'were more likely to be insecure' (ibid: 102)¹⁰.

¹⁰ It might be added here, that these patterns are sure to be complex to disentangle as a parent's grief and mourning over their child's diagnosis as disabled would be difficult to separate from other unresolved issues from the parent's own childhood. Bringing in a psychoanalytic perspective, unconscious communication needs to be considered as disabled young people while being cared for excellently from a physical perspective are still occasionally subject to emotional abuse and neglect within their families, as I

Howe's review can be seen as broadly in tune with those presented earlier by Simpson (2005) from an object relations perspective. It might be that in some instances the parent experiences the birth of a disabled child as damaging to their internal objects and that the parent can feel a deep sense of blame and guilt for having produced the child, which results in the need for certain defence mechanisms. Bion's (1962) model of parent and child in a 'container-contained' relationship fits well with the view of the constellation of possible attachment behaviours described by Howe. Certainly the prescription offered by Howe for support and prevention of difficulties in families where a child is diagnosed with a disability (ibid:103) reflects the need for a containing and emotionally aware provision of professional services to the family¹¹.

In my own practice experience I have noticed that parents' difficulties in caring for their disabled child do not seem to directly correlate to the severity of the child's disability. This suggests that a parent's personal emotional history, including their own experiences of being cared-for by their own parents and carers, does indeed have a bearing on how they themselves will cope as a parent. Children deemed extremely difficult to care for (for example some children with autistic spectrum disorder) whose behaviour may be challenging in their own home, sometimes can be seen to transform when they are placed with experienced foster carers (Beek and Schofield 2004). Parental exhaustion, the need to be offered support in learning appropriate parenting skills and for respite from caring roles play a large part in this, but the emotional component is also involved in the capacity to care. Perhaps some foster carers are able to cope partly because they do not carry the burden of damage to their own sense of self, which Simpson has outlined.

know from my own practice experience. Immaculate physical care can sometimes divert professionals' attention from the distressing emotional experiences of the young disabled person.

¹¹ This includes: the need to provide practical and economic support to families; information about their child's disability; professional support around the two themes of helping parents to come to terms with the diagnosis and the opportunity to work through any unresolved attachment issues from their own childhoods. This last point is an important one, as parents of disabled children themselves have identified that emotional support should be available to them, particularly at the time of their child's diagnosis of disability or chronic illness (DfES & DH 2003).

4. Adolescence and Transition

The final area to be considered in this multidisciplinary review is the life-stage of adolescence as it relates to the notion of 'Transition' for learning disabled young people. Clearly, the experience of severe cognitive disability will have a major impact on identity related issues of adolescent development and it is expected that this study will throw light on some of these. First, some definitional issues relating to adolescence are going to be introduced. After that, a brief look will be taken at significant elements of adolescent and pubertal development available in the normative developmental literature, to set the scene for this study of young severely learning disabled people in their psychosocial context. This will include some details of physical development, psychosocial and psychosexual development and then the notion of adolescence as process. In the last section, adolescence as a transitional process will be considered, as this links with the social policy dimension for learning disabled young people.

a. Adolescence: definitions

Some see the concept of adolescence, as a distinct phase of human development, as culturally, economically and historically bounded arising only with industrialisation and the extended education of young people (Aries 1962). There are many contemporary examples of non-western cultures where young children move out of a state of childhood due to the imperative that they work¹² (Patel et al 2007) and at the other extreme, some young people experience greatly extended adolescent life phase (Thomson 2004)¹³. Given that the very notion of adolescence is itself contested, it is unsurprising that there are different definitions as to its age boundaries. Patel et al (2007) cite the WHO definition of adolescence as falling between the ages of ten and nineteen while these

¹² Patel et al (2007) citing Blanchet 1996, give the example of Bangladesh where six year olds who have started work are no longer regarded as children and Tobin and Freidman, (1984) who describe the Hmong of southeast Asia, in whose culture childhood ends at twelve or thirteen years.

¹³ Thomson et al (2004:2) show that patterns of extended adolescence in the UK 'are unusually differentiated, and structured by social class' with patterns of accelerated transition to adulthood in poorer communities and extended adolescence in more middle class examples.

authors come up with a looser definition of ‘young people’ who, as distinct from children and adults, fall between the ages of twelve and twenty four years.

b. Domains of development

i. Physical development

Adolescence involves intense experiences of change in the physical body and its chemistry, arising from the process of puberty. Significant hormonal changes trigger two sets of body changes in puberty, involving firstly the development of sex organs and also broader changes to brain, bones, muscle and other body organs (Boyd and Bee 2006)¹⁴. There are two major growth spurts in the brain, firstly from the age of thirteen to fifteen years. In this phase, the cerebral cortex develops in areas which control spatial perception and motor function. Cognitive functioning improves during this time as well. The second growth spurt is from about seventeen years into early adulthood and during this time the frontal lobes of the cerebral cortex develop, improving logic and planning abilities.¹⁵

ii. Social, sexual and emotional development

Stanley Hall, in his 1904 work ‘Adolescence’, is often cited as the first psychologist to focus upon the idea of this stage as a transition between childhood and adulthood (Boyd and Bee 2006) using the term ‘sturm und drang’ (storm and stress) to illustrate the turmoil which tends to be seen as characteristic of this time. In contrast to this view,

¹⁴ For girls, the development of primary sex characteristics (ovaries, uterus and vagina) takes place alongside secondary ones (breast development and pubic hair). Boys’ primary sex characteristics see the development of testes and penis along with the secondary characteristics of voice pitch, beard growth and pubic hair.

¹⁵ The adolescent’s body gains height, as much as six inches a year in some cases, with girls achieving adult height by around sixteen years while boys may be continuing to grow into early adulthood. The body’s growth may be uneven, with hands and feet tending to grow before the body’s trunk, leading to the view of adolescents as ungainly in bodily gait (Boyd and Bee, 2006).

Freud did not see adolescence in such dramatic terms. As Sugarman (2001) shows, Freud saw the shaping of the most important aspects of psychosexual development as residing in processes at work in the earlier years of life (oral, anal, phallic, oedipal and latency stages). By adolescence, the final 'genital' stage of development is reached when teenagers begin to reach sexual maturity and Freud saw personality and sexual development as already largely shaped by this stage. Adolescence is seen instead, as presenting an opportunity for earlier infantile sexual impulses to be re-worked and integrated into the personality, unifying 'the sexual and the tender' (Waddell 2002: 141, drawing on Freud's 'Three Essays on Sexuality' 1905). Freud's thoughts on adolescence have been developed further by others working in the psychotherapeutic field and more will be said of this below.

c. Erikson's psychosocial model of the lifespan

Erikson (1963) extended Freud's ideas, by conceptualising human development as an eight-stage psychosocial process; a 'model of a changing individual operating in a changing society' (Sugarman 2001:91). In this model, as society makes different demands on the individual over time, so the ego must adapt by resolving certain crises which can be identified at each life stage. Focusing on the adolescent stage, Erikson (1963) described the crisis to be worked through during this phase as 'Identity versus Role Confusion'. The huge physical and hormonal changes of adolescence alongside the sense that adult roles lie ahead, cause the young person to question 'all samenesses and continuities relied on earlier' (1963:152) and new forms of identity are to be tried out. Resolution of this stage, Erikson suggests, leads to the creation of ego identity built upon the successful working through of the earlier stages of psychosocial development and the emergence of certain 'virtues' (hope, will and purpose). 'Fidelity' is seen as the outcome sought from the adolescent stage of development.

Blos (1962, 1967), from a psychoanalytic perspective, also sees adolescence as a staged process, suggesting there are sequential developmental tasks to be negotiated. The aim is for the adolescent to develop from the relative calm of latency, towards the stormy phase

of separating from their parents. Blos developed Mahler's ideas, which describe the process of individuation in early childhood as 'hatching from the symbiotic membrane' (in Kroger, 1996:53) and adolescence as a second 'individuation process' (Blos 1967:163) leading to the young person establishing an identity separate from the parents.

d. Contemporary psychoanalytic views of adolescence as process

Waddell's (2002) writing on psychosexual development exemplifies the move within contemporary psychoanalytic psychotherapy to view adolescence more as a process than as transformation from one state to another. In contrast to Freud's earlier formulation, adolescence is now understood to be a time when vital processes shaping the personality take place. Fired by the appearance of the embodied sexual and physical changes of puberty, conflicts and wishes arising from sexual and aggressive feelings of earlier stages (particularly from the oedipal stage) can re-emerge. As Waddell shows however: 'The important difference is that the genital changes of puberty mean that these desires can actually be carried out' (ibid: 143).

This leads to the thought that relationships are central to the experience of adolescence; relationships with adults as well as peers. Waddell suggests that the conflicts of this stage of development can be coped with and thought about by young people depending on several factors:

..for example, on the quality of the original containment of infantile impulses and feelings; on the degree of stability achieved during the latency years and on the internal and external pressures which the young person has to contend with (ibid: 142)

In this study of severely learning disabled young people, it is unclear to what degree these experiences will be shared with non-disabled peers; the role of cognitive impairment will be likely to have an impact. Clearly the young people will be likely to develop the bodily changes of puberty and hormones will play their part, affecting mood and demeanour.

Just how parent-carers will respond to these changes, having cared for their child already through the earlier oedipal phase is an area which has not, to date, been systematically studied.

e. Adolescence as a time of oscillating identity: 'becoming a subject'

Contemporary psychoanalytically orientated therapists and theorists have begun to look at adolescent processes in terms of the concept of 'subjectivation' (Cahn 1998) or 'becoming a subject' (Kennedy 2000). Such ideas draw in part upon Foucault's thoughts on 'the constitution of subjects' (Simons 1995:19). As Simons explains, Foucault (1982) develops the idea that the limits of subjectivity are determined by the three axes of truth, power and ethics. Addressing the particular characteristics of power, Foucault suggests that it can be both limiting and subjugating while also it can be enabling:

Such power (or limiting conditions) produces a subject who is both 'subject to someone else by control and dependence, and tied to his meanings of the word *subject*' (1982:212). The first meaning implies power as coercion and domination by another, while the second refers to the constraint of being limited by one's identity (Simons 1995: 31).

Cahn (1998) looks at the both internal and external influences on the adolescent in a manner which echoes these ideas. While there is a sense that the adolescent is moving towards a more stable, adult state of mind in which the 'psyche becomes more structured, giving way to increasingly organised forms' (Cahn 1998:150) this adult status is precarious:

the process of becoming-a-subject will continue throughout life, and the subject will have to invent himself constantly through the necessary links he has to create as well as in the way those relevant links are perpetually called into question' (1998:151).

Cahn describes the ‘identity-related anxieties’ of adolescence and ‘the simultaneously hyper-exciting and hyper-threatening quality of the object’ (1998:150). An ‘unbinding’ process is at work in which old links are rejected and new ones taken up; the person remains ‘open to the unknown’ or ‘persists in the mechanical and the identical’. These processes are influenced both by internal forces (‘from the drives’) and external ones (‘from the environment and from objects’). For Cahn then, this is a process ‘of differentiation rather than of individuation-separation’ (ibid:151). He characterises this by suggesting that the young person or subject ‘will become other while remaining to the same extent himself’ (1998:152).

Kennedy (2000) has also looked at the idea of ‘becoming a subject’. As Briggs (2002) has described, instead of seeing adolescence as a process of ‘hatching’ a new identity, it may be conceptualized as an oscillating process, moving between moments of separation to times of greater dependence on parental figures. The adolescent is seen as experiencing times of being ‘subject to’ events; moments of powerlessness, when they cannot conceive of a state of separate identity, to moments when they become ‘subject of’ experience; powerfully able to embody their own independent identity.

f. Applying normative models of adolescent development to severely learning disabled young people: What questions arise for policy, practice and research?

This study is looking at adolescents with severe learning disabilities, during a phase of life which is usually described by policy makers and practitioners working with them as ‘Transition’ (DfES 2001; DH 2000). The idea of Transition has been adopted to ensure that the experiences of learning disabled young people are ‘normalised’ (Wolfensberger in Race 2003)¹⁶. Lifespan models of development are therefore used to provide a template to place over the experiences of learning disabled young people, ensuring that

¹⁶ Wolfensberger’s work on normalization and social role valorization has contributed strongly to changing professional and eventually societal attitudes towards learning disabled people. Wolfensberger helped to form a meticulous theoretical underpinning for the notion that learning disabled people should be integrated into mainstream life; ‘normalized’ (Race 2003). From here, social role valorization was developed as a method of theorizing the underlying values and social attitudes which led to the social devaluing of all excluded groups.

they are offered age-appropriate opportunities in families, schools and social activities. This point was particularly important within the education sphere, because segregationist attitudes meant that children with severe learning disabilities were denied access to education; deemed 'ineducatable' at the time when universal education was created in Britain (Wood Committee 1924, described in Marks 1999). There are also implications for the arrival of adulthood for learning disabled young people, as this starts in a very concrete sense on their eighteenth and nineteenth birthday, with regard to the social and educational provision upon which they are often very dependent. On these key dates, responsibility for planning services to meet young people's needs shift from child-centred to adult services, with changes of relevant legislative arrangements and often planning at this stage of life has been very poor (Morris 1999; DfES & HM Treasury 2007) ¹⁷.

Clearly the developmental model upon which such social policy for learning disabled people is based, has more in common with the idea of adolescence as transformation than as a process of oscillation between different states of mind and body. In my own experience of working with adolescents with learning disabilities and their families, I have found that the transformative model of adolescence ('Transition') can present anxieties for both child and parent. It can be argued that such a 'fixed' notion of development may be problematic. Parents are often anxious about the idea of independence for their child and they may defend themselves by taking on a role of 'perpetual parenthood' (Todd & Shearn 1996:57); that is they may be unable to imagine their child has any potential to have an independent life or that they may need to change and adapt their roles as carers. Resulting from this, there may be difficulties in seeing their adolescent child's development as acceptable and desirable, rather as Simpson has identified (2004; 2005, above).

Tisdall (2001) has contributed in this area, by questioning how writers on the 'life course' have thought about learning disabled young people in adolescence in terms of many

¹⁷Broadly speaking there is a move from assessments of need which are based on Children Act s17 (DH 1989) and special educational needs policy and practice (DfES 2001), to provisions under the NHSCCA, (DH,1990). Recent policy and practice developments focus increasingly on the process of transition with the appointment of transitions workers, transitions 'champions' by local authorities etc.

‘transitional’ or ambiguous stages and states. There are confused messages and views held about childhood itself (as will be outlined in chapter two when childhood research is considered); whether children are considered citizens in their own right, or whether they remain the responsibility of their parents (with all the different age-related rules to participation in life). For disabled young people, issues of dependence and independence which affect all adolescents, are added-to by wider societal perceptions of disability that tend to see these two states as polar opposites, with disabled people necessarily the receivers rather than the givers of care (Morris 1993, in Tisdall 2001).

The idea of adolescence as a time of oscillating experience, with the aim of achieving some sense of mastery of both one’s own internal world and claiming a space and identity within the external world, is one therefore which has presented a particular concern for learning disabled young people, their families and on the wider scale, professionals and social policy makers. The problem would seem to be how to enable young people with considerable care needs to become ‘subject of’ experience (to draw on Kennedy 2000). That is for learning disabled young adults to enjoy some control and embodiment of their own identities intra-psychically and in wider society, while recognizing that the learning disability itself may impose limitations given individuals’ cognition problems, care and dependency needs and the resultant challenges these present for separating from parent-carers. There will be times, I would suggest, for people with learning disabilities just as for non-disabled adults, when being ‘subject to’ the care of others is inevitable (Shakespeare 2006). The White Paper ‘Valuing People’ (2001) and current moves towards individually held budgets can be seen as examples of social policy on learning disability and adults in need more generally (the ‘personalisation’ agenda, DH 2008) which try to get to grips with this problematic area; how to promote independence while acknowledging and catering for dependency needs.

g. Summary, conclusions and research questions:

This chapter has set about reviewing and critiquing contemporary understandings of identity development, severe learning disability and adolescence. A case has been made

for studying identity development from a multidisciplinary, psychosocial perspective. Various approaches under the psychosocial ‘umbrella’ were considered, including those which reached out from the traditional sociological domain. Social constructionist ideas, upon which much of the academic discipline of disability studies is based, were the first to be thought about and these were critiqued in terms of their weakness in helping to account for the emotional, lived experience of disability and learning disability in particular. It was argued that it is essential to consider emotion and subjectivity when learning disability is discussed, given the sometimes tragic history of learning disabled people and the strong emotions which appear to emerge around the subject, on both personal and societal levels.

The theme of self and identity in late modern society were discussed next, as some important issues have been raised about how both learning disabled young people and their families’ lives have been impacted upon by the rise of individualism in contemporary society. A critique was offered of such perspectives, making use of the work of family studies and disability academics who stress how themes such as duty and cultural expectations can still be seen to play a major role in mediating parent-dependent children relationships in contemporary society, in many instances. In this review however, it was suggested that social policy and professional practice which operates to provide support to learning disabled young people and their families in the United Kingdom, tends to follow the individualistic mode, pursuing as it does the theme of personalisation of social care (DH 2008). In collaboration with this, social work practice with disabled children also still pursues the social constructionist approach (Middleton 1996; DH 2000; Read et al 2006). These approaches both emphasise the importance of independent agency for learning disabled young people and hint at the potential for members of society (even families) to inhibit and limit that independent agency. It may therefore be that these ways of viewing severely learning disabled teenagers present problems for their parents who are struggling with the reality of their children’s continued dependence upon them.

This project then proposes that psychoanalytic and attachment approaches should be brought into the frame, to extend and deepen understandings of the emotional and relational aspects of family lives of severely learning disabled young people as it is this area that presents a gap in current knowledge. The multidisciplinary, ‘practice near’ approach of this project has included clinical and practice related writings of psychoanalytic psychotherapists. Psychotherapists, who have long worked with issues of emotional distress and relationship difficulties with learning disabled young people, have much to contribute in terms of assisting in the project of researching identity development from a psychosocial perspective. The traditional psychotherapeutic approach to learning disability emerges from the notion of learning disability as representing a traumatic insult to the young person’s personality and to that of their parents’. From this perspective, learning disability can therefore be seen to present certain challenges to early infant-parent relating. On the one hand, parents can be seen to enter a ‘melancholic state’ (Simpson 2004:73) when the idealised, wished-for baby is lost and typical defence mechanisms are set-up to cope with these feelings, some of which distance the parent and child from real engagement with one another. On the other hand, impairments themselves can impact upon a child’s potential to relate to their parent. Attachment theory was alluded to as studies have shown that while insecure attachment patterns may be more common overall in disabled young people, with those whose disabilities require close, regular and predictable parental contact with their child (such as severe cerebral palsy) secure attachment is particularly evident (Howe 2006).

The final dimension to be explored within this critical review was that of adolescence. It was suggested that contemporary social policy and practice with learning disabled teenagers tends to derive, through adoption of the principles of ‘normalisation’, from a transformative notion of adolescent development: the idea of adolescence as ‘transition’ from childhood to adulthood, from dependence to independence. Such traditional approaches to adolescence were critiqued by offering instead the idea of adolescence as process. Adolescents do not ‘hatch’ into little adults, but instead they move between states of mind in which they embody their adult subjectivity to a greater or lesser extent. These processes are impacted upon by their own changing, pubertal body and their drives

and instincts, in relation to how they are treated by, and respond to, the external world. The processes of becoming a subject are then in themselves psychosocial in nature, encompassing as they do elements both of the internal psychic and physical self and the responding external social world. Young learning disabled people are affected by the same adolescent processes as their non-disabled peers and this project will seek to uncover some of the issues which such impairment can add to the picture.

Making use of this knowledge, it would seem that severely learning disabled young people's development occurs within a complex matrix of physical and emotional dimensions, mediated by relationships on the social, familial and personal levels. Given the lack of research on the theme, this research project will therefore concern itself primarily with exploring the emotional and relational aspects of severely learning disabled adolescents' identity development, while remaining within a psychosocial whole. The broad range of issues to be explored will therefore necessitate considering the following research questions:

- a) Young people with severe learning disabilities may be expected to reveal complex and shifting sets of identities in the same way as other non-disabled young people of their age. How can these processes be apprehended through a research methodology?

- b) Identity development during adolescence has been described in relation to processes of subjectivation; that is young people reveal shifting states of mind, sometimes experiencing a greater sense of subject status and at other times appearing more 'subject to' their experiences. These experiences can be seen as comprising external, relationships and characteristics as well as internal, intrapersonal features. What are the 'external', physical and embodied aspects of identity and developing subjectivity for severely learning disabled people and how can these be captured by research? What kinds of internal, shifting states of mind may be detected and again, how might research methods facilitate an understanding of these processes?

c) Young severely learning disabled people are likely to be living at home, within matrices of care and dependency with parents, carers and other family members. How can a research methodology begin to detect and to capture these relational patterns?

d) It may be supposed that if there is a close link between trauma and disability for learning disabled young people and their parents, it will be possible to observe difficulties in the parents' ability to hold the idea of their teenager as having the potential for independent thought and identity. Are such potentially detrimental processes discernable in the emotional interaction between them and how might these be understood?

e) The social policy notion of 'transition' of young learning disabled people from childhood to adulthood incorporates a notion of the birth of independent adult subject. This might be viewed alongside contemporary views on individualism in late modern society and the drive towards 'personalisation' of social care, with its emphasis on choice, autonomy and personal freedom. Can a research methodology begin to explore how these ideas and principles sit with family members who are often heavily involved in caring for young people with high level dependency needs and cognitive difficulties?

The next chapter will seek a research methodology which best enables an exploration of these wide ranging issues affecting learning disabled young people and their families.

Chapter Two

Methods Employed to Research the Young People

1. Introduction

The previous chapter made the case for placing emotion and relatedness at the forefront of the study of severely learning disabled young people's identity development. Traditional social constructionist accounts of disability, it was shown, have tended to neglect these elements while more recent accounts of disability, the self and identity in contemporary society have not achieved sufficient depth in their consideration of the emotional impact of learning disability either. Following this line of thinking, the challenge is set to identify a method of researching which is capable of capturing the complex interplay of emotion and relatedness within and between family members, in families where there is an adolescent with severe learning disabilities. The research is to be undertaken within the field of the family as it is evident that increasingly, severely learning disabled teenagers remain living with their families rather than, as used to be the case, moving to institutional care (Read et al 2006).

A range of factors have to be considered in developing a rationale for the methodology for this project. First, the fields of disability studies and childhood research are going to be touched on, as certain ethical and technical issues are raised by researching in these domains; issues which need to be thought about at the planning stages of the work. Next, broad choices between different methodological approaches will be elucidated to weigh up their advantages and disadvantages in relation to the aims of this study. The chosen methodology is then to be described with explanations provided for its fitness for purpose with an airing of possible limitations it may present. Finally the task will be to show how the methodology might be put into practice with consideration given to issues of validity, sampling and generalisability of findings.

2. Researching experience: matters of ethics and technique

a. Childhood research

Current debates concerning researching children's experiences have attempted to move beyond the idea of children as passive objects, to the notion that children have rights and agency (Greene & Hill 2005). The United Nations Convention on the Rights of the Child (1989) and The United Kingdom Children Act (1989) have led the way for research by stressing the importance of consulting with children on their views about decisions affecting their lives (Hill, 2005). While researching childhood experience is now seen as an important aim, Greene and Hill (2005) show that there is work to be done on shaping methods to perform this task. They criticise social constructionist perspectives on childhood for example for relegating 'experience' from the centre of concern to the psychological realm. Mainstream psychologists have in turn, they show, adopted an approach which preferences biological determinism to attempting 'psychological' explanations (ibid:2). For Hill (2005) childhood research led by psychologists fails to understand children's experience: 'the developmental paradigm has portrayed children as deficient adults rather than competent human beings in their own right' (ibid:62). The challenge of meaningfully researching children's lives however, comes when consideration is given to the way in which, as Hill concedes, adults and children differ in 'ability and power' (ibid:62).

In attempting to find techniques with which to research children's subjective experiences, Greene & Hogan (2005) propose that researchers might employ a 'multiplicity' of approaches. Edwards et al (2006:6) provide an example of this kind of multidisciplinary research in their study of sibling identity, by drawing on a range of theoretical perspectives with which they hope to provide a 'mirror ball or kaleidoscope effect'. Here, social constructionist and psychodynamic approaches are drawn upon to bring together ways of understanding children's social and emotional worlds. Qualitative research of this kind constitutes what Denzin and Lincoln (2000) describe as a

‘bricolage’; a bringing together of different, contrasting methodologies which help to form an understanding of a subject’s experience across a range of domains.

Greene & Hill (ibid) pose a technical question about how children experience their lives and the consequences of this for research. For these authors, children must be conscious subjects if they are to account for their experiences. What then of children who are pre-verbal or who have limited communication skills, such as those whose lives are to be researched in this project? Without a sense that the child is able to be aware of their own subjectivity in this way, then the only way forward is for researchers to make inferences, Greene & Hill argue, for example through observing their child subjects. This, they argue, is a problematic area as it is impossible ever to fully grasp the experience of another person.

The notion that subjectivity might be placed at the forefront of methodology is one that is challenging to traditional research methodologies such as these, but this idea will be returned to shortly as it is a central premise of this project. Instead of being a hindrance it is going to be argued that working with ‘inferences’, which draw on subjective experiences, feelings and emotions of both the researcher and the research subject, can provide the basis for a fruitful, exploratory methodology.

b. Disability research

There are parallels between the drive to consider ethical concerns in childhood research and the rights-led approach adopted in disability research. Disability academics have strongly criticised research methodologies which mimic the ‘medical model’ in that they suggest that an ‘expert’ researcher can somehow capture and comprehend the experience of disabled subjects (Davis 2000). Instead, an approach is recommended where disabled people are recognised as expert in their own lives and they should play a part in designing and planning research projects (Barnes 1992; Stone & Priestly 1996, in Davis 2000). Barton (1996) explores the notion that disability research should be emancipatory in design. He suggests that the sociological imagination should not just be engaged in

learning about disabled people, but instead it ‘contributes to the *benefit* of disabled people’ (Barton 1996:5). In putting forward this perspective, Barton proposes that questions should be posed about research projects involving disabled people, for example; ‘Is this a necessary activity’, and, ‘What does it entail and how is it achieved?’ (ibid).

One area which has perplexed rights-driven researchers working with severely learning disabled children and adults is the subject of consent and conscious participation in research. How is it possible to involve and empower severely learning disabled adolescents, as in this project, in designing and planning the methodology? Arscott et al (1998) address the issue of consent. Careful assessment is needed to ascertain the level of understanding learning disabled subjects have of what they are consenting to, nevertheless: ‘It is important that people with an intellectual disability are not excluded from research studies’ (Arscott et al 1998:82). Detheridge (2000) stresses that the development of means of communication with severely learning disabled children, is a key and empowering aspect of researching the experiences of those children. She however cites Stalker and Harris (1998, in Detheridge 2000:114) who ‘report that no examples were found in the literature of researchers finding ways to gain consent from people with a profound level of impairment’.

Stalker and Connors (2003) have continued to investigate how enhancing communication skills can improve the sensitivity of research methodologies to disabled children, but again difficulties are identified when researching the perspectives of children with severe learning disabilities. While these authors describe their development of a creative range of interview schedules incorporating visual aids and activities, they did not find these helpful when making contact with children with high levels of cognitive impairment. For two children in their study, the authors identified that eye pointing, head turning and other forms of non-verbal communication were important, but as researchers, they did not have the time to explore these with the children. Instead, they relied on information supplied to them by parents and carers. It would be necessary, they conclude, to spend some considerable length of time with those children ‘to become familiar with their ways

of communicating and be able to distinguish, for example, what crying meant on one occasion from what it meant on another' (2003:33). They propose that 'an ethnographic study using participant observation over many months' (ibid) might be one way of gaining this understanding.

In researching learning disabled adults' experiences, biographical and autobiographical methods have been used, along with broader studies of identity following the 'bricolage' approach. Three strands of research can be identified and these will be described briefly as they provide alternative methodologies which might be appropriate for this study.

Looking at the first strand, Middleton and Hewitt (2000) describe the use of life story books to enhance the quality of care planning with profoundly learning disabled adults. By capturing the past and details of individuals' biographies, these authors show how carers can be assisted to appreciate the agency and 'personhood' of service users. Citing Cheston (1994), Middleton and Hewitt (2000:264) suggest that for learning disabled people, a life story book 'provides an identity-enhancing account of their life'.

Second, Atkinson and Walmsley (1999) address the issue of the lost life stories of people with learning disabilities. These authors argue that only scraps of life stories or biographies of learning disabled people are retrievable from literature, hospital records and newspaper stories, due to the discriminatory social attitudes that have existed towards learning disabled people. Autobiographical records have recently been generated during emancipatory research, they suggest, but these tend to have what they describe as 'a performative function'; that is they have their common theme 'oppression and how people cope, or have coped with, institutional life, poverty, deprivation, abuse and discrimination' (ibid 211). They propose autobiography as a method by which a richer picture of learning disabled people's lives might be made available; one which focuses on more than a 'tragedy model' of learning disability. The notion that research might try to capture the more ordinary aspects of the life experiences of learning disabled people is one that the current project endorses.

A third strand of research, emerging from the self-advocacy movement, has identity as a focus and it looks at how subjects have managed or not managed to incorporate disability with other aspects of their identities. Beart (2005) for example, found that despite their taking part in self-advocacy groups, a large proportion of those defined as learning disabled by professionals, perhaps unsurprisingly given the stigma attached, disowned the label of 'learning disability'. Another example of a study which focuses on identities and how these are experienced, this time by disabled children is that of Watson et al (1999).

Watson et al (1999) researched young disabled people's identities by employing a range of different techniques, rather in the tradition of the 'bricolage'. Interviewing a group of more than three hundred young people with a variety of disabilities (sensory, physical and learning disabilities) the researchers discovered that the young people described their experiences of social isolation, exacerbated by attendance at special schools away from their own communities. Greater dependence on adults than non-disabled peers was described due to young people's care needs and also that lives are led to some degree in public. Rather like the adults in Beart's work described above, the young people did not only define themselves by their 'disabled identity'. At times they saw value in recognizing themselves as disabled, but at other times they acknowledged their gender, race, personal tastes and other identities as taking precedence.

To summarise the preceding two sections before moving on, issues of ethics and technique have been highlighted and critiqued in relation to research in childhood studies and disability studies. In both fields, much thought has been given to the ethics of research in recent times. In childhood research the notion that children should be seen as agents in their own right has emerged as an important issue, and consequently their experiences should be researched. Where there are worries for traditional sociological approaches in drawing inferences from what children say due to their lack of adult subject status and consciousness, some researchers have moved to the methodological technique of gathering a range of data; a 'bricolage' of observation and commentary from subjects whose ability to give clear voice to their view of the world is held to be in doubt.

While this is a good way forward in the main, there is a risk that by gathering an eclectic range of data, the findings may end up being mainly descriptive and lacking any attempt at integration into the 'psychosocial' whole of children's lives.

In disability research, with its rights emphasis, ethical issues are placed at the very centre of concern and there is something of a dilemma for academics who will only research in areas where disabled people can be partners in research: how is it possible to research ethically when subjects are unable to give informed consent, yet how can the needs of severely cognitively impaired individuals be understood if they are not researched? Researchers working with severely learning disabled children have focused upon the technique of refining and improving their communication skills, but they have accepted that where straightforward interviewing cannot be used, techniques such as participant observation might need to take its place. Some disability researchers are also employing the idea of biography and 'bricolage' as a way of providing a range of information on disabled people's lives, with a welcome emphasis on understanding the 'ordinary', everyday aspects of learning disabled people's lives (Atkinson and Walmsley 1999). While these are useful they can also be critiqued as the techniques have not so far been used to research emotionality and relatedness in an integrated, psychosocial fashion.

3. Thoughts on potential approaches to researching the experiences of severely learning disabled young people

To recap briefly, research questions were set out at the end of chapter one which centred initially on the need to explore the young person's internal and external relational fields; how is the young person experiencing themselves and others around them, as an adolescent, as a young person with impairments and in relation to other aspects of their identity? The questions then move more clearly into the field of dependent and caring relationships. These concern the way in which parents and carers respond to the changes the young disabled person is experiencing and the complexities involved in fostering the notion of the developing, separating young adult in the making when dependency issues are so central. Finally, the research questions moved on to consider the social policy

notion of transition and what this means for families with severely learning disabled young people in their midst.

Researching these themes of emotion and relatedness within the complex field of the family implies consideration of a multitude of variables. It is not anticipated that by pursuing quantitative methods of inquiry, by way of carrying out surveys and the gathering of statistical data, the complexity of individual lives, experiences, feelings and relationships would be explored or accounted for in any depth. Flick (2002) suggests that the complexity of most real life phenomena, such as are the focus of the present study, are not reducible to empirical studies which attempt to identify simple cause and effect relationships. Studies which rely on such an approach have the tendency to put the cart before the horse; that is they identify a methodology which determines what should be the object of study. Instead, she advocates some forms of qualitative method:

Here, the object under study is the determining factor for choosing a method and not the other way round. Objects are not reduced to single variables but are studied in their complexity and entirety in their every day context. Therefore, the fields of study are not artificial situations in the laboratory but the practices and interactions of the subjects in everyday life (Flick 2002:5)

While there is an important place for quantitative methods in researching learning disabled people's lives, for example researching single variable issues related to social equality (access to housing, leisure, respite services and so on¹⁸) researching experience and emotionality requires a different approach. For this reason, qualitative methods are turned to. The present study, which is exploratory in nature, will need to identify a methodology which has the potential to uncover knowledge about identities within the complex fields of emotionality, relationship, adolescent development and learning disability as they emerge in the context of the family.

¹⁸ Every Disabled Child Matters is an example of a group which uses available survey data and research on disabled children's lives to campaign for improved services

4. Choices of methods

So far, a menu of research methods applied to childhood research and disability research has been referred to and all of these present potential methodologies for this project. Coming under the heading of qualitative approaches, biographical methods were described in relation to disability research. It would be possible to consider using biographical method in researching severely learning disabled young people and this would involve the co-construction of biography by means of collating information relayed to the researcher mainly from parents, carers, siblings, friends, school teachers and so on. This has the potential of providing rich data (Middleton and Hewitt 2000; Atkinson and Walmsley, 1999). But where the young person has severely limited communication and cognitive impairments, the data would be derived from the perception of those around the young person rather than necessarily representing the young person's own feelings and experiences (Morris 1999). Watson et al (2006: 91) comment that 'children's views differ significantly from those of their parents or carers' and while this would be seen to be an obvious statement in relation to non-disabled children's research, it is a factor which is not always given due consideration when severely learning disabled young people are the object of study. In this study, the subjective feelings and experiences of the young people and their immediate social network are the object of the research and so biography is not thought to be the right methodology to follow. Instead, observation and the notion of 'bricolage' or the multi-disciplinary approach¹⁹ will be considered as possible ways forward.

Participant observation, as a research method, has long been employed by ethnographers from the Victorian era till now. In the early days, anthropologists such as Boas and Malinowski thought of their discipline as a science, drawing on the natural sciences in the drive for an empirical approach (Atkinson and Hammersley, 1995). In contemporary times, anthropology has concerned itself more in debates about the role and status of the observer as the notion of positivism in the social sciences has been called into question

¹⁹ 'Bricolage' (Denzin and Lincoln 2000), also referred to as 'multi-disciplinary' approach (Marks, 1999); 'mirror ball or kaleidoscope effect' (Edwards et al 2006:6); or 'polyphonic' (Davis 2000: 200).

and the issue of whether the observer can ever be seen as neutral arises (Crapanzo 1986, in Davis 2000). The notion that observation can provide an opportunity for the reflexive study and moderation of experiences over time is proposed, such that a 'story' can eventually emerge 'which represents the interaction between the culture of the ethnographer and the cultures of those he/she has studied' (Davis, 2000: 193, describing the work of Okely 1994). Given the reflexive potential of observation, this project which seeks to explore subjective experience of the young people may be able to draw usefully on a form of participant observation.

In exploring the varieties of stance available to the observer, Gold has shaped a typology which is often referred to in methodology literature (Gold 1958, in Flick 2002:135; Atkinson and Hammersley 1995). This suggests that there are four potential roles for observers: the complete participant; the participant-as-observer; the observer-as-participant and; the complete observer. If this study is to make use of observation in its methodology as recommended by some (Stalker and Connors 2003) the placing of the observer in relation to the observed will need to be thought about carefully. In chapter one, mention was made of researchers who make use of Foucault's ideas to comment on the disciplinary, controlling 'gaze' under which disabled people have led their lives (Twigg 2006). In order that observation might be employed as a research technique in an ethical manner, the researcher will need to use their observational gaze reflexively so the learning disabled person is encouraged to 'return the gaze' and to communicate their wishes and feelings in such a way that these are comprehended and described in research. In this way, the ethical dilemma of how to research the lives of people who are not cognitively able can be aired. Using this approach, the observer has to find a way of recording as objectively as they can the actions and reactions of the subject to the situations they find themselves in. The 'bricolage' approach mentioned earlier will help in achieving this, as observation will need to take in the varying perceptions and comments of those surrounding the learning disabled young person and the researcher will have to 'triangulate' by importing in other areas of knowledge to shape a 'whole' case study whose aim it will be to provide an account of 'experience'.

5. Subjectivity and the double hermeneutic

So far it has been established that the researcher will need to find a methodology that is reflexive; that is the researcher needs to consider what they are bringing into the field of study as well as what they might be able to observe about the subject. It will be remembered from chapter one, that psychotherapists have contributed to the potential for research through their unique experience of encountering and building relationships with learning disabled people in clinical settings. This adds a new dimension to research as it takes us beyond the point where disability researchers and some childhood researchers have become stuck. It seems that through being overly concerned with rights and ethics, disability researchers have accounted for the experiences of severely learning disabled people more through gathering a broad range of data than by having a means to interpret it or to make 'inferences' as we heard about earlier in relation also to childhood research. So when Davis (2000: 200) discusses 'polyphonic ethnography' he is gathering descriptions of disabled children's lives and then applying an analysis of the 'cultural and structural contexts within which these lives are played out'. Lost in this account, I would suggest, is the dimension which the psychotherapists can add; that of emotions and relatedness. Sinason (1992:6) has described how emotional intelligence may be 'left intact and rich' despite subjects' significant cognitive impairments. A reflexive methodology will be required in this study therefore, which can give due weight to the young person's experience and feelings (their 'subjectivity') mediated through their non-verbal and emotional cues as well as through conscious and unconscious communications from the parents, siblings and carers, within the wider 'social field' of the family. In other words, while the bricolage of a wide range of contributors is needed in this research, at the centre there needs to be a method of exploring the emotional worlds of the young people in the study.

Hollway and Jefferson's (2000) development of 'free association narrative interviews' exemplifies a method by which psychoanalytic concepts have been used in social science research ('psycho-social research') as a means of incorporating emotionality. These authors looked to go beyond the traditional social constructionist approaches to

researching fear of crime, by drawing on the notion of the ‘double hermeneutic’²⁰. This implies the bringing together of the researcher’s and the researched person’s subjectivity and they make use of the notion of the ‘defended subject’ to do this. In psychoanalytic psychotherapy, defence mechanisms are seen as forming a necessary way for all of us to cope with the anxieties of life which result from our innate drives and through the experiences life throws at us (particularly through our experiences of being parented)²¹. Hollway and Jefferson designed a way of using reflexivity as researchers to uncover some of these elements while interviewing subjects and during the data analysis stages. To do this, they employed techniques such as sensitising themselves to transference and countertransference processes in a systematic methodology²². Through noticing and recording their feeling responses to their subjects, it became possible to build theory about how unconscious factors maybe influencing people’s fear of crime. In this way a bringing together of social factors and emotionality can help to shape a fuller, psycho-social exploration of subjects’ experiences.

6. Infant observation as a research methodology

Hollway (2004) has recognised that use of reflexivity and subjectivity in research contexts can be extended further than this, taking research beyond purely language based interviews, into the area of observational methods. She has begun to use psychoanalytically informed infant observation methods in psychosocial research settings, preceded by other researchers who have used the approach to research within psychotherapy and related fields (as described in Rustin 2006). An adaptation of infant observation methodology is now proposed as a potential research approach for this study. Two main reasons for this are that infant observation methodology has the potential to provide an emancipatory approach, addressing some of the ethical barriers of existing methodologies in an active and dynamic fashion. It also provides a technique with which to research emotion and relatedness in young people with severe cognitive difficulties

²⁰ The double hermeneutic is a theme explored by others more generally when developing qualitative research methodologies (for example Schwandt, 2000)

²¹ There is an account of the shaping of defence mechanisms in chapter one

²² These unconscious processes are described in more detail later in this chapter

and their families. What follows now is a brief explanation of the background of infant observation and its uses, then an exploration of the pros and cons it presents as a research method and finally a description of how it might be employed in the current context.

a. The origins of infant observation and matters of technique

The origins of infant observation as a research methodology lie firmly within the practice domain. Bick (1964) provides an account of its usefulness as a technique to provide psychotherapists in training with a powerful pre-clinical experience. From 1948, trainee child psychotherapists at the Tavistock Clinic, carried out two year observations of babies from birth on. Bick (1964) describes several reasons for carrying out these observations. First, they are intended to ‘help the students to conceive vividly the infantile experience of the child patients’ but also to help them understand ‘the child’s non-verbal behaviour and his play, as well as the behaviour of the child who neither speaks nor plays’ (1964:558). Added to this, is the opportunity afforded students of learning in the context of the family:

‘...to observe the development of an infant more or less from birth, in his home setting and in his relation to his immediate family, and thus to find out for himself how these relations emerge and develop’ (Bick 1964:558).

Much attention was paid to the stance to be adopted by observers and to managing and organising the observation. Visits to families were to take place for an hour each week. Note-taking was prohibited as it prevented the observer from freely following and emotionally tuning-in to the events unfolding in front of them. Observers were expected to remain neutral; they needed to be ‘inside the family to experience the emotional impact’ but they should not ‘act out any roles’ such as giving advice or seeming to approve or disapprove (ibid). Bick emphasises that the observer needs to ‘find a position from which to make his observations’ and to ‘allow the parents, particularly the mother, to fit him into her household in her own way’ (ibid: 559). Observing within a family can be an intense emotional experience for students; one which will need to be ‘processed’ by

them individually and during seminar discussions, which enable them to compare and to make sense of the emotions involved.

During training, psychotherapists are encouraged to learn to notice and to make sense of the feelings which arise in the self during interpersonal contact. Often the feelings which emerge may hint at unconscious or hidden, unacceptable elements and these provide information with which tentatively to piece together ideas about why a person responds in certain ways to the situations and relationships they encounter. Inevitably students have feeling responses to the experience of observing and these can be powerful in nature; hatred, envy and love can be evoked for example. In the seminar setting, students are enabled to explore these elements; for example beginning to distinguish between those which may come from their own previous experience of relationships and which may act as a hindrance to understanding (as in 'the countertransference problem' as defined by Money-Kyrle 1956, in Hinshelwood 1991:258) to those countertransference experiences which may provide useful information with which to understand the emotional responses of others (Heimann 1950; 1960, in Hinshelwood *ibid*).

So while students are not encouraged to act or advise, they begin to learn to distinguish between the impact of their own experience and their assumptions about what is 'normal', and the feelings which they may have projected into them by the infant and members of their family ('projective identification'). Through presentation of notes written up after each observation at seminars, students learn to reflect upon their observations, triangulating any 'findings' by discussing ideas in the group and testing these out over time.

b. Infant observation as a research tool

Rustin (2006) provides a review of the uses of infant observation as a research paradigm, arguing that while it has much in common with clinical methods and research, it is also 'productive as a new source of knowledge' (2006:35) in its own right. Troubling perhaps to more traditional, laboratory-based researchers on human development (who choose to

focus upon ‘manifest and observable’ phenomena) infant observation, like the clinical practice of psychoanalytic psychotherapy, seeks to come to an understanding of less tangible ‘unconscious mental processes’ (ibid:39). Rustin accepts that observation is weaker epistemologically than psychoanalytic practice, as the passive stance of the observer precludes the active development of transference or the opportunity provided by making interpretations to formulate and test hypotheses.

Infant observation technique does however, offer some advantages over psychoanalytic practice as a research paradigm. Rustin describes how the technique enables observation and learning about the infant’s development in the context of their relationship with their primary carer (the ‘nursing couple’, Winnicott 1964) and their family. This experience unfolds in front of the observer as it happens, so there is no need to attempt to reconstruct events from one party only, as in the consulting room.

Rustin describes how infant observation provides the opportunity to watch how the infant’s mind develops, their inner world forming in the context of ‘the relational matrix of its primary family’ (ibid:41). One particular contribution to research (which has in turn impacted upon clinical practice) has been infant observation researchers’ interest in the concept of the ‘container-contained’ relationship of parent and child (Bion 1962) and the consequences of deficits of containment for the child.

c. Issues raised by adapting the methodology:

Clearly to adapt such a model, which is designed to help make sense of the earliest stages of human development in the context of the parent-child couple, to researching teenagers with severe learning disabilities is something of a leap. Several major differences appear at once. For those in the study for example, their adolescent development is likely to be uneven; characterised (as was described earlier) by movement between different states of mind (Bion 1962), but also affected to a significant degree by the intrinsic nature of their cognitive difficulties. It is likely to be a complex process for the researcher therefore, to un-pick and to make sense of the identity development of the young people. This

contrasts with the gradually unfolding and to some extent predictable series of developmental changes over time which might be evident in an observation of a young infant. Also, use of the methodology implies some expectation that family members will be seen to be interacting closely with the adolescent, as one would expect to be the case when observing a parent and a young infant. Given the age of the young people to be researched in this study, such close parent-child interaction may not be evident. The influence of the 'observer effect' therefore needs to be considered. Are parents spending more time (or less) with their disabled child simply because a researcher is present?

In mitigation of these problems however, it is anticipated that the methodology will be flexible and open enough to make it possible to gain understanding of the experiences of the young person and other family members and carers over a period of time, enabling the piecing -together of a view of what is 'normal' for them. It is expected that by observing a number of families, there may be revealed some common experiences and themes, but rather in the spirit of participant observation approaches, variation from the expected may lead to new areas of knowledge (Hunt 1989).

d. Adapting infant observation methodology to new research contexts

Briggs (2005:24) describes infant observation methodology as one of a variety of 'emergent methods' which offer an alternative to 'objectivist' approaches in social work research. These methods are seen as being particularly useful for researching a relatively neglected aspect of social work practice; 'emotionality and the processes of relationships' (ibid:26). By way of illustration, Briggs (1997) drew on infant observation methodology to research young infants at potential risk. This research developed a model by which a 'container-contained' relationship between parent and child could be understood. The 'shape' of containment available to young children was related to the process of children's development in each case.

Others have used the approach to consider emotional aspects of learning in the classroom setting (Price 2001), to multidisciplinary training for health practitioners working with

older adults (Davenhill et al 2003) and more recently, to studies of mothers' identity development following birth of their first child (Urwin 2007). Rustin (2006) defines five research agenda which are emerging from infant observation research: the development of the infant psyche and the integration of body and mind; the study of containment and its disorders; therapeutic infant observation; neo-natal intensive care, and other hospital contexts and; cross-cultural studies in infant observation. The present study aims to continue within the tradition of infant observation research paradigms and may be expected to contribute to several of these agenda described by Rustin.

7. Sampling, validity and data analysis

In planning qualitative research, the issue of sampling needs to be given careful consideration (Silverman 2000; Flick 2002). While in quantitative studies the aim is often to consider large samples of people, who are representative of a whole population, the subjects of qualitative research are more often small in number and to be considered and researched in some depth (Silverman 2000). The notion then arises of purposive sampling, that we 'choose a case because it illustrates some feature or process in which we are interested' (ibid:104). In this piece of research, severely learning disabled adolescents are the focus, so purposive sampling will be undertaken to identify young people fitting this description. From a small number of samples, it is then proposed that detailed case studies should be developed in order to look at the emerging issues in depth.

Briggs (2005) describes how infant observation forms one of a number of possible methods of data collection which is amenable to an emergent style of research approach based around the creation of case studies. Stake (2000) provides a helpful development of the use of individual case studies as a form of research methodology within a qualitative frame. The argument is made for using single case studies which have a long tradition in the formulation of new hypotheses in the social sciences and in medicine (Radley and Chamberlain 2001; Greenwood and Lowenthal, 2005). Using this technique, detailed description and observations may be undertaken as a form of data collection. The researcher then moves between the theory used to inform the approach and the data

presented, to annotate the data ('thick description'). From this, emergent categories arise following grounded theory approach (Glaser and Strauss 1967). Further reflection and moving between data and theories enables the production of hypotheses and theories, from which the research project is written up and shaped.

In this research, which depends very much upon the reflexivity of the researcher in being able to recognise and name unconscious emotional processes in the context of the family observations, the role of the research seminar is particularly important. The reliability of the research data may be increased by making active use of the process of 'triangulation' (Flick 2002: 226). Detailed write-ups of the observations (my 'field notes') would need to be taken regularly to research seminars. There, other researchers who were familiar with psychodynamic infant observation were able to offer their own reflections and interpretations of the unconscious processes which emerged during the research. Also, supervision was arranged for me with a psychotherapist who works with learning disabled young people, thus adding to the range of knowledge available to me in beginning the process of data analysis. Flick (2002) suggests that triangulation which takes place during the process of data analysis increases its scope, depth and consistency and therefore its overall validity. She warns however, that findings should be viewed as suggestions rather than assertions given the subjectivity involved in qualitative research.

8. Planning the research

a. Refining a methodology in practice

In planning the research, an adaptation of infant observation methodology was thought suitable to the circumstances of this particular project and there was a fair amount of discussion about how to go about the work. Traditional infant observation usually involves visiting parent and baby from birth on, for a period of a year or two years (Bick 1964) for an hour each week. Researching severely learning disabled adolescents using this methodology however presented some different issues for consideration. From a practical point of view, I was aware that the young people would be at school each day

and they may well wish to attend after school clubs and activities. Finding a time to visit may therefore be problematic, I speculated. More fundamentally however, I was uncertain how parents would view my wish to observe their teenage son or daughter and over what period of time I should propose to carry out the visits.

Initially it had been thought that I would approach families with the plan both to interview the parents and to carry out a short period of observation of the severely learning disabled young person. As this idea was discussed in more depth with my supervisors however, we concluded that the benefits of observing might be counteracted by my interviewing the parents. Psychoanalytically-informed observation, such as I planned to do, relies on the observer taking on a non-interventionist stance (as already described). By following-up a period of observing with a research interview, it was felt that my questioning might feel overly intrusive. I knew that life for many families with a severely learning disabled child could be very stressful and I did not wish to add to this by both interviewing and observing them. While there certainly were questions which I could have asked parents and other family members in an interview about their experiences, it was anticipated that infant observation methodology would offer a different approach which might make accessible knowledge so far unexplored by researchers in the field of disability or childhood studies. The intention was to use this approach to centre primarily on the young disabled person's subjective, emotional experiences. It was anticipated that the gleaning of some factual and conscious commentary by family members might be lost by using observation in this way, but that there was much to be gained in the 'missing' domain of emotionality and relatedness by adopting an observer position.

In terms of sampling, I adopted a purposive approach as mentioned above, seeking out families who would fit the research themes. Young people needed to be in adolescence and they should have severe learning disabilities. I sought families who were thought to be managing well in their care of the learning disabled young person, so as to focus on strengths and coping in the families. I knew that while any family can struggle at times, severe disabilities in a family can impose a great deal of stress on parents, carers, siblings

and the young person themselves, so it would be useful to find out what features in the people and their relationships I was going to observe made them resilient.

I intended approaching families with the plan to carry out the observations for six months, visiting once a week for an hour at a time we might all be able to keep to. My initial approach to families with this plan was fairly flexible as I did not know whether anyone would be willing to allow me to observe them. I did however feel confident that it would be possible as I clearly remembered, from my experience as a practising social worker, how families expressed annoyance that no-one ever spent the time that was really required to get to know them and their disabled child. This underlying belief in the project made it easier to persist and to work positively towards establishing relationships with the researched families when they did come forward.

b. Finding families

Given the nature of the research I planned to undertake, it was unsurprising that it should take some time to find families willing to take part. Once agreement had been granted for the project at the University Ethics Panel, I set about networking among people I used to work with, phoning and writing to different agencies that I heard of that worked with young people with learning disabilities, to see if families might be located. It emerged over the weeks that the process of identifying families worked best when a personal contact referred me on to a friend or a possible lead. Eventually I made contact with two families, each with a member who was in their adolescent years and who attended school for children with severe learning disabilities. Both families agreed to me observing them for the first six month period and then as these drew to an end, two others responded and were willing for me to observe them, making the sample four families in total.

c. Preparing the families for the observations

Before commencing the observations, I made an appointment to meet the parents and the young person concerned to discuss the project. During this visit, I provided the parents

with written information about the aims of the research and I asked them to sign a consent form. I explained that I would be visiting to observe the young person and their family and that it would be helpful if they could try to carry on as much as usual as they could when I was visiting. It was agreed in each case that while I was there to observe principally the disabled young person in the family, we would allow a pattern of observing to emerge according to what both the parent and the young person felt comfortable with. In this way a dynamic approach to ethics was developed, well adapted to researching in the intimate circumstances of a family. I made it clear that the parents were in control of the process and particularly at first, I regularly checked with them to see whether they were happy with where I positioned myself and what I observed until something of a routine was established. During the observing periods, as I will later describe, I occasionally 'policed myself' by turning away from situations it felt too much to observe or I 'tuned-out' if a personal conversation was taking place by phone for example, when the person had no option to escape my presence. In all, the stance of an observer is an intellectually active position (Le Riche & Tanner 1998) where ones own feeling responses to the events around and about are noted to the memory and reflected upon, while at the same time one remains alert to new and unfolding activities in front of one in an often bustling home.

Once I had made contact with the families in person all four continued with the research, though it was made clear that participation remained voluntary throughout. During the account of the visits which will follow it will be apparent that it was not always easy to commence or to maintain a pattern of visits with some (indeed any) of the families. The difficulties I encountered in this area will form a starting place for the case studies on each young person and their family, as the understandable ambivalence members of the families felt towards my presence at times will provide some clues as to the emotional climate of the home. Making use of this type of research approach, which involves some degree of emotional engagement with the research subjects who are living in difficult circumstances but who want their story understood, is innovative in nature as many traditional methodologies shy away from this (Hollway & Jefferson 2000). Clearly the

ethics of the approach needed to be thought about throughout the work, the necessity being that I maintain a sensitive, reflexive approach.

d. Preparing myself to observe: the ‘stance’

I had previously carried out a one year observation of a young baby as part of my doctoral studies, so I had an idea at the outset of the state of mind with which I would need to commence the visits. This would require me to remain open to experience, yet remembering that the opportunity to observe represented a gift from the family to me and a clear priority was that I actively respect feelings within the family. To paraphrase Bick (1964) I needed to allow the parents to fit me into their home in a manner which best suited them. There are commonalities between this form of observation and participant observation carried out by ethnographic researchers (Flick 2002). Following Gold’s typology of the four different potential roles of observers (Gold 1958 in Flick 2002:135) I was to adopt a position as ‘the observer-as-participant’. I thought it unlikely, given the lively homes which I expected to encounter, that I would be able to be a ‘fly on the wall’ observer (Le Riche and Tanner 1998) or a ‘complete observer’. I was prepared to adapt my role as best suited the families I was to encounter and to learn from events as they unfolded.

From previous practice and from my studies in the area of learning disabilities, I also knew that it was likely that I would meet strong emotions and feelings on visiting the families in such intimate circumstances. I was aware that feelings associated with damage and disabilities are frequently extremely difficult to live with, so individuals may project these as a form of defence mechanism (Klauber 1998). These feelings, if I found them, would provide important data for the research project. I was also aware however, that I would need to be able to reflect on my position in the families and in relation to the data in a supervisory setting, so that I would not become overwhelmed by what I might experience and to ensure that I maintained my reflexivity and sensitivity.

I arranged to carry out the visits mostly at the end of the afternoon with the families, when the young people had returned from school. Once I had finished the observation hour, I returned home and as soon as possible wrote-up my experience in a full account. Often this consisted of as much as five thousand words, presenting me with a large amount of data to analyse. The field notes that I maintained were very much my own subjective 'reading' of the events which unfolded in front of me. One way in which the families' own experiences might have been incorporated more into the research would have been to have asked them to maintain a diary during the period when I was observing (Flick 2002). This might then have enabled me to have a different form of access to what the parents and siblings were experiencing, but importantly it would have been difficult to represent the severely learning disabled young person's view by this method. In the event, it was arranged that I might bring write-ups of the visits to seminars and to individual supervision throughout the observation period to facilitate 'triangulation' of the data as described above.

e. Data analysis, building case studies and the issues raised by being a practitioner-researcher

Given that I was discussing the observations regularly during the research phase, I maintained note books with comments and early theory formulations as I went along. I continued to read on the research themes during this period, building ideas and to watch to see what developed. Once I had completed the observations, I tabulated the visits to commence the data analysis more formally following the principles of grounded theory (Glaser and Strauss 1967; Silverman 2000). Going through the notes closely, I began to code themes which emerged and to cross-reference within and then gradually between the different observations records, connecting these with theory perspectives I had already been exploring, including those described in the previous chapter.

The next stage was then to begin to construct case studies around each individual family. I preferred with the case studies, to maintain some sense of the passage of time and the unfolding narrative of the observations in the writing. By doing this, the process of

identifying and pursuing particular themes is made more complex as these themes do not always fit clearly within a chronological format. The case studies are a necessary compromise between my wish to hold on to the 'story' of each observation in all its richness (the 'horizontal axis') while retaining a 'vertical axis' which is more concerned with specific themes identified during the data analysis. As I wrote the case studies they became fairly lengthy accounts, providing detail and analysis as they develop. I chose to keep them in this form as it is only through accounting for my observation experience in some depth that my own subjectivity and that of those I observed can come across fully. Due to the severe cognitive disability of the young people I observed, it took time for me to begin to be able to understand their emotional and relational worlds, information often emerging incrementally over many weeks. I wanted the presentation of data to bring this across as fully as possible and in a manner that I have not seen before carried out in research on identity with this particular group of young people. A final stage of data analysis is therefore incorporated in the discussion chapter which develops and compares the themes and experiences between the case studies further, into new formulations of theory and knowledge.

One other point which is relevant to make at this stage is that in coding the data, I was particularly aware of the influence of my dual status as both practitioner and researcher. Although I had left practice before commencing the observations I was, I believe, still closely identified with my previous professional role as a social worker, practising in the same area (with disabled children and their families) that I was now researching. This form of researching which might be described as 'practice-near' (Marsh and Fisher, 2005) presents both positive attributes for the research as well as negative ones.

On the positive side my previous work experience led me into this complex and little-researched domain and I had, as I described earlier, a sense of confidence that the project had a sound basis. This helped me to persist even when the research uncovered painful and upsetting insights into the experience of the young people and their families and it was not always comfortable for me either. In a sense this enabled me to cut corners at times, as I felt I was meeting responses in the young people and their families that were

familiar to me and this permitted me to move to a deeper level in terms of my speculations on the emotions and behaviours I observed. Open to criticism however is the point that I took with me into the observations, preconceived experiences and expectations of what I might find. I had to work to retain an open mind and to see things which might be normal to me as themes which might require further reflection and consideration. In mitigation of this criticism, it can be said that seminar discussions and supervision often forced me to re-think my attitudes to the researched families and so this issue of subjectivity was very much open to reflexive processes in line with thoughts about the 'double hermeneutic' involved in any social research endeavour (Hollway and Jefferson 2000).

In coding the data, there are examples of themes which I identified with 'old eyes'; things which I found familiar from my previous work experience but thought important to consider (for example the way in which households are organised to allow space for the disabled young person). Other themes however, emerged with the help of 'new eyes' and the process of observing rather than practising enabled this. It would be unusual for example, for learning disabled young people to be able to talk about their sexuality development or the aggressive attitudes of their parents towards them during a normal social work interview. These themes, and other important areas, were enabled to emerge during the observations.

9. Summary and conclusions

It is proposed that an adaptation of infant observation methodology should be used to explore the experiences of a small group of severely learning disabled adolescents who are currently living with their families. Observation of this kind is an open and flexible form of research technique. As such, it is well suited to qualitative research endeavours which seek to bring understanding to complex life situations, such as the emotions of family life which are the focus of this study. Researching such an area requires an appreciation of the 'double hermeneutic' and it is argued that infant observation provides this; it offers a reflexive approach to research which encourages exploration of the

researcher's responses to the complex subjectivities they encounter in the 'fields' of study. The researcher's perspective is not simply informed by ideas which arise in their own mind during the observations. Instead their ideas which originate in what they see, but also what they feel and notice more generally as observers become the subject of examination and discussion in the shared forum of research seminars and supervision. These discussions also draw upon psychoanalytic theory on the functioning of the emotions and relationships as well as broader fields of knowledge (for example from sociology, psychology, disability studies and social policy).

This form of methodology brings a new perspective to researching severely learning disabled young people as it enables examination of non-verbal, felt and lived experiences which are not adequately captured by existing approaches. Although the method incorporates close observation within the family setting, it offers an ethical approach as the observer is required to reflect throughout on how they are influencing the family as well as on how family members are influencing them. Safeguards are offered through provision of professional supervision which encourages a reflexive, sensitive approach to the work.

Data obtained during the research encounter is to be analysed as has been described, by the use of discussion in seminars and supervision and then coding to draw out themes. The researcher intends developing case studies around the emerging 'story' of each observation as well as by identifying cross-cutting themes which emerge within and between each of the cases. While the sample studied is to be small in number, it is argued that the findings which are to be generated will have greater validity than might be possible through a quantitative method, because of the careful and close examination of the data and the way in which the research remains 'close to the context in which information is gathered' (Radley and Chamberlain 2001:325).

Chapter Three

The Anderson Family²³

1. Introduction

I first met Billy Anderson's mother Maggie at a parents' coffee morning run by a voluntary agency which offered services to local disabled children and their families. Staff had let parents know that I was going to visit and they had already had an opportunity to read my prepared information sheet on the research project when I arrived. Maggie was friendly, humorous and very open about her family's trying living circumstances when I met her. She agreed to me visiting to carry out the observation visits without any further questions. Her lack of curiosity surprised me, given that I would be observing her family at close quarters.

2. Establishing contact with the family

While Maggie had accepted the idea that I would visit in principle, it was actually much more difficult to get to meet the family at home. On three occasions over the month after I first spoke to her, my planned visits were called off, due in part to Billy's fragile health and a hospital admission and other appointments which arose for family members. Each time Maggie explained what had happened, taking care to get in contact with me before the planned visiting time. I wondered at first whether Maggie had felt pressurised by me or by the agency into having me visit her. The coffee morning had been a social gathering where I spoke with a number of mothers about their lives. Did she feel doubtful about the idea once she had considered the level of commitment involved in having an observer visit weekly?

²³ For brief biographical details on the Andersons and the other families, see appendix. Names have been changed.

Eventually I addressed more directly what I assumed might be some ambivalence towards my proposed visits by offering to call-off the planned observations. I acknowledged that the family was very busy with visitors and difficult to manage events in their lives and the arrival of a researcher in their midst might not after all have been a welcome occurrence. Raising this issue proved helpful as it enabled us to discuss the advantages and disadvantages of my visiting the family. In retrospect I was able to ponder whether I had been too pushy in trying to press on with my research and that Maggie may have felt this pressure from me. I found that it was necessary for me to stop worrying about whether or not the visits would go ahead, to enable her to make a free choice about whether or not she took part. Given this choice and the space to reflect a little, Maggie decided that she would after all have me visit. In this manoeuvre, Maggie had been able to take some control of the situation and this observer-subject relationship, so central to the project, had come to life. The techniques involved in the process of engaging families in the research project are of interest here, as they imply the need for development of a working alliance and a sharing of power between us. Developing an observer position required careful and respectful acknowledgement of parents and other family members' feelings. I had to remain thoughtful and conscious of my position throughout the observation in order both to remain alert to the emotional dynamics and to the need for the family at times to maintain their boundaries.

At the fourth planned visit I did at last meet Billy and his family, but I already had a sense that the routines of this family's life were unpredictable and subject to change at short notice. It seemed as though Billy's complex needs occupied centre stage in the family and others worked around these.

a. Arriving and establishing an observer role

My observation stance upon arriving was to try not to intervene or to change family routine. I knew I would not be a 'fly on the wall', but I was surprised by how difficult it was to gain any real distance and objectivity in the swirl of activity which I found during my first visit. The visit took place in the late afternoon of a weekday and several family

members immediately competed for time and space with me. They appeared needy, exhausted and as though each wanted me to hear their story of family life. I struggled to find an observer position within the family and this continued to be the case as I was enlisted to help with homework and to hear about the latest developments with the children. The sitting room which we occupied was fairly cramped because Billy's bedroom and bathroom had been constructed out of the main downstairs living quarters for the family; walls moved during a builders' conversion some years before. It seemed perhaps that there was an imbalance of the emotional as well as the physical space available within the house, as I was called upon immediately to pay attention to Maggie and Billy's two siblings.

b. Meeting the family

During the first visit, I saw Billy after a period of about half an hour as he was receiving personal care in his room for the first part of the visit. Before he joined us, I had a chance to spend time with the rest of the family. Firstly I met Maggie who, as my observation notes written up after the visits show, greeted me warmly:

She is a white woman in her late 30s or early 40s, with a girlish round face and dark hair and eyes which seek contact (1:1). Sean and Catherine also put in an appearance:

The older child Catherine is a slim, girl of about 8 or 9 years old, who looks a lot like her mother- with dark hair and pale white skin.... Sean, who is 6 or 7 years old, was wearing his white school shirt. He has short, fair hair and a slightly dishevelled look. (1:2).

Tim, the children's father and Maggie's ex-husband, was a little more elusive:

A middle aged greying man also appeared- Tim who I'd met before. He was of large build, white and he said hello, keeping a serious expression on his face. During the hour of my visit, he sat somewhere out of sight behind the kitchen area. I wasn't sure what he

was doing there- listening to us or reading or doing some work, or perhaps just not feeling part of things he removed himself from earshot. (1:2).

c. The family and how they made use of me: observer or listener?

I had been curious if Maggie would have some particular ways of making use of an observer. It appeared that my presence provided an opportunity for her to share with me some of her worries and difficulties in three main areas: managing Billy's complex and unpredictable health needs; organising the unreliable and ineffectual, as she saw them, band of carers who arrive twice daily to help out with Billy and; coping with her other two children who she found at times demanding and attention seeking. Comments were made on the latter problem, softly when the children were just out of earshot.

As I sat in the living room, Maggie described the trying time before Christmas when Billy had been hospitalised for two months with a serious kidney infection. She summarised the complex nature of his health and disability needs during the visit (tube feeding, reflux on oral feeds, seizures, major back surgery and kidney problems) and I strained at the limits of my knowledge to comprehend the issues she described rapidly and in great detail. When I reflected on this encounter later, I felt that perhaps Maggie was testing me to discover how much I understood of her life dilemmas and how much I could contain and manage for her during the short time we had together.

In this first meeting with the family, I experienced a competitive element. There appeared to be little emotional containment from any adult figures and each family member seemed to place me in 'parent' role. Sean communicated his opinions by loudly voicing 'boring' while his mother tried to speak, blanking-out his mother's tirade of needs and problems which seemed not to relate to him. His sister Catherine, while this was going on, sat slightly apart weaving a doll's scarf on a toy loom, making occasional comments to help me notice what she was creating, to ensure I did not forget her. It was an exhausting and demanding task to listen and pay attention to all of them and I had not even met Billy yet.

d. Meeting Billy

This visit, and subsequent ones, took place at the end of the afternoon and I often found that Billy was very tired following a full day of activities at school. This was my first observation of Billy who had been brought into the living room by his carers, following his bath:

Billy sat upright and close next to me on the sofa. He turned to me, with tired but enquiring eyes to see who this new person was. His posture is very upright, assisted by spinal surgery Maggie had described to me earlier. I turned and said 'hello Billy' and as we were so near, gently tapped his hand, which was next to mine. Billy is a slight lad, who is probably average height for a 14 year old, but who is very slim. He has the same dark brown hair and eyes as his siblings and mother, wearing his hair fairly short and nicely cut. Billy looked exhausted and his eyes were falling closed from time to time. He seemed very relaxed and sleepy. (1:10)

Just before Billy had arrived, Sean had sat on the other side of me with his homework. I felt I should offer to help him with his spellings while Maggie went off to prepare some food for Billy. I recorded in my observations notes later, the slightly bewildering experience of trying to take everything in; of Sean, Catherine and now Billy, in his own way, vying for my attention. Sean needed help and encouragement with his spelling. I noted later that 'he was like a sponge, soaking up any attention'(1:6) while Catherine had by now taken up another craft kit to show me, a children's tea set which she was to paint and bake in the oven. In the midst of this, Billy somehow managed to make contact with me:

Billy whose hand was right next to mine, lifted it and placed it on top of mine and I gave his hand a squeeze, and held on for a minute. He looked at me, sleepily (1:6)

I was surprised by the speed with which I was recruited to help out and to take on some of the emotional burden of the life of the family. Another aspect of this moment was an

awareness of how swamped I felt, panicky and wondering what I had let myself in for. I found myself asking how would I manage to leave Billy and his family at the end of the visit and how would I establish enough distance to be able to observe more and participate less in future? For the time being I held those thoughts in mind, focusing on the end time of the visit as an important boundary, an escape plan perhaps. An understanding of projective identification might help to explain some of the feelings during this first visit; a sense of panic that I might not be able to escape from the household, perhaps mirroring the feelings of some family members. Billy's touching of my hand seemed to indicate some hope however that he could indeed reach out and establish contact with others. I was intrigued to find out how clearly his personhood and his identity would emerge in the subsequent weeks, as on this first visit, he seemed distant and sleepy.

3. Feeding & emotional labour

Early during the first visit, Maggie told me of Billy's feeding problems. He had in recent times moved from having a removable naso-gastric tube, to a permanent gastrostomy tube, enabling liquid food to be fed straight into his stomach through a 'peg'. Before having this procedure I was told, Billy had been under-weight, he had suffered reflux and risked aspirating food into his lungs. Maggie informed me that medical advice was to limit the amount of food he should be give orally, as there remained a fear of him aspirating the food, something which could place his health at serious risk. Maggie and Tim however appeared ambivalent in relation to this advice as they persisted in offering Billy some food orally suggesting that he liked it and that 'Billy deserves still to be fed' (1:5). Near the end of the first visit however, when I observed Billy being fed by his mother, it appeared that the process was difficult and at times arduous for him:

Billy was managing to take in quite generous spoonfuls, swallowing with some difficulty and choking a little from time to time. Maggie offered encouragement and gently touched his throat to encourage swallowing. (1:6).

One way of viewing their persistence in feeding Billy orally was that they were sceptical of medics' recommendations on this subject. Or perhaps they were denying the extent of Billy's disability? I noticed however, that Maggie took great care to ensure that Billy had home-cooked food and though perhaps uncomfortable with the physicality of swallowing, he seemed to have benefited from the nurturance of the food, both nutritionally and emotionally as he appeared calm and relaxed in his mother's care. Billy rapidly fell asleep after his feed and I noted later how relaxing it had felt to sit next to him. This reminded me of the peaceful feeling of sitting with a much younger child or infant after they have fed.

For Billy, whose ability to express himself was severely limited, feeding represented a time when he could be seen to take charge of himself and the events of which he was part, even if only briefly. In the feeding relationship, a rhythm of giving and receiving between parent and child was possible, giving the parents a chance to feel good about nurturing their son and helping him to grow. Perhaps their comment about how Billy 'deserves' to be fed orally refers also to their needs as parents, that they deserve the experience of a meaningful emotional contact with their son?

While this had the potential to be a positive link between parent and child, the way in which the parents delegated this task at a later stage to relatively unknown carers might also indicate that the intimacy of caring for Billy could also be exhausting and possibly disappointing and painful for them. The parents' apparent ambivalence towards feeding Billy orally might then mirror a more general ambivalence towards their son. While satisfaction was to be gained by being able to meet his needs so directly, the act of feeding Billy also pointed up his limited potential for development and taking charge of himself and his own needs in the future. Providing care for Billy in this way was therefore emotionally as well as physically demanding for the parents.

4. Lurching from one crisis to another

When I first met Maggie at the parents' drop-in she had told me, while laughing, that her family lurched from one crisis to another, mainly concerning Billy's difficulties. One such crisis had occurred between my first and second visit, as Billy had fallen from his bed while being looked after by two carers. Maggie described how she had heard the fall from the living room and ran in. She had been unable to discover exactly what had happened as the carers had been evasive, unable or unwilling to account for what happened.

On my second visit, I was only able to see Billy at the end of the time, as he had been lying in his bed resting. He was indeed a shocking sight:

Billy was lying in his bed, which is a hospital one which raises and lowers and which has fabric cot- sides fitted either side. He lay, with his head nearest the door side of the room, with two huge, purple, bruised eyes and fading, grey bruises extending down by the sides of his nose. There was a large 'egg' bump in the centre of his forehead. Billy looked sleepily up at me from lying position as I came in. (2:4).

The lack of information available to Maggie to account for how the accident came about was understandably very difficult for her to cope with. It was impossible to discover whether the carers had been neglectful or whether Billy's disability was such that accidents were likely to happen to him, despite the carers following the care regime diligently (for example if Billy was prone to strong and unpredictable movements).

5. Accidents and hidden hostility

Visiting again two weeks later, discussion of Billy's accident was still in the air and by now, Maggie was very angry at the response of professionals to recent events. Her social worker had not managed to visit for several days after the accident and no formal investigation had been held to quiz the carers over what exactly had happened. The

household seemed chaotic and I noticed that Catherine, Sean and Maggie all wanted to have my attention:

I felt Catherine's desperation to gain my attention, competing with Sean who was circling, trying to get a word in. Maggie had also joined us, standing on the edge of the group, between where I was sitting and dad on the sofa. She said it had been 'quite a week', last week. As she spoke, Catherine got between me and Billy and I was aware of wanting to see Billy- he seemed so much more active and communicative than I'd seen him before. It was frustrating that my view was blocked and that I had to listen to everyone in the family all at the same time. (3:2).

Maggie went on to say how angry Billy's hospital consultant and the local police child protection team had been over the accident. While she was filling me in on the details of how upset and outraged those who knew Billy were, I observed that he had now been left unsupported on the sofa and I had a real fear he was about to fall over again, un-noticed as he was by those around him today:

Billy by now was finishing his tea and the carer took the plate away, leaving him for a minute on his own on the sofa which made me feel anxious as I knew he had fallen from his bed a few weeks ago and I wondered how safe he was propped in this way and not in a supported chair. Billy moved to a slightly lopsided position, but no-one repositioned him. (3:2).

This led me to ponder the emotional content and meaning of the accident for Maggie. During this visit and several others afterwards, Maggie's unwavering fury with the carers and professionals involved in the accident at times seemed disproportionate to the event, indicating perhaps that she was projecting her feelings into them. I too found that it was easy for me to feel angry at the supposed negligence of the carers, without considering the difficulties that they might have been struggling with. It is well known that private agency carers are often not well paid, trained, or supported, so it would be best to know how to improve their ability to do their job than to condemn them out of hand. The fact

that she seemed not to notice during this visit that Billy might fall again, despite his sitting right in front of her however was something I was in a position to witness as an observer and it hinted that other emotional dynamics might be involved.

If parents defend themselves against the thought of their disabled child's vulnerability and dependency, then there is a real potential for neglect in this kind of situation. In my own practice experience with disabled children and their families, neglect does emerge as a concern occasionally in families where physical care is good and superficially it appears that parents are coping well. Uncovering hidden feelings of anger towards extremely vulnerable and dependent children is often one of the most difficult to work-with situations for a practitioner as parents, understandably, will fiercely deny these feelings of rage, murderousness and hatred. The offer of practical support services does not necessarily solve problems in this kind of situation.

It is not possible to explore feelings like this as an observer, but it was perhaps the case that Maggie was using me here to bear witness to her feelings and I wondered how well the professionals were managing to offer her this kind of containing support. For the parents it was important to have an investigation carried out into the circumstances of the accident. In this way, different perspectives can be aired and measures to prevent future accidents considered. It seemed as though no one had learnt from the accident, or reflected on Billy's vulnerability and the risk he faced. There was a lack of grip on the issues of concern for the family by the social workers who had failed to visit and to take the subject seriously. This was quite a frustrating experience for me as an experienced social worker and I found that I had to limit my wish to become more involved; to 'take on' and work with this angry parent.

6. Siblings, projection and blaming

Billy's siblings, particularly Catherine, also seemed to be blamed at times by the parents when life was stressful.

Maggie said that Billy gives her 'no problems' - if you take him out shopping, he's easy going and is happy with what ever you buy him. With Sean, he always says 'you've spent too much mummy, I don't want all that', while Catherine is 'never content and always wants more from me. It must be attention seeking, that's all- she wants any attention, negative or positive.' (3:5).

As an observer of the family, it had seemed to me that Billy's wishes and feelings were often difficult to elucidate, despite the parents spending much time and energy trying to work out what he was experiencing. A constant state of vigilance was required to ensure he was feeling comfortable and in case his fragile health failed. Acknowledging that Billy imposed these stresses on the parents was mostly too painful to do, as he was so vulnerable and at times he seemed so passive. Catherine on the other hand was lively and very able to articulate her needs in a way which seemed difficult for both Tim and Maggie to bear.

Over the weeks, there were many occasions when Maggie took the opportunity to talk to me about her worries for Catherine. It appeared that teachers at her school were well aware of the stresses at home and Catherine had been offered counselling there as well as help with her poor educational progress (she had an Individual Education Plan to help with her educational needs). Maggie talked of Catherine being bullied at school on occasion and described later during the observations that she her daughter had gained a diagnosis of dyspraxia, which helped to account for her poor performance in her written work. Maggie appeared dismissive of the counselling offered to Catherine, hinting as it did that some of the girl's problems might have had an emotional cause rather than being simply intrinsic to her 'difficult' personality.

I found myself wanting to overstep the observer role at times, wishing to defend Catherine from her parents' negative views of her. In one account for example, Catherine's pre-pubescent anxiety about the changes happening to her body was revealed by her parents complaining that she was near impossible to buy clothes for. There was little capacity in the parents to notice her anxiety, Catherine's difficulty choosing new

clothes contrasting strongly with the account of her as someone who ‘always wants more’ (above). When the parents were children, no one showed them such sensitivity so why should Catherine receive this now?

Maggie went on ‘when I was a child, my mum just turned up with a bag of clothes and you had to wear what ever she bought you, no argument’ (13:2)

Billy it seemed then became idealised as the one who gave his mother ‘no problems’ while Catherine adopted the role as the most difficult and demanding; the one in the family who openly stated that she wanted to have as much care and attention from her parents as her disabled older brother.

Sean adopted another position, as a ‘good boy’ who was helpful, compliant and undemanding. I did however notice that there were times when Sean managed to have his own way by subverting parental authority. Several times he was mildly rebuked for pinching an ice-cream from the freezer or some sweets from the cupboard without asking first. In the main, I observed that Sean did not seem to elicit the same level of parental criticism or anxiety for his naughtiness as Catherine’s behaviour did. This is not to say that the parents’ view of Catherine was negative at all times. The girl was a youth member of the same first aid organisation that Maggie belonged to and there was evidence that Maggie identified at times in a positive manner with Catherine, hoping that she might eventually train as a nurse as she had hoped to herself²⁴.

²⁴ Catherine’s experience brings to mind the siblings research reviewed by Sanders (2004) described in chapter one, which suggested that sisters can sometimes be expected to take on greater caring roles than brothers.

7. Billy: identity, communication and impairment

a. Billy: emerging personhood and identity

As the visits proceeded, Billy began to emerge from the passive, sleepy character I had first met. During the third visit for example, as Tim was planning to leave the house, Billy seemed very in touch with his father:

Tim said quite a tender, private goodbye to Billy. He lent into his face and spoke in his ear, 'Do you want me to go?' Tim said to him louder and Billy shook his head back from side to side showing 'no', with a sad look just discernable on his face (3:5).

Later on, Maggie sat next to Billy and he relaxed, seeming comfortable and contained by his mother's presence:

She snuggled in to Billy and he looked at her, then gradually as time passed, his eyes closed and he eventually fell asleep (3:6).

When I visited for the fourth time, Billy seemed to take more space and commanded greater attention than on earlier visits. As I arrived he was already in the sitting room and I noticed that he looked different, more of a teenager. I remained unsure that I was accurately picking up what he might be communicating at first:

Billy was wearing a basket ball sweat shirt and tracksuit trousers and a silver chain around his neck...I came through and said hello to him. I moved to sit on the sofa fairly near to him, but not right up next to him. I left a space between us. He turned his head to the side as I said hello, but I didn't feel sure if he showed recognition in his eyes. His eyes would fix on me for a second and then move on, making me feel unsure how to try to interact with him. Billy's eyes are very big and expressive, so I felt very much as though I wanted to interact with him, but also aware of not wanting to swamp him. I sat back a little on the sofa. (4:1).

After a short while, Billy spoke out:

Billy still sat next to me and he moved his head around a little, making smacking sounds with his mouth and surprising me with a loud vocalization, a teenage (broken voice?) sounding vocalization, perhaps to draw attention to himself. He sounded and looked annoyed, as his face showed a little frown for a second. His mum called from the kitchen, that his tea wasn't quite ready yet, as it was very hot. (4:2).

Billy's ability to take this space and to assert his presence in this moment seemed to suggest that he could be a 'subject' with an embodied sense of himself and his own needs, even if these were basic needs he was expressing of hunger and anger, however briefly voiced. My experience of Billy on this visit was that he was thus able to garner respect and attention, albeit briefly, from those around him. I was still sitting next to him and I responded:

I saw Billy's hand was extended over towards me and I patted him, saying 'I bet you're hungry now' and 'it's coming soon Billy' to him. He still seemed animated, wondering when he would eat. (4:2).

b. Billy: communicating uncertainty

Following the accident a month earlier when the parents had dismissed the regular carers, life seemed to have become more unsettled. By the time of my fourth visit, I noted that there was yet another new pair of carers present to help Billy. This was the third new set of carers in four visits. It was a particularly awkward moment for everyone when Deirdre, one of the new carers, set about giving Billy his tea observed not only by me, but also by both parents:

Deidre stood uncertainly in front of us and Maggie brought the plate of food through for Billy... Tim brought the plate over to her and seemed unsure whether to hand it over or not. Deidre took the plate and made to spoon some into Billy's mouth. He seemed to take

the food quite hungrily.. It seemed to be an effort for him to take each mouthful, and the chewing was a little laboured for him, but the mouthfuls were going down fairly quickly. Dad hovered a little anxiously and then returned to his chair, leaning over a little to keep an eye on Billy as the feeding went on. It seemed strange to have both parents at home, while a stranger was feeding their son. (4:3).

Deidre then left and as we sat with Billy, Maggie seemed to become more able to reflect on her son and she commented that he was unsettled and that he had been so since the accident. Billy began to complain with moaning vocalisations while both parents tried to understand what was wrong. They quizzed him by asking questions one by one: did his stomach hurt and they wondered together how they could relieve his apparent pain and discomfort? They were unable to uncover what the problem was and they were left with the feeling of their own limitations as parents.

c. Billy: impairment, dirt and shame

While they checked him over, I found myself feeling very conscious of Billy's body and how he carried scars with him:

I could see his tummy and the scar across the right hand side, along with the gastrostomy peg and his incontinence pad under the top of his trousers. I felt he seemed so damaged. (4:5).

On this and during later visits, I noticed that I found it difficult to look at the signs of damage and impairment visible on Billy and that mess was quickly wiped away. For example when Billy's father had spilled water on his son when trying to give him a drink through his gastrostomy tube, I noticed how 'annoyed and disappointed' Tim had seemed in himself at allowing this to happen (4:6) as he wiped it up. On a later visit, I noted that Billy had 'a little bit of yoghurt still round his mouth' (7:3) and how uncomfortable seeing it made me feel when it was not cleaned up, as though it pointed-up his lack of control over himself and his impairments. Billy was in general, kept very clean and

Maggie professed that she found the thought of him getting dirty, quite uncomfortable. She showed me pictures from school, of Billy experimenting with touching different substances:

Another picture showed Billy with his hands in a big plastic box full of tinned spaghetti. Maggie said, 'you can tell when they've been doing tactile activities as he comes home smelling of tomato or shaving cream. The other one they do is cornflower and water. I can't bear to touch that'. Maggie showed a disgusted face when she thought about Billy making a mess. He doesn't seem to do this at home at all. (7:5).

I wondered how this fear of Billy seeming dirty might be reflecting feelings of shame and fears of exposure in front of me as an observer from outside the family²⁵.

d. Billy: rectifying impairments

Billy was someone who was not allowed to be dirty or messy, yet his body bore the marks of impairment and the attempts made by professionals to rectify these:

As his upper body was bare, I could see the peg fitted on Billy's front, into his stomach and his back, scarred from top to bottom where the back op had been done several years ago to straighten him up. His body seemed scarred and damaged, though recovered, resilient and his skin looked clear, strong and healthy, with a good colour. (12:5)

I was aware that Billy had been operated upon for sound medical reasons, yet it was distressing to witness the true extent of the scarring and radical nature of the procedures he had undergone. I wondered what meaning these events had had for Billy whose learning disabilities were significant. One hint I received was during my final visit when Maggie alluded to a medical procedure which was designed to test his kidney function:

²⁵ As described earlier, Simpson (2005) looks at this sensitive area, suggesting that parents of disabled children often to him seem to feel unnecessary guilt and responsibility for causing their child's impairment. It is as if something very deep and shameful is continuously exposed when a child's impairments are seen.

She went into detail about how it can be difficult to help him lie still for an hour while the test takes effect. A radioactive chemical is placed in a canula attached to his hand. Maggie said 'they offer anaesthetic cream, but that takes an hour extra, in which case we'd hit rush hour, so I just make him have it without'. The medics then look to see how the isotope travels through the kidney. 'It takes two of us to hold him, while they do this, one at the top and one at the bottom, at his feet'.(13:3)

Billy then was capable of protesting when in pain or discomfort. It was very distressing indeed to consider how he would cope with extended periods of post-operative care in hospital when his capacity to understand the reasons for the pain and the length of time he would have to suffer it was so limited. The difficulties this presents for parents who have other children to care for simultaneously, homes to run and jobs to do can seem overwhelming.

8. Household structure, roles and sibling relationships

Managing Billy's needs required Maggie to operate her home at times rather as a clinic. She was the 'nurse' and the siblings and her partner 'health care assistants'. Sean was not always comfortable with this arrangement. For example on the third visit, a little before Billy fell asleep, Maggie had been carrying out care tasks with Billy which involved passing water into his gastrostomy tube:

She easily attached the syringe to the peg and the liquid drained fairly quickly in. She refilled the syringe twice. I noticed Sean was hovering around watching, a bit nervous. He said jumpily 'look you've spilled it' and mum said 'it's not much, can you get me a kitchen towel please Sean?' Sean got up and quickly helped out, so she could dry the area round the peg. (3:5)

I wondered how taking this role affected Sean as this was not the last time I saw him seeming nervous around his older brother. During a later visit, Maggie described to me

how she had relied on the children when they went away to her mother's for a week at half-term holidays, to be on call to fetch the medication, should Billy have a major fit:

'I told the kids that if I shouted, at any time of day, they had to run and fetch the red box behind Billy's wheelchair. If he has a fit, I have to give him this medicine and they're not allowed to tell anyone. My four year old nephew would get hold of it and then who knows what' she said (11:3).

People had to understand, Maggie suggested, that theirs was not like other families. Her social worker had commented that the siblings Sean and Catherine needed time with her too:

'I can't do things like that. Families aren't like that. I have to run from fetching and carrying them places, to cooking their food and everything else'... 'They always say that I need to do more with the other kids, but it's not realistic' she said. (11:2).

While Maggie had to remain exhaustingly vigilant and 'on duty', enlisting the siblings' help from time to time, there was also a sense gained over the period of observing of the normal and ordinary nature of the siblings lives together. During the eleventh visit, I noticed how the family were grouped:

Apart from dad, the rest of them were united in front of me, Catherine in next to her mum, Billy next to Catherine, and Sean hovering to the side of Billy. I noticed that Sean had his foot resting on top of Billy's foot, which was clad in brightly decorated socks, resting on the foot plate of his wheelchair. (11:4)

The simple, unconscious intimacy of Sean touching his older brother's foot seemed to show that treatment of Billy could be ordinary and less reverential than appeared to me previously. The observation of this added complexity to the notion of sibling relationships. I began to understand the reciprocal of relationships within the family, thus challenging my unconscious assumption that Billy had nothing to give to his brother and

sister. It might have been difficult to elicit this information and learning from a more formal interview situation.

9. Care practices and ambivalence over Billy's adolescent transition to 'independence'

Maggie appeared to be capable of carrying out a sophisticated range of care practices with her son Billy. These practices included acts which required patience and persistence such as feeding, washing and communicating with Billy, while others were quasi-medical or nursing procedures, such as cleaning and maintaining Billy's gastrostomy apparatus. Leading on from the latter form of care practice was the expectation of Maggie that she maintain a vigilant stance in relation to Billy. This was necessary in order to monitor the complex interaction of his physical health status with knowledge of his impairments and how these affected him, mixed with how he was communicating his underlying mood or feelings about his physical and emotional state from minute to minute.

Maggie was able to recount the times when things had gone wrong, when she felt the care had not been quite attentive enough, and the consequences of this for Billy were dire. One example of this was given during my first visit when Maggie described how Billy's kidney problem had only come to light at a point when his condition was really quite bad, his inability to express his pain verbally having limited her chances of seeing what was happening earlier on. Clearly the requirement that these care tasks be performed implies an extension and development of the parent role well beyond normative bounds. Indeed, this is a 'no win' situation for the parents as even with vigilance, there is no guarantee they would notice Billy's declining health, given his impairments. This raises questions for professionals. It may be relatively easy to offer practical care support, but how do you enable parents to 'switch off' emotionally from caring?

During the observations I witnessed how hard Maggie and Tim worked to maintain a state of vigilance with regard to Billy. It appeared more difficult for them however to think more generally about his development as an adolescent in the transition to

adulthood. On my ninth visit for example, Sean found an adult's razor in the bathroom upstairs and he caused consternation by cutting himself while pretending to shave. This led Maggie to think about Billy when she described a recent incident with one of the carers:

Maggie said 'one of the carers asked the kids for a razor to shave Billy the other day'. She looked horrified at the suggestion. 'He doesn't need it yet' she said and Tim agreed. She wondered, seeming to ask me, at what age boys need to start shaving and I said 'I guess at different ages, depending when they start puberty'. I said 'well Billy you're a teenager, so it won't be long before you need to shave' and Maggie said 'well you don't want to start shaving yet, as you can't stop once you've started, can you?' (9:4)

I had found myself, rather inappropriately given my observer status, trying to draw Billy into the conversation, perhaps to encourage the parents to imagine him as an adolescent, with changing and maturing needs. Maggie's response had suggested that she was in no hurry to see Billy as a young adult. Indeed her closeness to him, and the requirement that she provide for his intimate care needs limited the potential for her to see him as a developing teenager. Thoughts of loss became associated in my mind with this incident, loss of potential in Billy to move on and to form relationships with others outside the family. Even a reference to a former 'girlfriend' of Billy's on an earlier visit seemed disconnected and isolated, rather sad:

Another picture showed Billy and another girl 'your girlfriend' Maggie said. I asked and she said, 'well Billy used to go in with the senior pupils sometimes, as he was in a class with some children who couldn't do much. They don't do that any more.' The young woman was 18 and in senior class. Nothing else was said about their being girl and boyfriend (7:5).

One theme alluded to here is that of Billy's sexuality. The razor appears to be a symbol of changes associated with adolescent transition and Maggie seems to recoil from thought of this. The possibility of Billy having a girlfriend is mentioned, but this is not dwelt

upon, as though the idea has no resonance with the young person they know and care for. It appeared an extremely difficult task to expect of a parent, engaged so closely in providing physical care for her teenage disabled son, to be able to stand back and to think of him as a sexually and physically developing young man.

Following the theme of transition to adulthood, on another occasion Maggie described how difficult she had found a recent meeting at school set up to plan Billy's future:

There were people from Connexions and other places. 'I was quite annoyed with it as he's only 14'. I asked what they had in mind for Billy as he grew older and Maggie said, 'well I'd like him to stay with us for a couple of years after he leaves school at 19- just like the others will. It's only fair for him.' She was upset though, as the advice was to seek residential care for Billy soon after 19, as once he reaches 25 'they won't consider it'. Maggie sounded shocked at the 'system' which seemed insensitive and uncaring. (12:5).

For Maggie to be able to conceptualise Billy as someone capable of separating from her, living independently from her, quite a considerable journey had to be made between now and Billy's eighteenth birthday when social policy and law dictates that Billy's adulthood would arrive. The family worked so hard to maintain Billy at home, to keep him well and comfortable, that there appeared little time of emotional space to step back, to view his wider needs as a developing teenager and there appeared no wish for him to become independent from them²⁶.

²⁶ As described in chapter one, Simpson (2004) looks at how learning disability can become a 'refuge from knowledge' within the family; that parents' inability to see their young person as an individual without the distortion of their defence mechanisms can limit the adolescent's potential for development. Added to this formulation should be the role of wider social institutions which should be there to help the parents in managing these difficulties, with creative solutions to the varied wishes and needs of severely learning disabled young people and their families.

10. The role of paid carers: learning to engage

The interactions between carers, Billy and the rest of the family often formed a focal point for the observations. As has been described early on in the observation sequence, a crisis occurred when Billy was allowed to fall from his bed while in the charge of two carers. This led to a three month phase, from the second visit to the tenth observation, when the care-plan had broken down and different carers were called in at short notice from new agencies to help the family. In this phase, I counted at least nine different and new people brought in to assist Billy. The work they carried out with Billy seemed to be characterised by times when they operated in a somewhat disconnected sense with him, when it felt as though Billy was 'acted upon' by these temporary workers, who did not know him. The whole family found this time extremely difficult. Maggie described her frustration at having to do the thinking 'for' the carers:

Maggie went on to say that a carer asked her for a towel yesterday and after she'd brought one, they said 'no, a face towel' and Maggie said 'why didn't they just ask for a flannel?' All in all it seemed Maggie felt exhausted by trying to help the carers to do their own job. (10:4)

If the care plan had been designed to provide the family with respite, a break in their caring responsibilities, it might be suggested that in fact the 'support' was only adding to family stress. Billy and his sister were finding it stressful also, to manage these new people:

Maggie told me as Tim continued to feed Billy, that 'it's been awful with this new agency. Billy hasn't been settled for ages. That's why he's not sleeping properly, he's so unsettled. It's really affected all of us, especially Catherine who's been awful' (9:3).

Towards the end of the period of observation, it was possible to see the efforts that the carers were making to move from a disconnected, servicing kind of care, to a more containing, emotionally connected form of work. During the tenth observation, I

witnessed a painful sequence, when at first I felt concerned that the carer Jo's actions came close to abusive in relation to Billy:

...and Jo once again lent over to Billy and said 'can I go now? Yes or no?' to Billy, imitating dad's way of asking Billy questions. He looked at her, but didn't react. Jo, perhaps frustrated at his lack of reaction, gently grasped his leg, his upper thigh, slightly shaking his leg from side to side to get his attention. She moved over and went to kiss Billy on his cheek, first on his right and then his left side. Again, Billy couldn't move or make any choice about whether or not she should do this (10:2).

I felt very uncomfortable watching this action of Jo's. Although she shook his leg only slightly it felt inappropriate, as though she was containing some aggressive feelings and impatience towards Billy, perhaps to do with his lack of comprehension of her words or his helplessness. She then tried to mitigate this by another awkward action, that of kissing him. A few weeks later, the atmosphere had changed and the action of the carer (Becky is Jo's co-carer) in kissing Billy seemed less concerning, partly as Billy seems to respond and to be less 'acted-upon' than in the previous observation:

Becky came back in to say goodbye to Billy, calling across the room, 'goodbye Billy' with a friendly smile. Billy smacked his lips spontaneously, to show goodbye in his own way. Becky responded to this by coming over and pecking him on the cheek. Billy seemed unaware of the significance of his 'kiss' but looked at her as she spoke to him 'OK Billy, see you tomorrow then' (12:3).

I had noticed during some of my observations that Maggie liked visitors to engage with Billy in this way. She often sat him next to me for example and would comment if Billy looked in my direction or if I patted his hand. Emotional engagement of this sort seemed to give her a moment to rest or to focus on other activities within the home, providing her and the rest of the family with a more genuine form of respite than an un-engaged, 'acting-upon' form of help.

11. The parents re-prioritise: engaging Billy

In response to the uncomfortable feelings described earlier on in the observation sequence, when the parents stood by awkwardly while the inexperienced carers fed Billy, the parents had decided by the ninth visit that they would resume feeding their son themselves.

Tim came back in then, with a plate of hot food for Billy. He mashed it on the plate, checking its heat level. "Time for you to have something to eat Billy?" Tim said to his son. Billy looked up at his dad, watching him closely. He anticipated the mouthfuls by watching his dad and was relaxed and comfortable with being fed. Tim confided to me that he and Maggie have decided not to let the paid carers feed Billy anymore, now that his oral intake has been so reduced. They let the carers give the tube feeds, but prefer to give Billy his tea themselves. "Ever since (the accident I presumed he meant) I can't trust the carers. You never know if they're feeding him properly". Tim went on to say that some of them are alright, but some of them don't seem to take the proper care... Billy continued to take his tea, watching his dad. Tim related closely to Billy, saying "have you had enough yet Billy, yes or no?" Billy was responsive, nodding to communicate his wishes, though as before, Tim seemed a bit unsure if Billy was giving a clear response, so he would ask again several times to try to form his own view. (9:2).

In this sequence, several things seemed to be going on simultaneously. The couple seem to be unified, to have been able to come to an agreement on the issue of Billy's feeding. Responding to the concerns of professionals over Billy having any food orally, they have taken responsibility for the risk this entails. Billy is relaxed and communicative in his father's care, able to lead and have his father follow in expressing and having his needs met. He is achieving 'subject' status, where he is acknowledged as an embodied individual in charge of his own body, even if only in a limited fashion. The cost of this to the family might be that the idea is reinforced that Billy is only safe in his parents' care, limiting the choices open to him and the whole family.

12. The continuing need for projection and blaming: keeping a wound open

Maggie still found it difficult to contain and manage her own feelings at times even with this more worked-out division of care. In one later observation, I noted that I found it difficult to sit with her.

It was getting late and I was feeling more and more tired and a little low in blood sugar- a bit jittery. Maggie carried on talking to me, holding my gaze and in my vulnerability I saw how tough and demanding she can be- very difficult to escape from if she wants your attention. I wanted to go, but it was hard to get away. (10:6).

This was at the end of a visit when Maggie had been explaining how she had been dealing with the issue of the carers who had allowed Billy to fall from his bed, many weeks before. There had been a lengthy account of how one of the women had applied for a job at Catherine's school and how Maggie had intervened, in a very powerful way, to ensure that the carer was not employed.

Maggie was very exercised by these events and I did wonder how the situation could be 'got hold of now' as she was talking about involving the press once the solicitor's action is finished (10:5).

I remembered the earlier observation when I had seen Billy slip down dangerously and un-noticed in his seat while these angry stories were retold. Blame was still in the air and some very punitive, angry feelings still at large. Perhaps the social worker had tried and failed to find an accommodation between the different parties, a way forward. The need for social work agencies to strive to contain and to manage such a process seemed evident. I also felt concerned that Maggie might resist resolution of the issues. By maintaining and worrying at the 'open wound' of the accident, the cause of which was not resolved, apologised and recompensed for, Maggie was letting other people know how she still felt. The wound, I speculated, exposed anger with those carers who failed

Billy and the family, but also perhaps some of the other difficult to acknowledge feelings associated with parenting a child with so many needs.

13. Relationships within the family: not much room to find your heart

The family succeeded in achieving moments when Billy's needs were better contained and he was able to adopt 'subject' status within the family, a 'depressive position' of realistic engagement with his emotional needs. But these moments were difficult to sustain given the competing demands of others within the home. Catherine continued to be blamed by her mother perhaps as a way of discharging the anxiety that Maggie was managing and this blaming could become fairly extreme:

People say the disabled child in the family is the problem but it's her that's got the disability in this family... Billy doesn't have any problem like that'. Maggie was trying to find a word to describe the problem that Catherine has. 'She's sort of difficult, like she runs around everywhere, causing problems, while Billy just stays still. It's a bit like that mild autism, Aspergers, those kids who are nearly normal, but are really crazy.' (11:2).

Sean, who was with us, listening at the time came up with a question which seemed to illustrate the problem Maggie was dealing with:

Sean was hanging around again and wanted to know 'how do you find where your heart is?'

Although Sean might have wanted an anatomical account of the location of the heart for his homework task, Maggie's response brought to mind for me the demands placed upon her in trying to meet the needs of family, including those of her very severely disabled son. Maggie's heart had, like the image she describes, had to be squashed up somewhere inside her, feelings put to one side to accommodate the huge emotional and physical tasks she had to undertake daily:

I said it (the heart) was just here, showing him and he went over to his mum, who described for him just where his heart was. She wanted to tell me also about a woman she'd read about who had worn a corset for decades, and whose heart and other organs got squashed up into her chest cavity as a result! (11:2)

The pain of dealing with this daily reality could I realised, be made more difficult for Maggie when the contrast between Billy's state of being and Catherine's was brought home to her, as in a later visit:

Catherine came in from outside, bouncing in wearing her swimming costume and Maggie immediately stopped discussing her. She had her hair in bunches to either side of her head, wet from swimming in the pool outside, a picture of health and vitality. (13:2).

This image of Catherine as a free, healthy spirit must at times have been galling for Maggie and Tim to witness, not only as they compared Catherine to Billy and the restrictions placed on him by his disabilities, but also to themselves, as adults encumbered by the cares and worries of meeting the many needs of their family.

I wondered often about the couple and their relationship during the observation period. They offered little to me consciously to explain the circumstances of their marriage break-up, one limitation of this approach to researching being that it did not permit me to probe areas which did not appear naturally during the visits. What I did learn however was that although they were divorced, Tim played a major role in caring for the children. I met him on many of my visits and on one occasion Maggie described calling him in the middle of the night for advice on how to manage Billy who could not sleep. There were many occasions when the two parents consulted each other about how to care for Billy and his siblings during my visits. They appeared in fact, to have sorted and divided parenting tasks between them efficiently and at least while I was visiting I did not witness arguments and disagreements. It is perhaps the case then that something had happened to the relationship to spoil its intimacy. While the couple remained capable of working

together to perform the practical tasks of parenting, at some stage the heart had gone out of the relationship.

14. Finishing the observation visits

As with all of the families I visited as an observer, I was aware of the need to remind the Andersons (and therefore myself) of the fact that I was soon to finish my visits. I knew that by providing attentive observation of the family it was possible that unconscious processes might be aroused by the ending, mirroring those which can emerge at the ending of therapeutic work (Jacobs 2004 describes these processes in relation to psychodynamic counselling relationships). In the event, as I prepared to finish my last visit, I found both parents very united, holding me in conversation about Billy and some activities they had planned for him while Sean and Catherine played outside in a paddling pool. I had given them a present of some cinema tokens to thank them for allowing me to observe the family, as I knew they liked to visit the pictures as a family group. As I tried to say good bye Tim kept speaking in an animated way, perhaps to mask feelings of awkwardness, which made it difficult for me to concentrate on Billy who was sleepily lying in his bed near where we were talking. We managed to say a warm good bye in the end, thanking each other, while Billy continued to doze. I left feeling relieved that I had finished, but sad and thoughtful about the family. While I had not assumed a practitioner role during my visits, I was left wondering who would take up the role of listening and watching Billy and his family once I had gone.

15. Learning from the observation experience

The first contact with Billy's mother Maggie had encouraged me to think that it would be easy to gain entry to observing Billy and his family. Maggie was actually more mindful of maintaining a strong boundary around her family than I had expected and she needed to be fully in control of the decision before allowing me in. I had to be active in my negotiations with her to find a way to let her think the decision through, so she might make an informed choice about letting me in to observe. Over a period of six months, I

managed to visit the family only thirteen times out of a possible twenty-four or so. This reflects how unpredictable life was for the family with medical needs arising for Billy and other family events cropping up, but I do think that Maggie may also have been keeping me at arms length for some of the time. Perhaps it was painful to have an observer in the home, whose presence may open-up thinking space for the family. Maggie dealt with the anxiety she felt about life caring for her vulnerable son, I observed, by strongly projecting into those around her, professionals and others involved in their lives. Feelings of guilt and fear of reprisal can come up once the angry projecting finishes and it may be that at some times that she did not wish to show a public face; when it all felt too much²⁷.

My first observation visits enabled me to experience the agitated, anxious nature of everyday life for this family. Maggie communicated to me immediately her feelings of urgency about the fragility of her living situation and her fear of Billy having a health emergency. She and the two other children Catherine and Sean vied for my attention and I felt like a parent struggling to meet all of their emotional needs. Tim, the father, was kept at a distance and he did not seem to take on a strong parental role while I was visiting.

I found myself becoming more of a participant than an observer, as I stepped in to help with the children's homework and listened to Maggie's difficulties. Billy by contrast appeared often to be calm and sleepy, out of touch with the high emotion of family life around him. When he had a serious accident, a few weeks into the observations, I was alarmed by the possibility of the parents' feelings of hatred towards him, masked as it appeared to me, behind their fury with the carers who had allowed him to fall.

The observer role did not permit me to intervene and I had to contain my feelings of concern about the family situation, wishing that a 'good' practitioner from outside would come along and help the parents to manage their feelings. I found that I could offer some

²⁷ This may be viewed in object relation terms as movement between paranoid schizoid and depressive positions in Kleinian object relations theory, as outlined in chapter one.

containment by listening to Maggie as she voiced and emotionally communicated her feelings, but I felt that I wanted to take her on, to intervene and to take charge which it was not appropriate for me to do. Maggie, I believe, used me to vent her feelings around this time and later in the observations and at times this was hard for me to manage²⁸.

I witnessed the parents expressing feelings towards their children, which seemed to evidence projective processes. They idealised Billy's unselfish outlook, they saw Sean as helpfully self-deprecating, but Catherine on the other hand was described as self-centred and unfeeling in regard to her parents' problems. Catherine in particular appeared to have to cope with strong angry projections from her parents and I was concerned that she may have experienced 'symptoms' as a result (a diagnosis of dyspraxia, bullying at school, poor educational progress). Sean as well as his sister had to take on caring burdens with Billy, as they helped their mother on a practical level and they were expected to share the state of anxiety and vigilance Maggie had to take on for fear of Billy having a health crisis. There were however moments of warmth and ordinariness observed with the siblings' spending time together and in their relationships with their parents.

I observed the parents' struggle to understand how to meet Billy's needs and with how to make use of paid carers' support effectively. He seemed fragile and difficult to reach because of the extent of his cognitive and physical disabilities and the parents suffered along with him when he experienced pain or discomfort. It was very hard for them to see Billy as a developing adolescent in transition, or for them to conceive or to wish for him to be independent of them. All evidence of dirt and mess was removed from him and there was discomfort around the notion of his sexuality, however veiled. I experienced Billy as more alert at some times, able to be more present and to take a space in the family; though this was fairly rare and I as I met him only at the end of a long school day he may have been unusually tired out during my visits.

²⁸ While it was emotionally draining to observe Billy and his family, the practicalities of observing were less complicated than in some of the later families where the young people were more mobile. I found I was able to remain mostly in one place within the home, observing events as they unfolded.

The parental couple had divorced some years before, yet I observed that many aspects of their relationship still seemed to be alive, with Tim spending much time in the home helping out and being on-call at all hours to Maggie. I could only speculate on how their marriage had ended, but given the intensity of feelings within the home and the exhausting level of care and vigilance necessary to provide for Billy and his siblings, it would not surprise me if the couple had split apart, feelings of blame and recrimination having become too much to bear²⁹.

²⁹ Simpson's (2004;2005) work which relates to parents of learning disabled children goes into detail about the possible defensive structures which may arise in such circumstances (as described in chapter one). While my comments here about the couple's relationship are speculative, there were some clues from Maggie that she had found her ex-husband less helpful than she wished in providing care for the family and that she thought him rather like another child.

Chapter Four

The Brown Family

1. Introduction

I made contact with Kate, eleven year old Daniel's mother, on the same occasion that I met Maggie Anderson from the first family observed, at a coffee morning run by a local voluntary agency for disabled children and their families. Rather like Maggie, I found that Kate was open, friendly and happy to take part in the research, an attitude of mind that puzzled me to begin with given that having an observer meant something of a commitment for this busy woman. Later on, when observing, I learnt that Kate was a teacher who had experience of working with children with special needs; her professional background setting her apart from the other parents in the study. Kate was not working, having given up her teaching career several years earlier, while her husband Ian had a well-paid job in the private sector. The marriage was Ian's second and he has older children who he remained in touch with.

2. Meeting the family and becoming an active observer

When I met Kate, I was curious to understand why she was so open and willing for me to make observation visits to her family. In my previous social work role I had met some families who wanted outsiders, particularly professionals, to see what their lives were like so that awareness of the stresses they faced might be better understood. This was my earliest assumption on visiting Kate and her family and I wanted to see whether I was correct in my view or whether other concerns might emerge, perhaps related to her professional status and her identification with me as a researcher. Having carried out observational visits to families before however, I also knew that I should be thoughtful

and respectful in relation to someone who so readily allowed a researcher into their home; there might be other issues to consider of which I was, as yet, unaware.

When I arrived, Kate was clearly expecting me and she busied herself around the kitchen at this hectic late afternoon time. She cheerfully welcomed me and once asked, completed the consent forms without any questions or sense of curiosity as to what I was aiming to do. Daniel's younger brother Andrew was not so sure about having me there:

'He looked straight at me in a way which contrasted with his mother, who made little eye contact... [saying]...who is she?' (1:1).

Andrew's direct challenging of me felt quite withering and I wondered how common an experience it was for him to have new people, strangers, carers and professionals invade his home. Daniel arrived on the scene then, in the family area of the kitchen:

In the kitchen was a small boy, with short brown hair. He was winding his arms around himself as he stood near the table and Kate introduced him to me as Daniel. 'He's just come back from his respite unit' she said. I said 'hello Daniel, nice to meet you'. Daniel looked fleetingly at me and he continued to wind his arms about himself, talking and whooping to himself in low tones. Daniel had a pale, freckled skin and his short fringe framed his face. He wore slightly ill-fitting, track suit trousers and jumper and he looked a little tubby. After a minute he slipped out of the room, upstairs. (1:1)

A short while later Daniel's legs could be seen at the top of the staircase and I could also hear the sound of fast-running water from a nearby tap. Kate wearily expressed concern about his habit of playing with water and the risk of flooding the house and dashed off after him, 'groaning' when she heard the sound of water flowing upstairs (1:2).

Responding to her groan and to the fact that I could see how busy she was trying to cook a meal while watching several children, I offered to go upstairs to Daniel the next time the water sound could be heard.

As an observer, I could have remained in the kitchen, leaving Kate to deal with everything else which might develop in relation to Daniel over the weeks, attempting to adopt an objective, 'fly on the wall' stance. I felt however, that I was going to need to take a more active position in the family if I was going to research Daniel, a mobile young man, and his family. I feared that if I did not take an active stance I would possibly see little of Daniel, as it had already emerged that he did not stay around the rest of the family space for much of the time. Clearly it was necessary to feel my way, to find a way to observe in this new and unaccustomed role. I responded in the moment by becoming more active than I had in the first observation with Billy and his family and reflecting on this development in supervision later it was agreed that this was to be expected given the different nature of the two young people's disabilities. Kate had unconsciously communicated her complaint to me about having to meet many demands and I responded by acting, thus setting the pattern for the observation from there on. I noted the peculiar position I was adopting in the family already:

I went upstairs, feeling OK about doing this, though I'm still pretty much a stranger to the family and in another situation it could have been very intrusive of me to wander freely round someone's house (1:3).

3. Being with Daniel

a. Being with Daniel and noticing the potential for shame

Although it is something I had experienced before in my practice as a social worker, I noticed that the simple act of being in the same room as a young person with autism can feel at first quite odd. I was aware that Kate may be wary, curious to see how I might react on meeting her son, whose behaviour did not conform to social or interpersonal communication norms:

I asked if it was OK for me to go up to see Daniel in his room and Kate said yes, he was watching a favourite DVD and filling a mop bucket with water. She seemed a little

flustered as she told me this, perhaps because by describing his activities this somehow highlighted their oddness. I wondered if this was an important moment, where Kate might see me not reacting with shock at Daniel's oddness- I was aware of the need not to seem surprised or disapproving. (1:2)

I was already imagining and speculating on how it was that I was viewed by the family, in order to find a space to observe. The research process was an active one in which nothing might be taken for granted, in which I had to consider my own subjectivity and to speculate on that of the family members. I had in actual fact, met many young people with autism through my previous social work role, and so was fairly accustomed to the feelings aroused by being with someone who makes no obvious attempt to look at you or to communicate. To move into a research role however, I had to be alert to the unconscious processes at work; that I was containing quite a degree of Kate's anxiety at my arrival in her house. The experience of arriving raised the thought that at these times when people from the outside world penetrated the home, feelings became exposed; feelings it seems which reflected shame at Daniel's difference.³⁰

The moments when I noticed this were rare during the six months of observing; occurring at this opening moment when I first visited, but once more some weeks later, when a friend of Andrew's visited the family:

As soon as Daniel got onto the trampoline, the friend recoiled and jumped straight off, as though frightened of Daniel. I'd never seen this response before. Most of the friends tend to take the cue from the brothers and just ignore Daniel. Kate and I were both watching from the kitchen... Kate made a small groan of acknowledgement (14:3).

Observing Daniel in his own home therefore presented a particular kind of opportunity. It was a chance to see him being with his parents, siblings, their friends and carers in an

³⁰ Klauber (1998) looks at how parents can re-experience feelings of trauma over their child's diagnosis with a severe disability, when encountering professionals later on. This may account for the anxiety that I felt I had to contain here. This is discussed in chapter one, as are Simpson's (2005) ideas on learning disability and shame.

environment that, while sheltered and apart from, was also affected by the attitudes, influences and feelings aroused by contact between the family and the wider world.

b. Being with Daniel and beginning to see with his eyes?

When I went upstairs on my first visit to observe I therefore had to watch Daniel for the purposes of the research, but also with a view to keeping him safe having unconsciously allowed his mother to place me in this position as his ‘minder’. I found him displaying what might be thought of as an array of typical autistic behaviours, involving repetitious, self-stimulating activities:

I found Daniel in the bathroom, filling the red mop bucket with water from the tap and flicking water around the bathtub and wall behind. The floor was already quite wet and as I had taken my own shoes off, my feet felt damp. (1:3).

I commented to him that he was splashing about and my interruption seemed to put him off, spoiling his reverie. Daniel quickly left the bathroom, returning to his bedroom:

...there was a tall cabin bed, with a futon sofa underneath it. On the far side of the room, was another large TV. Playing on the TV was a DVD of Hunchback of Notre Dame- Disney version. I laughed to myself as I'd been planning to use the image of this disabled cartoon character to illustrate stereotypical social attitudes towards disability, with a student group in the next few weeks. (1:4)

I tried to put aside my adult, interpretive thoughts about the content of the video Daniel was watching in order to gain some understanding of what was interesting him. The menu page of a Disney cartoon DVD was now playing the same short tunes over and over again. I decided to join with him in watching and listening to see the pattern playing out.

The menu screen was divided into quarters, playing a set of four different salsa-style, quite raunchy tunes, varying according to which of the four characters was being highlighted. The tune cycle went on for about a minute and after a moment's silence, the sequence repeated itself. It took me a couple of cycles of the music playing through to see the pattern behind what was happening. Daniel was engaged with the music and held his arms high above his head as the music cycle came to and end, anticipating the bouncy intro-music. (1:3)

I used the technique of speaking out, speculating on what Daniel might be thinking to see if this helped him to get used to me being there and for me to understand his perspective, for example commenting; 'you like this music and the pattern?' (1:3)³¹. The speech, perhaps its gentle tone, seemed to help Daniel accept my presence and he occasionally looked back after this to see if I was still there with him. I felt pleased, even a little 'high' myself, once I could see the pattern and what Daniel was finding so pleasurable.

After a few minutes I noticed feeling uncomfortable in sharing Daniel's music 'high' and I decided to leave him to his music. As I returned downstairs I noticed that he had oddly 'bricked-up' the fireplace in his room with a great number of video cassettes, all with the labels pulled off making it impossible for others to identify their content. The use he made of these videos seemed to represent a motif which arose time and again with Daniel. He broke experiences down into their constituent elements, thus removing the categorising, labelling and symbol-making tendencies which most people bring to such experiences.

Over the six month period that I observed Daniel, I had many chances to see his preferred way of relating to the world, which often revolved around activities such as water flicking and repetitive listening to Disney DVDs. My initial response to this was to admire Daniel's attention to detail and his aesthetically pleasing fine motor skills; as

³¹ This is reminiscent of the kind of technique made use of by Anne Alvarez, as described in 'Live Company' (1992). Speaking out in this way takes me beyond a pure observation role, but I felt it necessary at the time as I was trying to help Daniel to accept my presence.

though he opened up new ways of seeing and manipulating the world around him. On the second visit, I followed him outside into the garden on this dark, January afternoon:

He sat with his legs crossed, so he could get right next to the paddling pool. As he flicked the water in the air, I could see a pattern of water droplets arcing in front of him, almost like a firework sparkling in the air with the lights of the house behind him. It was really quite beautiful as he'd developed the skill almost to hold the water droplets in the air in front of him...I felt quite in awe of Daniel. He seemed intent on perfecting his skills... I could also see Daniel was getting gradually wetter. (2:4).

So for me, Daniel became an object of fascination, admirable for his oddness; an autistic character, a recognisable stereotype from popular culture in films such as 'Rain Man' (Levinson 1988). Yet the consequences of his behaviour, his gradually getting wetter outside on a cold January afternoon, provoked anxiety in me as an observer and the wish to take charge.

4. Care Practices

a. Care Practices. Balancing the needs of siblings

I was struck during the first observation, by just how hard Kate had to work to stay on top of activities within the house. She had four young boys to care for and at times she moved frenetically about, never sitting down or seeming able to round them all up together to co-operate or to collaborate with each other. Kate's attempts to prepare food for the boys during my first visit seemed emblematic of this problem. It was late afternoon when I called and I saw that she did not sit down once during the hour of the visit. I noted also that Kate's food preparation plans were thwarted when both Andrew and Daniel refused the chilli she had prepared and she resigned herself to heating-up some hot dogs. Earlier she had been preparing eggs for the children. This struggle over getting the food right seemed to represent the difficulties for Kate of providing care and nurture for all the boys individually, while attempting to keep up with Daniel's particular

needs. There was a guilty, regretful moment too, when Kate remarked that her youngest son John (6 years) was round at a friend's house and that 'he had almost moved in with them' (1:4).

During the second visit, I learnt more about the family as Kate entrusted information to me. Working her way through a pile of bills and reading a report on her third oldest son Andrew, Kate revealed an important piece of information that he, like Daniel, had a Statement of Special Educational Needs for communication difficulties, having only learnt to speak at four years old. Kate also let me know that Daniel was going for a stay at a new respite unit the family were funding themselves. This was to enable the rest of the family to have a holiday apart from Daniel over half-term. Thus she used the time I was around to catch up with the needs of the rest of her family and to plan for the future, trying to ensure that every family member was considered. As an observer, it felt as though Kate was rapidly assuming trust in me, handing me information about intimate, personal aspects of her family's life. I was aware of the need to try to contain her wish to tell me too much too soon; to offer a kind of 'containing befriending' relationship³².

The issue of fairness is one which arises in many studies of siblings (Sanders 2004; Mitchell 2003). It appeared that Kate was working hard to treat her children fairly, attempting to compensate for times they missed out because of the amount of time and space Daniel needed.

b. Care practices. Mother's vigilance in managing Daniel

While trying to cater for her sons' different food requirements in the first visit, I noted that Kate needed also to make sense of Daniel's world. Daniel had just returned from a weekend at a residential respite centre and she showed me the written records of his stay,

³² As a research technique, I was taking an observer as participant position (Gold 1958, in Flick 2002) rather than a pure observation position. When Kate offered information about what was happening with various family members there was a strong emotional content to what she was communicating. I would note this afterwards, though I did not relentlessly pursue the themes she raised. I was aware that I was not offering long-term therapeutic support and I felt as though she may have wanted this. This is where the idea of a 'containing befriending' stance comes from.

along with his home-school book, which together painstakingly accounted for his activities, moods and behaviours over the previous three days while mother and son had been apart. She imaginatively reconstructed his time away from her as a parent of a very young infant might do if they were apart:

She showed me from the records that he'd been a bit unsettled at first, but he'd enjoyed the days afterwards. Kate wondered why he'd been unsettled... she remembered there had been new furniture at the respite unit and that might have been it. (1:4)

Kate's role in forming a bridge between Daniel, his family and the outside world was emphasised for me as I made a minor blunder on leaving the home at the end of my first visit there, which seemed to undermine her efforts to connect him with others. I spotted a school photo on a shelf as I was at the front door and admired it before I noticed that Daniel was missing. Kate quickly explained that it was from the other siblings' primary school, but I felt very aware that I had unconsciously drawn attention to the painful fact that Daniel was different and absent from this picture of 'normal' life.

5. The discomfort of the observer and the learning from this

It was difficult to find a position from which to observe Daniel over the subsequent weeks, my dilemma reflecting the ambivalent place he occupied within the family. In order to begin to learn about his view of the world around him, I allowed myself to become a little like him, perhaps a little 'autistic', to focus in on the world of objects in the way he was doing.

On my third visit to the family for example, I noticed that he seemed to be connecting with me and by attempting to see the world as he did, I found that I felt bewildered by the lively household, peopled with the boys and their friends, eight in total that day. It was hard to observe so I found myself:

...trying generally to absorb the atmosphere, rather than to know everything and everyone' (3:1).

Kate was busy cooking food for the children and she directed me upstairs to find Daniel, who was watching a favourite DVD, 'Jungle Book', on his own. He turned for a moment to look at me, dancing in the meantime to a tune:

He looked over at me and came over to stand right next to me, almost touching my arm before moving away. It felt like an almost affectionate movement, perhaps checking out that I was standing there. (3:2).

Immediately after this however, a young friend of John's, Daniel's youngest brother, came into the room. He pointed at Daniel, saying to me 'what's that?' I was surprised when I realized he was referring to Daniel, not the television film or an inanimate object within the room.

The feeling that Daniel was invisible or somehow alien within his own home was compounded later during the visit when Peter (the oldest, fourteen year old brother) arrived and marched into Daniel's bedroom to show his newly pierced ear, the piercing having been carried out at a friend's house in an amateur fashion. His mother Kate struggled to mask her fury at this rebellious, even risky action, as she wanted to know if the equipment had been sterilised. While she managed this lively encounter with teenagers Peter and his friend 'Idiot' who accompanied him, Daniel was in quite a different space:

Daniel, meanwhile, was in the room still, moving round the boys. They ignored him and no-one said anything to him. I saw him go up to Idiot's back, seemingly fascinated by the rain droplets on the back of the waterproof fabric. Twice, he tried to flick off a drop of water or to touch the fabric. Idiot remained facing Kate as the boys tried to win her over, not noticing Daniel. (3:4)

In order to observe Daniel I was finding it necessary to become a little like him, noticing the minute broken-down aspects of the complex and hectic life of the home. By the fourth visit however, I came to question and rethink my observer position.

During the fourth visit there was a tense atmosphere and an argument going on between Andy and Peter. I found Daniel in his bedroom which felt cold and which smelt faintly of urine. He was nestled under his duvet and I noted he seemed 'tired and a little listless' (4:1), perhaps a little forgotten about up in his room, away from the heated social environment of the family downstairs. He looked up at me and then went back to watching the television. After a while I left him alone, returning to the kitchen for a cup of tea. Finding it difficult to know where to stay in the house, I then returned to see Daniel:

I wandered back upstairs while she made the tea, to see Daniel. He was still watching the video and hadn't moved. I sat on the floor again and made a comment about the song which was playing. After a few minutes, Daniel pulled the cover right over himself and with the occasional movements he was making, I felt uncomfortable and thought he might be masturbating. As soon as I thought this, I got up and said 'I'll see you later' and returned downstairs. (4:2)

This was very difficult as I felt that I was intruding on Daniel, even harming him by being there and this thought horrified me. But I realized that possibly he was also intruding psychologically and emotionally on me. If merging with others was Daniel's way of relating to them, then knowing about his developing sexuality might be part of that process of getting to know him. I went back downstairs to put some space between us. Learning about Daniel's sexuality in this way meant that I had to appreciate that he was not simply vulnerable little disabled boy, growing in age but 'trapped' in a young boy's body, a view often made popular by media and cultural perspectives of disabled children and adults (Shakespeare et al 1996). Instead he was a developing adolescent with the usual range of instincts and desires, albeit complicated and made public by the experience of autism.

It took time to process this experience, partly through talking about what happened in supervision in the next few weeks. I reflected on my role as an observer in these intimate family situations and how inevitable it was that a range of difficult feelings and experiences would be encountered. From an ethical perspective I found that I changed my attitude towards Daniel in the meantime, becoming more thoughtful and emotionally boundaried when observing him. It seemed that it was not possible just to be with Daniel, without being an active, emotionally thoughtful, ‘adult’ observer.

6. Home: refuge or jungle?

On the fifth visit I sat more of the time with the rest of the family, making occasional forays to see Daniel, who still spent most of the time in his room. His favourite video Jungle Book played and I began to watch more closely the unfolding story. I noticed how Mowgli is kept safe by the adult animals around him, blissfully unaware of the frightening tiger Shere Khan who wants to kill him. Unsure whether Daniel had a sense of the overall narrative of the film, I nevertheless began to wonder whether he was in fact like Mowgli, taking refuge in repetitive and safe behaviours on his own in his room, while the rest of the household was a jungle in which hostile and at times unfriendly thoughts and feelings about him held sway. I was seeing evidence of this, just occasionally, when Daniel’s brother John for example reacted excitedly to mention that Daniel was to travel to his respite unit the next day:

Kate said ‘we’re taking Daniel to respite on Thursday’ and John immediately said ‘hooray’. His mum quickly ‘shooshed’ him and the conversation moved on- no discussion. (5:3)³³

³³ The spontaneity of John’s response shows one way in which observation methodology may be getting to underlying feelings present in the family that might not be available through traditional interview techniques.

7. Observer resists, but becomes more involved. Learning about Daniel's disabilities and abilities

By the time of the sixth visit, I was tiring and struggling to keep up with the weekly observation visits. There had been a break the previous week as it was the children's half-term holiday and I had agreed to ring Kate before the sixth visit to confirm the time:

When Wednesday arrived, I was at work and 'forgot' to ring as I had immersed myself in writing something in my office. My mobile rang and it was Kate who wanted to tell me it was still alright for me to come for the visit the next day. I was caught off guard and surprised that I had forgotten to ring. I apologized to Kate. She was clear and focused on the phone to me. She didn't seem angry that I'd not phoned, she just wanted to organize herself, her family and it felt me, for tomorrow. (6:1)

During this phase I continued as an active, participatory observer as Kate slotted me into a role as an additional 'minder' for her family. Although this was a useful and necessary position from which to observe, my unconscious resistance as evidenced through forgetting to ring her indicates that I was finding it stressful. I was finding observation as a research method exhausting as I was allowing myself to be used by the family, but I was also working hard to write-up, reflect and process the emotional content in-between visits.

Kate had contacted me before the sixth visit to let me know that she was to be away for most of the time and she intended leaving Sharon, her privately funded 'mother's help' in charge of all four boys and their new puppy. On arriving I met Sharon, who was pleasant and capable. She was attempting to impose some order on the brothers, who were unruly and exuberant in their mother's absence:

John and Andrew resumed their wrestling. They mimicked the American wrestling programme on TV in the living room... John would throw himself at Andy, who would

retaliate by punching John while holding him under his arm to keep him still. The punches weren't hard and John was enjoying the play. (6:2)

Both Sharon and I tried to calm the brothers and we then sat with Daniel for a while in his room, Sharon relaxed, comfortable and physically close to Daniel:

I found Sharon nestled on the sofa underneath the cabin bed, with Daniel leaning back comfortably on her. She looked around at me saying 'it's the same old video again' pointing to the Jungle Book on TV. I sat on the wooden floor, a couple of feet from the two of them. Daniel was watching TV, but also holding his hands above his head. He started to smile and smack himself on his forehead. He did this repeatedly, quite hard and he would laugh a little hysterically after each strike. Sharon tried to divert him by talking to him about the TV. She said, to me, that she must have seen this video a hundred times- she knew all of it by heart. (6:3)

I was surprised at Daniel's presentation as quite 'disabled' during this time; self-harming by smacking his head in a manner I had not seen previously and I wondered if this was connected to the absence of his mother. Sharon noted the number of times she had seen the video while caring for him and the silly inconsistencies she had noticed in the animation. While Daniel seemed to enjoy the simple repetition and attention to micro-level detail, Sharon had become bored by the continued watching and re-watching and even a little disappointed with Daniel:

She looked down affectionately at Daniel as he lay cuddled up near to her. 'You don't talk to me and I feel a bit left out sometimes, Daniel' she said. (6:4)

On the next visit Daniel was communicative, lively and sociable in great contrast to his presentation on the previous visit when his mother was absent. He led his mother round the kitchen identifying things that he wanted to eat:

She helped him to choose what he wanted to eat by letting him lead her by the hand to the different cupboards. She opened the cupboards, fridge and freezer one by one, narrating events, saying 'do you want something in here?' (7:1)

Unusually in my experience, Daniel also interacted with two of his brothers. First Peter, the eldest, helped Daniel to stroke the puppy:

As Peter held the puppy to give her a cuddle, Daniel walked up to him and placed his hands flat onto the puppy's fur, holding them there for a few seconds. Peter took his brother's hands and helped him to touch the puppy. (7:3)

Later, Daniel joined his younger brother Andy on the trampoline:

Daniel went over to join Andy on the trampoline. He climbed up with him and began to bounce with his brother. They timed their bounces well together, each achieving a satisfying, but safe height. Then I saw Andy take Daniel's hands and the boys looking at each other, as they continued to bounce. Next, they both sat down on the trampoline opposite each other, legs crossed, continuing to bounce. (7:4)

I also learnt on this visit of Daniel's musicality as I heard him singing a series of nursery rhymes tunefully and recognisably. Greatly surprised by the difference in Daniel during this visit, I mentioned this to Kate, who acknowledged his abilities. It seemed difficult to hold this in mind however and while mentioning Daniel, she thought about the new puppy:

Peter decided to fetch some dog treats and Kate pointed out that he needed to make the puppy 'sit' before rewarding her. She reminded him they were going to need to take her for two walks a day from tomorrow as she's now old enough. As I stood looking out through the conservatory at the younger boys, Kate laughed and said that they often use the same words to talk to Daniel as to the puppy (7:4)

Thus Daniel and the puppy are associated with each other in Kate's mind, an indication perhaps of her frustration and disappointment with her son's limitations. As an observer, I could see both perspectives on Daniel; that he varied hugely from what appeared a very learning disabled state of mind, to a more active, socially and emotionally engaged one. As his carer Kate would have to cope with this variation and the knowledge of his potential as well as his impairments³⁴.

8. Care practices and three forms of parental vigilance

Care practices for Daniel seemed to encompass three elements of vigilance for Kate. Although similar to those in the first observation of Billy, these differ in emphasis in accordance to Daniel's needs as an autistic young person. First, Kate had simply to keep an eye on him for much of the time; to ensure he was safe and not damaging items around the house. The house itself had to be secure, to contain him within its boundaries as he had a history of absconding into the local neighbourhood. Secondly, she kept her mind on him; thinking about him, with him and for him, to try to stay one step ahead of his likely needs which he is often unable to communicate clearly. Finally, Kate provided practical care; helping Daniel with everyday activities such as toileting, eating, dressing and so on. While these constituent elements of caring are normal aspects of the parental role, Daniel's impairments added to and deepened the level of attention and work Kate had to do. She seemed in my experience to do a pretty good job of staying on top of these elements, but her exhaustion was evident too at times.

On the thirteenth visit for example, many of these elements are observed. Kate was at home with the four boys and two of them had friends over. She was cooking for the boys, while telling me about a chaotic series of events which had recently happened. The police were called following an incident when Peter and a friend were beaten up by some older boys. These older boys also stole Kate's handbag after chasing Peter into the

³⁴ Howe (2006) when reviewing attachment research on disabled children, showed that this kind of inconsistent emotional and behavioural patterning can lead to insecure attachment, as described in chapter one.

family home. While I listened to the tale, some of the children came in from the wet garden, carelessly adding to Kate's work:

I noticed a trail of wet footprints across the conservatory floor and some damp clothes on the floor. I went over and picked up a green school jumper, placing it on the back of a chair. (13:2).

On this occasion, Daniel was still in the family car outside the front of the house, refusing to come in. He was, Kate said, adamant that the family was supposed to go shopping that afternoon, one of his favourite activities. I went out to see him:

[I noticed that] Daniel was playing with an aerosol can. I immediately opened the door and saw it was de-icer and the car smelt strongly of solvent (13:2).

It is possible to see during this account, how I had allowed myself to overstep the observer role by becoming vigilant myself, taking-over some of Kate's caring tasks during my visit. I picked up the children's wet things and removed the aerosol tin from Daniel, who was on his own in the car. So much was going on but in the middle of this Kate was thinking about another perplexing aspect of Daniel's behaviour:

Kate said that Daniel was now not wiping his bottom with bath towels... but he seems to be washing himself with water from the toilet. She worked this out after going in to the loo after him. We agreed it was a fairly logical thing to do, as he's learnt about washing and he wants to be clean after the toilet. (13:4)

By this stage of the observations I had become well acquainted with the complexity and at times chaotic nature of life within the Brown household and I had opted to help out rather than to stand back, simply observing in a passive manner. Kate appeared to welcome the small amount of assistance I was offering in sharing some of the practical tasks of caring. She also used my presence to verbalise her feelings about Daniel so that I was able to share some of the emotional aspects too.

9. Mother's enmeshment with Daniel: chicken or egg?

The vigilant state of mind Kate was adopting as parent and carer of Daniel seems to overstep the usual requirements of a parent of a young adolescent. Whereas parents would expect to operate inter-subjectively with their child, trying to imagine and predict their state of mind, Kate appears to do more than just her part in this. She seems to be re-experiencing Daniel's life for him, almost to live his life on his behalf, feeling the bits that he has missed somehow, projecting into his world to try to work out how he should react to and anticipate activities in the world around him. This might help to explain the puzzle of why respite breaks seemed at times to provide so little rest and recuperation for Kate, while I observed the family. It seemed to take a great deal of effort to re-live Daniel's time away from her, to piece things together so she could understand how he was thinking and feeling after a break.

The high degree of attentiveness that Kate paid to Daniel was reminiscent of the kind of emotional care required by very young infants³⁵. The difference for Kate and Daniel however, would seem to be that Daniel showed little drive, as even a young child would, to move on from a state of total emotional engagement with his mother who it seemed had to lead the dance and to keep it going at all times. For Kate, there was little hope of respite from the neediness and emotional dependency of her son as, unlike non-autistic children, Daniel's developmental potential to separate seemed limited.

It was impossible given Daniel's age, to accurately unpick how their relationship had developed over time; to tell how much his current presentation reflected Kate's difficulties separating from her son and how much was innate to his condition of autism. Nothing I experienced in observing Kate with her family indicated that if she did have difficulties in separating, that this was outside the normative range of parental behaviour. Certainly Kate's close preoccupation with Daniel and the peculiar nature of his emotional

³⁵ As described earlier, Stern (1998) has shown that young babies are engaged very closely with their caregivers in a kind of emotional dance in which needs are communicated and responded to sensitively

relating did make the household feel a little ‘mad’ at times³⁶, but it is possible that her behaviour was a reaction to Daniel’s innate impairment in relating³⁷. To some extent, there was no purpose in speculating beyond this point on the ‘cause’ of Daniel’s autism. During the subsequent observations however, the intervention of Daniel’s father gave a clue that he does have developmental potential and that his autism is not fixed in one particular way of relating to himself and others.

10. How the parents made use of the observer to help think-through a way to be with Daniel as an adolescent

Over the weeks I was observing Daniel and his family, the season changed from winter to spring and the weather warmed. Daniel became more freely able to spend time in the garden, enjoying his favoured activity of water flicking from the end of a hose, in a water-filled wheelbarrow and on the paths and surfaces of the garden:

The trick seemed to be for him to flick the water with one hand holding the hose, while he tried to catch up with the water by flicking the fingers of the other hand, perhaps trying to mimic the water droplets, but always half a second behind the actual water. He was getting a little excitable while flicking, making some sounds (eee) and jumping up and down a little. Occasionally he was incorporating a bit of genital rubbing after a successful water flick. (10:2).

Daniel’s activities were very sensual and after time I noticed the pleasure that he took when manipulating sound:

³⁶ This is something I have witnessed often in my social work practice; that homes where autistic children live are odd to visit as domestic objects have to be locked away out of reach, TVs are fixed to the wall high up and parents are preoccupied by the need to contain their autistic child’s challenging or risky behaviour.

³⁷ Alvarez’s (1992) writing on the ‘double helix’ effect is a helpful here however, as she shows the complex interplay of the innate condition and the parents’ response to this as impacting on an autistic child’s presentation and development.

He carried on flicking. I tried to attend to him again, and began to notice the auditory effect of his actions. I saw that he was flicking the water now onto the paddling pool, with a plastic, rattling sound and then onto the hardboard, with a wooden pattering. Then onto the concrete with a much 'deader' sound. The hardboard sound seemed preferable to Daniel, who speeded-up the flicking, till he achieved a sound like falling rain on the wood. He repeated this a few times and whooped, enjoying the effect (9:2)

During this time I remained puzzled about the position I should adopt as observer. Kate allowed Daniel to play with water in the garden and I would observe him in this play from time to time. Often Daniel became very wet and he would strip his clothes off. The sensual nature of the play was however obvious as Daniel would rub his genitals during the ritual. I took a lead from Kate by not intervening in his play, keeping my distance, but I would try to be helpful by finding him a pair of swimming trunks or dry trousers if he became soaked.

On the eleventh visit I met Daniel's father Ian for the first time. Kate allowed Daniel to play with water in the garden, but indicated to me while away from Ian that he did not like his son to engage in this play. When Kate commented that Daniel had taken his clothes off at the other end of the garden while playing with water, Ian shouted at him to dress himself. Kate seemed jumpy and nervous of his reaction.

By the time of the twelfth visit, it seemed that the subject of Daniel's play had been talked about further and that water was now banned, by Ian's authority. I felt a little defensive about this as Kate indicated that they as a couple thought that my visits had become an indicator to Daniel that he could strip his clothes off. I felt guilty and blameworthy at somehow making Daniel more disabled than he need be and the hint that the play had sensual and sexual overtones made me anxious that they parents might think I was encouraging this side of Daniel's behaviour.

I considered this carefully and reflected afterwards that I had tried to follow Kate's lead while observing Daniel. It seemed then that the couple were making use of me to work

out some difficult issues in relation to their son; that perhaps they were projecting blame for some of the things which seemed wrong and unacceptable into me. Was it alright to let him be or did one have to actively manage and direct his choice of activities at all times? Kate had to choose between the close, enmeshed relating to Daniel, where she indulged his wish to engage only in sensual play and the alternative which meant taking him on; challenging him to find more socially acceptable activities. Ian seemed to want to take a tougher stance, to have age-appropriate expectations of his son, though often it appeared that it was not he who had to enforce such care. This dilemma of whether to intervene or to let be, is one which preoccupies autistic young people and adults, their carers, policy makers and educationalists³⁸.

Ian's position on managing Daniel was perhaps mindful of his son as an adolescent who needed to cope to some degree with contact with the outside world. Raising the issue of contact with the wider social world brings shame back into the picture. Daniel's adolescent behaviour, in particular his sexual development, could not be hidden away as it is to some extent for most young men, nor enacted in socially appropriate ways (through sexual experimentation in private or other manifestations of peer relating). His emergent sexual identity, a subject of anxiety for most parents of adolescents, was played out to a degree in public as he found it difficult to learn or to care about social rules in the way non-autistic people do. For Ian, as father of the family, it was important that Daniel learn to behave in a manner which would not shame the family.

11. Life goes on: the impact on siblings

While concerns about how best to manage Daniel were in the parents' minds, the rest of family life continued around them. On the twelfth visit, I was able to see how Daniel's thoughtless handling of his brothers' belongings could impact upon them. The youngest boy John had celebrated a birthday recently:

³⁸ Charlotte Moore (2004) has written of her experiences of parenting her two autistic sons. She has created a home for them in the countryside where they can both wander freely in the natural environment pursuing their interests, while also receiving schooling and socialisation time at home. This 'both/and' position seems preferable to 'either/or' ones, where autistic young people may be expected to live to a 24 hour behavioural regime, or alternatively to have no expectations placed on their behaviour at all.

John came over, picking up a toy plastic guitar which was by the back door. Kate picked up another plastic toy, a wire and bell toy... John held the guitar and looked down at it sadly, as mum said that Daniel had put both toys in the water recently. (12:3)

Perhaps as a consequence of such spoiling behaviour and the difficulties of being around his autistic brother at home, John had formed strong friendships outside the family and his mother acknowledged that he seemed rarely to be at home. He appeared also to be capable of voicing his annoyance at feeling squashed-out by his autistic brother's needs as he was able to describe his pleasure at Daniel being sent off to stay in a respite centre. Despite this evidence of resilience in John, there were worries that Daniel, like a cuckoo in the nest, claimed rather too much of his parents' resources. His brothers appeared to be enacting their frustrations in difficult behaviour outside the home, a fact which might I speculated, be fairly shaming for this middle class family.

One such undercurrent of family life was that of the trouble which both Peter and Andy were getting into at school and within their local community. On the eleventh visit, Andy and a friend were reported to have 'borrowed' some bikes from other children, taking them to hide in a wood. The children had to be fetched from school in disgrace I heard. Peter though, was getting into more serious trouble. On the eighth visit I was told that he was behaving poorly at school and he talked of wanting to fight some other boys who lived nearby. On the fourteenth visit, Peter gave me the news that he had passed an entrance exam for a private school some distance away and there was a suggestion he might become a boarder at some stage.

While it is not possible to attribute these difficulties simply to having a disabled brother, I did wonder at the fund of emotional resources available to the family. Ian seemed to have to work long hours in order to provide financially, while Kate was stretched coping with Daniel and the others at home. As they appeared to be quite well off, the family seemed able to compensate for the limited emotional resources by sending Peter to a different school. Perhaps this had the effect of cushioning the impact of living with

disability in the family, also reducing the potential stigma experienced by this middle class family.

12. Banning water-play and what this meant to Daniel

By the time of my thirteenth visit, Ian's view held sway in the house and Daniel had been banned from playing with water in the garden. Over the next few weeks, it was interesting to see that Daniel had to accommodate himself to this new fact. The observation notes record that Daniel seemed at times 'listless' and 'bored' (visit 13). On the fourteenth visit however, something had changed:

Daniel had joined in at the edge of the trampoline and as an equal to the others, found his space effectively. Peter responded and faced him, the two of them coordinating the bounces nicely. It was an unusual piece of joint play or activity. They carried on for a few minutes. (14:3).

In the weeks following on from this, Daniel could be found at times to be playing football with his brothers and their friends, finding a way to interact with them, if a little reluctantly.

Andrew said 'good boy Daniel patiently to him and kicked the ball back in his direction. Daniel hesitated a little, allowing himself to respond at his own speed, a slow motion version of the other boys' footballing (15:2).

Daniel seems to have been able to engage more with his brothers during this later phase of the observations and this process was helped by Ian. Ian's expectations of Daniel seemed to point the way, to help him begin to tolerate the possibility of coping with the social world around him. It is possible that at least some of this shift was assisted by the presence of an observer in the home, as this unexpected consequence of observation has

been noted elsewhere³⁹. Kate also seemed to be able to think about Daniel in new and developing ways associated to his movement through adolescence, implying the possibility of change in the future:

Kate said that someone at church had asked would Daniel ever be able to contribute something to society, implying it was sad that he wouldn't be able to. Kate said to me that she had thought about this and believed that if he lived in a sheltered kind of house, like the ones run by her church, he could probably do quite a lot of cooking- he'd probably like that. She said that that was a way of contributing to his own kind of society and I found this a very warm and comforting thought for her to have about Daniel- and me too I suppose as it can be very painful being close to the sadness about Daniel's impairments and difficulties. (13:4).

13. Ending my contact with Daniel, the 'tinder box'

My last visits to the family were difficult and stressful with Kate I believe finding the ending hard as well as me. I had come to know the family well and to be accepted by them to a degree. Kate asked me to attend Daniel's annual Statement of Special Educational Needs Review at his school, which I did after thinking this through in supervision. I prepared a written report describing some of my observations of Daniel in his home and I was able to speak about this at the meeting which took place between the fourteenth and fifteenth visit.

On the fifteenth visit, those at home seemed listless and quiet. I spent time with Daniel who banned from playing with water, kicked the football to me a few times. Kate seemed a bit lost too, as she had misplaced her new bank card and could not decide whether or not to cancel it. I made sure to remind Kate that the visits were nearing an

³⁹ Rustin (2006: 47) has looked at the therapeutic, containing potential of infant observation, provided by: consistency of the visits which may enable the mother to spend time focusing on the baby; adding 'temporal structure' to help where boundaries may be missing from family life and where a mother may 'feel engulfed' by the baby's needs; and finally through the potential for the observer 'to absorb projections into them, without reprisal' which may model a form of reflectiveness of use to mothers. Some or all of these features may have been at work in this adapted use of infant observation method.

end, to try to ensure that the ending could be talked about. In the event it seemed that this tactic did not work well, many of the feelings about the ending of the observations remaining unconscious and unexplored.

Kate tried to avoid the ending it seemed to me, and consciously or unconsciously to express her anger at it, by absenting herself during the last two visits. She left me in charge of the children for quite a length of time on both visits and while this reflected her need to fetch and carry their siblings from after-school activities, it seemed more than coincidental that this should become a problem at the end of my visiting period when it had not arisen earlier on. On the penultimate visit Kate arrived late making me wait outside and returning late having left me with most of the children for nearly two hours. Hearing a song by 'The Clash' on the radio, 'Shall I stay or shall I go', I laughed to myself as I realised I was feeling quite fed up. I remained determined however, to see the planned observations through as I had said I would and to be mindful of the feelings Kate was letting me know about through her actions.

Daniel had been fairly relaxed and easy to contain on that visit as I knew the basic routine of his care needs. On the last visit however, when Kate left me in charge of him while she collected another child, I had a sense of how difficult caring for him might be at times. Daniel showed me that he wanted to eat some toast, by lifting my hand onto the loaf of bread. I noticed that he seemed quite grown up and adolescent:

I said brightly and assertively 'toast's ready Daniel' and at the second saying, he stirred himself a bit lazily and got off his bed, going down stairs first. I was struck by how teenage he seemed, slowly dragging himself off the bed and skulking down the stairs.
(17:3)

Daniel then wanted to go outside and I had a moment of worry as I could not find out how to open the back door:

He got up and moved over to the door, and as I went over to him he moved my hand to place it on the handle of the door. I tried the door, but it was locked... I hoped Daniel would be satisfied that he couldn't go out, if he could see that the door was locked. He was becoming a bit flustered, flapping his hands in frustration and vocalizing in a cross way, humming more loudly and insistently, to let his feelings be known. For the first time, I felt a little anxious about how to handle him. (17:4)

Peter, who was home, helped me to open the door and I kicked a football around with Daniel for a while. Daniel was responsive and we carried on in a repetitive passing of the ball between us which served both to hold his attention and to contain my anxiety at how I should manage being with him. At one stage Daniel surprised me by showing for the first time that he was capable of speaking:

He'd kicked the ball into a small place under the skateboard ramp and I said in voice I'd more likely use with a baby 'where'd it go?' Daniel repeated this to me twice in a sing-song though distinct, echolaic manner. (17:5)

Daniel's father Ian then arrived, I assumed later than planned, and I had a short time to talk to him right at the end of this final visit. We sat with Daniel, waiting for Kate to return home. It seemed that Ian had a clear view of my role as researcher. If Kate had to show me unconsciously, by 'dumping me' with Daniel for an extended period of time, how she felt about me leaving, Ian was able to verbalise some of his feelings about just how difficult he felt living with Daniel was for them.

'You don't know what Daniel has done to us' Ian said...I said a bit provokingly that he often seemed calm when I've seen him in the afternoons. Ian shrugged and said to Daniel: 'you're a tinder box- you never know when he's going to go off' and he got up and walked over to Daniel. He gently and playfully squeezed his son's nose between his two fingers, saying 'eh Daniel?' (17:6)

Kate then arrived home and I was able to thank her for the time she had allowed me to observe Daniel and his family. As with the first family, I gave them a present to thank them (a Disney DVD for Daniel and some cinema tickets for the brothers). Saying a quick farewell to Daniel who 'looked up in his expressionless way' (17:6). I left the family to sort out plans for their evening, feeling pleased to have held on to see Kate for one last time and quite relieved to have finished the observations.

14. Learning from the observation experience

At the beginning of the observations I had been puzzled about why Kate had been so uncurious about me visiting the family. When I reflect on what shaped-up during my first visit, it appears that I rapidly accommodated to her anxiety about me encountering Daniel, by showing that I was not affected by his 'odd' autistic presentation. In the same way that she had imaginatively to enter his mind, to think and feel on his behalf, I was acting swiftly to think for her, to protect her from being reminded of the emotional pain of the knowledge of her son's autism. I then took on the exhausting task of thinking and feeling about Daniel, as I assumed some responsibility for him during my visits, along with also holding Kate's anxieties in mind. All of this, I believe, made it difficult for me to think for myself during the early observations, as I moved about the house uncertain where to place myself and how much time to spend with Daniel. It also helps to account for why I acted out myself, by 'forgetting' my appointment to ring Kate around the time of the sixth visit. I only then became able to think, when I suffered the shock of an encounter (imagined or real) with the potential of Daniel's sexuality. This experience confronted me with boundary issues in a way that I could not ignore and this helped me to realise that I needed to assert an observer stance, over a complete participant one.

Reflecting on this experience is useful as there are parallel processes to the research role for social workers visiting families of disabled children. As professionals we can become very defended on the subject of disability so that we do not see in front of us impairment and the pain it may bring with it (rather in line with the defensive position of social model of disability theorists described earlier). This can lead, I would suggest, to

professionals making assumptions about what families need and to acting rather than staying with the emotional aspects of life⁴⁰. I acted over-protectively towards Kate at the beginning of my visits, immediately beginning to participate rather than observe; more of a helper than a researcher. Over the period of observing, I managed at times to move into a different position, but the complexities of conducting a family observation of this nature do I believe make inevitable this kind of difficulty in holding one constant position.

One way in which I managed to step out of a pure participation mode, was by attempting to contain and befriend Kate during the observations. Far from 'grilling' Kate on what she thought was going on in her family life I actually tried to dampen down the amount she seemed to want to communicate to me⁴¹. Observing life in this highly complex arena of family life meant being flooded with information on a conscious and unconscious level. From an ethical perspective, I held the boundary of an ending in mind right from the beginning as I wanted to mediate the powerful transference that Kate had to me on our first meeting. What I did in practice was to record what I was told and what I saw and felt, but I did not ask supplementary questions nor did I probe on the whole. This worked fairly well, though it may have added to Kate's frustration with me as revealed through her leaving me to care for her children in the later phase of observing.

Having reached a position where I could observe, albeit under problematic circumstances, I became more able to notice aspects of Daniel's functioning and his relationships with those he lived with. I was able to notice the aspects already mentioned; his tendency to get you to 'merge' psychologically with him in order to get you to do things with him and for him and most starkly, the variability of his states of mind from severely learning disabled and remote, to a more socially and emotionally engaged state of mind. I also experienced his siblings' patience, envy and frustration at the large amount of time and attention Daniel took within the home and the possible implications this had for them when their needs could not always be attended to.

⁴⁰ Waddell (1989) illustrates this by discussing the idea of the risk of adopting a 'servicing' kind of social work intervention rather than a 'serving' one.

⁴¹ This provides an interesting way of critiquing the notion that observation is not sufficient in itself as a research methodology and that it should be supplemented by use of questionnaires etc.

The parental couple also made use of me during the observations, to think and reflect on Daniel as a developing adolescent, suggesting that this form of research can have unexpected, beneficial consequences for the families observed. Their projection into me of an unboundaried, permissive kind of carer enabled them to consider more carefully first what Daniel needed in terms of boundaries (expectations of his behaviour, that he leave aside the repetitive forms of play in which things are made to disintegrate, feeding his fascination for the minutiae of things in their constituent parts) and second, what his future life might consist of.

Chapter Five

The Mohammed Family

1. Introduction

I met Asad and his family through a voluntary agency working with Asian families in an inner city area. There had been a mix-up about Asad's age, the agency worker thinking that he was two years younger than he was, and so on meeting him I was surprised to find that he was soon to turn sixteen years of age. This threw me into doubt during my first observation visit, as I had intended to look at young learning disabled people at the beginning of adolescence. In keeping with the developmental, exploratory nature of the research however and the willingness of Asad and his family to take part, I decided to go ahead with observations of Asad. He was entering an important transitional stage as a school leaver and as a member of the Bangladeshi community I thought that Asad's experiences would broaden the scope of the research project which so far had only included white British subjects.

2. Cross-cultural research: the danger of thinking too much?

Before visiting the Mohammed's, a Muslim, Bangladeshi family, I reflected on cross-cultural researching and the expectations I had of this. As a professional social worker I was well aware of discourses of oppression concerning ethnic minority British families, as awareness of such issues helps to frame social work interventions (Topss 2002). The observations took place just after the London terrorist bombings in 2005 when anti-Islamic feelings were being expressed in the media, so I wondered whether and how this theme might impact on the research relationship.

Anti-oppressive discourse located in disability academic studies describes the ‘double discrimination’ that disabled members of ethnic minority groups are said to face in British society (Chamba et al 1999). Professionals themselves have been shown by Bywaters et al (2003) to mirror the discriminatory attitudes of wider society in their practice with disabled Muslim service users and their carers. These authors have critiqued assumptions that are made about Islam and attitudes towards caring for a disabled child in the family. Citing other researchers (Shah 1995 and Katbamna 2000 in Bywaters 2003: 503) it is suggested that professionals often assume that for Muslims, the birth of a disabled son or daughter represents an act of God, which may be experienced as a punishment and that feelings of shame and guilt are often associated with this life event. As a response, families are criticised for adopting a fatalistic attitude, refusing available services and having low expectations for their child. Having already met non-Muslim families with disabled children where the emotions of shame and guilt featured, I was curious to compare these observations with those of Asad’s family.

Another important aspect of considering this first encounter with the family was to think about what being observed might mean to the family. As immigrants to Britain, the family may have already had a sense of being watched and judged (‘observed’) by the host community. Ahmad et al (2000) have written of the construction of ‘oriental’ identity, set in opposition to western identity, with themes such as ‘alienness’ and family structures which oppress women which have been set within ‘racialist discourse’ (ibid 2000:39). It is possible then, that as a researcher visiting the family, I might have been seen in this oppressive-observer light. On the other hand, Maitra and Miller write of the openness of some South Asian cultural groups, to ‘healing encounters’ carried out in public spaces with observers on hand (1996:114). While I do not think that the parents viewed me as a ‘healer’, they did know of my professional background in social work and as will emerge, they did seek answers from me to some questions which perplexed them about Asad. It is then possible that the parents viewed me with a more positive transference, or that, as in any encounter there might have been moments of positive as well as negative transference.

In preparing to observe, there appeared to be a danger of letting all this knowledge get in the way of simply seeing what was in front of me and forming a relationship with Asad and his family. Anxiety arose about how accurately I would be able to make sense of what I was observing and a concern perhaps that I might do damage or an injustice if I wrongly interpreted what I was seeing. In this series of observations I therefore attempted to achieve a balance between observing and maintaining an appropriate level of curiosity in seeking additional relevant knowledge about a culture different to my own, to piece together a psychosocial understanding of Asad and his family.

3. Meeting the family

My first visit to the family was on a hot summer day:

I arrived at their flat at about 4.00pm on a very hot afternoon. They live in a maisonette in a row of modern housing association properties, in an inner city area. Nearby are large commercial buildings, supermarkets and offices. As I approached the house, I could see there was a pleasant and well maintained play park nearby. While the area was right in the city, with little greenery around, it looked bright and well maintained; a nice place to live. (1:1)

Asad's parents, Mr Mohammed and Mrs Begum, greeted me courteously and with formality as I arrived at their home. I noticed that they were older parents, in their mid to late fifties. Both parents' appearances identified them as of Bangladeshi ethnicity and as Muslims, with Mrs Begum covering her head and Mr Mohammed wearing a beard in a traditional fashion. As a practising social worker I had previously visited Bangladeshi families who follow traditional dress and religious practices but I found it a different experience to visit as a researcher. I felt a little exposed in my western women's clothing and because of the formality with which I was greeted I reverted to something of a professional role by asking clarifying questions in a way I had not done on previous observation visits to other families:

I asked about who lived with Asad, feeling OK to be fairly directive in my question. We were all sitting fairly formally around in the living room, so I felt alright to clarify this. Mr Mohammed began to tell me and I thought I'd get out a notebook to write it down.
(1:3)

Although it was useful to make note of these details, I had not asked the other families so assertively about the make-up of their extended families and this seemed to be providing some useful information about researching this household. First, the importance of the family group needed to be recognised and given precedence from the very beginning and both Mr Mohammed and I seemed to recognise this by getting straight to that issue. In this way, the communal or extended family context was already being mentioned rather than a more individualistic notion of Asad, as the central focus.

Second, I wondered whether it told something about how I was dealing with the need to research in a cross-cultural context. I felt a little vulnerable and out of my depth as a non-Bangladeshi woman visiting the home and as a result perhaps tried to assume some control of the situation by identifying with my previous professional role. Mr Mohammed however, seemed comfortable about managing my arrival in his home. It seemed he had given my request to learn about his son serious thought before my visit. As Krause (1998) has noted from an ethnographic perspective, Bangladeshi society is organised along patrilineal lines with women marrying into their husband's families. Thus upon marriage, women give up their own kin groups, the husbands becoming head of the household. It was therefore from Mr Mohammed, as head of the household, that I had to seek consent to observe and to research Asad and the family. So although I was aware of the need to seek direct consent, if this was possible, from Asad as a young man, Mr Mohammed was already clearly asserting his power over his son in the family context:

Mr Mohammed said 'I have no problem with Asad. He can't speak, but he is no trouble. I'm happy for you to know about him' (1:2).

4. Meeting Asad

a. A formal meeting and the complexity of communicating

As with the earlier observations, commencing my visits to Asad and his family meant finding a position from which to observe. The stance I was able to adopt was shaped very much by Asad's parents' management of me as a guest in their house. While they were very courteous to me, it was difficult to move to a position when my presence might become more 'taken for granted' as occurred to some extent in each of the other families I visited. It was essential however, to remain adaptable to the wishes of the family, given that they were permitting me privileged access to their home. As in the first two homes I had visited I therefore viewed the position I was assigned by the family as possibly indicative of some of the dynamics to be experienced within the family, as well as of their cultural practices. With the benefit of hindsight, it might have been better to have adopted a different style of researching with Asad, perhaps acting as his carer and taking him to activities outside his home on at least some of the visits. The focus of the study was however to look at young people in the context of their family lives so despite the limitations, observing him at home did provide a valuable perspective on Asad's development. The tensions I observed, and to some extent became part of, were informative as I learnt more about Asad within his home setting.

Before meeting Asad, Mr Mohammed briefly informed me that he had been his son's main carer from the earliest days and that his wife had found life difficult:

Mr Mohammed said that he was the one who looked after Asad as his wife couldn't cope when he was small. 'He was difficult when he was small' he said. I asked about that and he said 'we lived on the 3rd floor of some flats and she couldn't manage, so I helped with Asad'. (1:2)

I wondered about the nature of their relationship, with father putting himself so strongly forward as Asad's main carer. Soon after this, Mr Mohammed brought Asad into the room to meet me, in rather a formal way:

He was small in stature... Asad had short spiky hair and he had a patch on one side where the hair seemed to have thinned, perhaps with alopecia I thought. He looked to me a little shyly and I said 'hello Asad' to him in a friendly way. Mr Mohammed gently encouraged Asad forward and he looked up at me, not keeping much eye contact. I felt wary of scaring him by being too confident or loud and brash. Asad came to sit, encouraged by his dad, to my right, on an armchair nearby. I smiled and this seemed to put Asad at his ease a little. He looked over to his dad for cues about how to react to me and Mr Mohammed would occasionally speak assertively to Asad in Bengali or English to encourage him.(1:2)

Between us, we made use of Bengali, English and Makaton signs to communicate and I found this difficult at first, Mr Mohammed stepping in to interpret if I could not understand Asad's words or sign language. At times, Mr Mohammed did not seem to understand his son either, so we pieced the communication together, going along with smiles and nods as well as spoken language to communicate.

Quite early on, during my first visit, we found ourselves led by Asad to talk about the recent bombs which had exploded in London tube trains.

Asad said something like 'boom' and his dad laughed again, slightly. Asad did this again to me and Mr Mohammed said 'he's telling you about the bomb last week' and immediately I nodded in a concerned way saying 'yes it was terrible. So frightening'... We talked a little more about that and how dreadful it had been, with Mr Mohammed saying 'who could do such a thing?' (1:3)

These very recent events were on all our minds and it felt a relief that Asad had enabled us already to share our distress, perhaps helping us to bridge differences between us. Mrs

Begum joined us at this point and Asad became more confident, trying already to tell me something about his relationship with both parents:

Asad was rather dismissive of his mum, waving her away and indicating 'chat' by closing his thumb and fingers together. 'Aba' he said beckoning his dad and then 'Ama' pointing to his mum with the 'chatting fingers', then flapping her away and saying 'Afa'. Mum laughed in a similar way to dad, just slightly, saying 'he say I always at my brother's house, or somewhere else' and Asad repeated his signs a few times. It felt a bit dismissive of his mum, but I'm not sure I fully understood what he wanted to tell me about her. It felt like he was trying to clear her from the house and that he wanted to be just with dad (1:4)

Asad often adopted a dismissive attitude towards his mother over the weeks that I visited him. I wondered whether this was to do with his position as a young man wanting to separate from his mother in a 'healthy', adolescent fashion or whether his dismissal of his mother reflected his early experience of being passed over to his father as his main carer. I found it difficult to work out the complex nature of familial relationships as it was hard to read Asad's communications⁴² and his parents were polite and guarded. One example of this was that while I did attempt to explain the purpose of my visits to Asad, it was difficult for him to comprehend and for me to explain. The sense Asad made of my presence was more immediate as he thought I was there in the role of others who visited him to take him out to the park for a break:

Asad jumped up and went over to the window, pointing to the park where he likes to go. 'Not now Asad' his dad said and then 'another time'. I asked 'do you like sport Asad?' and he nodded enthusiastically. I asked 'football? (he repeated this nodding) and basketball? (he motioned the height of the net). Dad confirmed that he liked sport and Asad showed swimming by signing. Asad thought I was there to take him to some kind of

⁴² Miller (1998:4) has looked at how learning disability which usually accompanies Down's Syndrome leads to communication taking place at a 'primary process' level; that there is a necessity to focus on the 'here and now' of communication and transference develops with a sense of fluidity between the identity of the therapist and young person concerned.

sport or to the park and dad had to say again 'no Asad, not now'. Mr Mohammed said that Asad has someone who visits (he wasn't sure where they were from) at the weekend sometimes, to take him out- to the local shops. (1:4)

b. Asad: images of damage and illness

During this first visit, Mr Mohammed began to tell me about Asad's early experience of cancer, which occurred when he was two years old. Asad had to remain an in-patient at hospital for seven months and his father lived there with him. He recovered, but only to have a relapse when the family went to Bangladesh several years later. Mr Mohammed drew attention to hair loss on one side of Asad's head, caused by bleeding during the illness. Asad was listening to our talk:

When talking about the illness, Asad pointed to marks on his arm and to his head, to show me where he had been affected. There was a small scar on his upper arm and dad said 'yes, you had tubes in your back all that time, to give you the medicine'. Asad then pointed to his ankle and dad said 'that was when you played football last week Asad' to help him distinguish between pain from long ago and a recent bump on the leg. (1:5)

For Asad then, there seemed to be difficulties remembering or distinguishing between events some time past and more recent ones. He was understandably impatient with us talking, so he walked off at this point while I was left to hear more from his parents:

Mrs Begum told me as I sat, about how 'Asad is easy, no trouble, except no speech'. They 'worry what happens when they get old' and I asked what they thought about this. 'He stay in this house and someone will have to look after him' dad said simply. Mrs Begum said 'he's no trouble now; not like when young'. I asked about that and Mr Mohammed described how Asad didn't walk till two or two and a half years and it was difficult with children close in age, in their flat. (1:5)

As if to dismiss sad thoughts about the past, Asad reappeared with a fashionable pair of sunglasses, showing them off by pushing them up and down on his head. Asad seemed able to rise above a sad and tragic image of himself in this entertaining way. It was difficult to get a true sense of how he saw his parents' sadness and anxiety. Asad simply seemed impatient when his parents expressed these feelings.

5. Transition: parents use the observation experience to look back and to look forward

During the second visit, Asad did not join us for a while. I sat with both parents and found that they seemed very preoccupied with memories of the past and hopes for the future, thoughts which were perhaps fuelled by my visits to them. To begin with, I noticed how furniture in the house did not seem to fit Asad:

I noticed that Asad's chair, on which he sat last week, is like a miniature version of the large and formal sofa on which I sit. It seemed strange, as though for a small child which Asad is not. (2:1)

The parents spoke about Asad leaving the school which he had attended since he was five years old, as though trying to take-in the enormity of what it meant to them for their son to leave; shocked at the way he had outgrown school as well as furniture. There was hope too, that the college Asad was to move on to would both keep him safe and provide him with good opportunities:

'I went to see it and it seemed nice' he said. 'They have children like Asad'. He went on to say that he'll be able to do work-type things there, like gardening. 'Asad likes gardening. There's a big picture on the wall of one young person. He's been working at hotel moving luggage about. Now he's going to do it permanently'. I acknowledged that this young person got work while at college and that this was the family's hope for Asad (2:1)

Mr Mohammed then continued the previous week's account of Asad's illness at two years old when he suffered from life-threatening cancer. In the description of the seven months when father had lived in the hospital with Asad, having given up his job, the sustaining strength of the extended family came across. Mr Mohammed described simply and very much still in touch with the sadness and worry of that time, how the family coped:

Mr Mohammed spoke slowly, reminiscing... 'Asad was feverish and couldn't sleep and was moving around all night.' He moved his fists around, mimicking Asad's leg movements. 'We took him to the doctors where they took blood tests and then we went back a week later and they told us'.... Seven months in hospital and 'they gave special, new drugs. All the family agreed he should take them'. He motioned a canula. 'One medicine given and then after five minutes, all his hair fell out. It happened three times.' I shook my head, feeling sad and affected by the story. Mr Mohammed told of how he lived in the hospital for all seven months. He described how his wife had stayed with the other kids, but 'when Asad was really ill, she stayed in hospital with us. My mother in law looked after the others.' I remarked how good it was that the family was strong together. He nodded. I asked how the other children coped...He responded 'oh, they were fine with their grandmother' (2:2).

The importance of the extended family in providing practical and emotional support to Asad and his parents at this time came across strongly. There was a risky decision to be made about Asad taking some new medication and this was shared by 'all the family' as Mr Mohammed stressed. The role that the grandmother played in caring for Asad's siblings while he was in hospital implied a taken for granted assumption that different members of the family would step in as required and that the siblings would hardly notice the difference. It was not possible for me to check this view out with Asad's siblings or grandmother during the observation, as they were not present⁴³. From Mr Mohammed's perspective however, the family does seem to have provided sustaining practical and

⁴³ There is a danger of idealising the extended family, suggesting that it is an endless source of support for Bangladeshi families living in Britain (Fazil et al 2002).

emotional support for him and for Asad in a manner which was less evident in the other families observed. There was hope too, that the extended family would continue to care for Asad into the future:

'We worry for the future when we're not here, but I talk to his older brothers and they say "don't worry, we will look after him" (2:3)

The parents then seemed to be using the experience of the observations to reflect on their worries for Asad, almost as though they wanted reassurance from me. Paradoxically they are aware however, that Asad's disabilities are in some sense protective, keeping him from the risks of non-disabled urban life for teenagers:

Mr Mohammed pointed to the noisy kids outside [the window in the park below], saying 'see, he's no problem, like them'. (2:5)

6. Asad. Living in the present

While Mr Mohammed was recalling the emotional experience of these difficult, traumatic times, Asad challenged this image of himself as vulnerable and weak. As he had the week before, Asad bounced in to the room while Mr Mohammed sat quietly remembering the difficult times. Again, Asad related to me as though I might be expected to take him out somewhere, indicating the park from the window. While I would have been happy to take him outside, Mr Mohammed did not want me to do this. Asad was puzzled about who I might be and he showed interest in my physical presence:

Asad touched my hand, pointing to my rings and I nodded in a friendly way. 'Do you have a ring?' I asked him. Asad nodded and dad interpreted this; that 'he will when he gets married one day'. Dad scolded Asad a little in Bengali, I think for touching my hand, as this is not very appropriate for a Muslim boy (2:3)

Future plans for Asad were alluded to here with the hint at the possibility of a marriage partnership for him at some stage. This is a theme which recurred during the final visit of observation.

7. A gap in my visits

There was a gap between the second and third visit of almost two months. During the first month I was away for a summer break, but then coming back in September it was very difficult to re-establish the pattern of visiting. We resolved that I would phone on the morning of my visits to ensure it was convenient for me to call. That way, Asad and his family could retain some flexibility and choice about what they might want to do on any particular day and this seemed sensible and ethical, given his age.

In response to the parents' sadness at Asad's lack of comprehensible speech on my previous visit, I brought with me on the next one some sheets with Makaton translated into Bengali. I hoped that they might try to look at these to help piece together their son's communications. My rather concrete, problem-solving approach missed the mark with Mrs Begum, who responded to these by saying 'he can't talk' and frowning slightly as she said this. Mrs Begum's distress was, it appeared, more to do with finding Asad's learning disability and his impairments stigmatising and difficult to cope with.

8. Growing up, curiosity and intimacy

a. Confusion for Asad: just how grown-up do they think I am?

At the beginning of the third visit we were all a little awkward; so much time having passed by since I had last seen Asad. He was shy and hid behind a curtain for some of the time while I sat with him and his parents.

I was aware that much had changed since my last visit, with Asad having started college. There was a complicated exchange, with each party misunderstanding elements of what was said and communicated. I began the exchange by asking about college, signing 'bus'

which was a word he had used previously to indicate college. I noted that Asad seemed 'a little empty and unengaged' and Mr Mohammed interjected that no, he travels to college by car, not bus. I asked Asad: 'sad- no school?' and just as he began to take more interest in what I was saying, again his father interrupted: 'no, he's OK now, finished school now'. I persisted rather mischievously, saying that Asad had been at school a long time, since he was young and Asad immediately responded by pointing at his young nephew who was sitting on his grandfather's lap, smiling and saying 'baby' and shaking his head. I acknowledged that 'no, you are not a baby'. This seemed very important to Asad:

'No you not baby' I said to him and Asad signed man in Makaton (beard stroking), saying 'man' indistinctly, but recognisably. 'Yes, you're a man now' I confirmed, more seriously this time. He pointed to himself with both hands saying 'sixteen' and I repeated this to him, nodding confirming 'yes, you're sixteen now, you're a man'. (3:4).

It seemed very important to Asad that this point be understood; a distinction made between him and this very young and dependent child. In the moment, Asad was expressing a strong embodied sense of himself as a grown man. He stood up to interact with his two year old nephew:

Asad had got up on his feet and he went over to his nephew and tickled him a little awkwardly, though in a kindly way. Samir looked unsmilingly at Asad and pulled away towards his granddad. Asad patted Samir gently, looking at me saying 'baby' to me. (3:4)

A little after this, Mr Mohammed passed the two year old Samir to Asad, confirming that Asad was responsible and to be trusted:

Asad got up then and went over to Samir. His dad spoke to him and passed Samir to his uncle. Asad held him gently and carefully, the boy accepting being handled by him. Mr Mohammed motioned Asad to take Samir downstairs. (3:5)

Mr Mohammed seemed to expect that Asad should be obedient and responsible. I noticed however, that Mrs Begum more frequently interjected with comments about her son's limitations, difficulties and impairments; her comments serving to be to remind the rest of us of these more worrying, perplexing aspects of her son. After Asad had left the room, we discussed the parents' views of his potential to travel independently to college one day:

Mrs Begum shook her head and said 'Asad not speaking' and she seemed very upset.
(3:5)

The parents showed me a card that Asad was to carry about with him, that explained how he could not speak and that anyone who was shown the card should ring his home number which it recorded. Mr Mohammed said they were very concerned that Asad should not travel on public transport and that they had had to campaign hard to get professionals to support their view. I was curious about this:

'Are you worried something might happen to Asad?' I asked and dad said 'yes, there are bad people out there who might try to take him away' (3:6)

The parents described how they would allow him to walk over the paved area in front of the house to the play park, but no further. They seemed to be very anxious about their son and I wondered how the picture of Asad as dependent might fit with the work he was doing at Further Education college, where usual practice is to encourage independent travel and the development of a social life for young people with a learning disability. Balancing the risks which faced Asad by going about unaccompanied in the community with his need to develop independence seemed a major dilemma for his parents. Currently their anxiety precluded a vision of their son as more independent or separate from them. This reminded me of times in social work practice when families were thought of as 'over-protective' of their disabled child and when professionals might try to intervene.

I found myself overstepping my observer role probably because of these memories of practice situations I had encountered previously. I tried to make things better by suggesting practical ways in which Asad's communication might be improved; by putting together a book with pictures that he could take round with him to illustrate his wishes.

'Perhaps a book', I ventured, 'in which he puts picture signs for useful things?' We sat silently for a moment, recognising perhaps that we couldn't give Asad what his parents really wanted: clear speech and to take away the vulnerability of his having a learning disability (3:6).

In this way, my initial attempts to try to make the parents feel better about Asad's future were rebuffed as they made sure I understood their perception of him as essentially limited and impaired; in need of looking after. The observation technique allowed me to use my own feelings to reflect on this experience as it was happening, as well as afterwards in supervision, so that it was possible for me to consider this unconscious communication of sadness and to think about my desire to try to make things better. It was also apparent that the milder degree of Asad's learning disability (he was less intellectually impaired than the other young people I had so far met) did not make life less painful or complicated for his parent-carers as might initially be assumed.

I did however also notice how Asad was reacting to these emotional communications from his parents as these sad views of him were only part of the story. These perceptions seemed to conflict with the positive view that Asad seemed to have of himself; a view which I imagined staff at college would be encouraging to try to help build his self-esteem and adulthood identity.

b. Asad shows his abilities and his curiosity, but remains a worry to his parents

Over the next two visits, I spent a little more time with Asad, gaining a better sense of his personality and interests, though communication remained difficult. On the fourth visit,

Asad let me know in a lively way what he had been studying at college that day. By a mixture of vocalisations and signs he explained that he had classes in cooking and art:

He had been to college this morning (I recognised his vocalisation for 'college', quite a guttural sound). He went on, with me prompting a little to list some of the things he'd done. 'Cooking' he said, showing a mixing sign with his hand, as though stirring a pot. At this I nodded and repeated, giving reinforcement by raising my eyebrows and saying 'ah, cooking were you today?' Encouraged by this, Asad showed a sign for art ('painting' with two fingers, as though on a canvas), saying 'art' at the same time. Again I was encouraging, nodding and repeating to be sure of what he was telling me. (4:1)

Mrs Begum then arrived looking really quite ill:

'I am too much worry about this boy' pointing over at Asad. 'I am ill, headache' she said holding her head with her hand. She did look pretty ill, quite in contrast to Asad who sat opposite to her, upright and on good form it seemed today... I said 'oh dear' and made a sad face to show I understood. Mrs Begum went on to tell me that 'no car come today'; the taxi had been over an hour late to collect Asad this morning to go to college and then it didn't come to collect him at 3.00pm at the end of college. Mrs Begum rubbed her head as she told me and repeated a couple of times 'I am too much worry about him' again pointing over at Asad. (4:2)

Asad was cross with his mother. He grimaced in response to her comments and twisted his fingers around at the side of his head to indicate 'crazy' about her. He also proudly signed and vocalised 'man'. It seemed that he had done what was needed, by taking the communication card (mentioned earlier) and showing it to someone at college who had managed to phone home, alerting his parents to the transport problem. Mr Mohammed arrived at this point and repeated his concerns about Asad's vulnerability at the college which was 'far away' from home.

Despite then the fact that Asad had seemingly dealt very well with the stress of his transport not arriving as expected, his parents only felt worry. They had little sense of him being capable of taking charge of his life at all and this appeared to exasperate Asad.

c. Asad: issues relating to intimacy and marriage

Asad began to show his interest in me in a manner which seemed to annoy his parents. Firstly he pointed to my work bag which I had with me, then tried to look inside it. I showed him that there were just papers in there. Then he touched my hair:

Asad, still sitting next to me, gently touched the top of my head. I had my face turned a little away from him, looking over at his dad, and I could hear his mother on Asad's other side, tutting away to stop him from touching me. He stopped, but did it again a few minutes later. Mum tutted again. This time I turned to him and he smiled shyly. (4:4)

Asad soon grew bored and left the room. Perhaps because their son had expressed curiosity about me, the parents then felt able to ask me questions about my family thus reversing the researcher/researched relationship. From here, the conversation in Asad's absence, moved to the more intimate theme of talking about their children's future relationships. Mr Mohammed described how he intended fixing his daughter's marriage as he had for one of his sons recently:

We went last year for my son's wedding. I went first, to sort out the marriage and then my wife and my son came out after.' (4:5)

I decided to take a chance then, to follow my curiosity in asking about Asad's future:

'...and Asad? Will he get married?' Both Mrs Begum and Mr Mohammed responded, Mr Mohammed saying 'we don't know. Maybe. Depends on meeting a nice girl'. Mr Mohammed shrugged and said 'we don't know what happens tomorrow.' (4:6)

Thus the parents indicated a view that someone might come along to provide Asad with a long-term relationship, enabling them to cope with the uncertainty of a future when they would become too old to care for him.

9. Preparing for Ramadan

About half-way through my visits, Ramadan approached and the family asked me to suspend my visits until the month of prayer and daytime fasting was over. It was important to the parents that Asad maintain the fast. When the subject came up:

Asad immediately shook his head crossly, showing no, he wasn't praying or fasting. Both Mr Mohammed and Mrs Begum scolded him and Mr Mohammed said 'yes Asad' quite assertively (5:5).

The parents were concerned that unlike his previous school, the college would not provide the support Asad needed to maintain the fast during the day:

At college there's no-one to help him, like there was at school'. (5:5)

By the time I next visited, following Eid, the parents were however both very proud that Asad had maintained the fast, perhaps as a sign of his growing maturity:

I said to Mrs Begum 'I hope you had a good Eid' and she nodded and said 'yes, it was good. Asad fasted' she said proudly. I nodded and responded 'Asad, well done. You managed to fast'. He seemed to understand and nodded too, looking grown up and thoughtful.. (6:2).

During this time then, Asad seemed to have managed to incorporate the different aspects of his identity to achieve a level of adult maturity, accepted and well- received within the Bangladeshi community⁴⁴.

10. The use of drawing to communicate with Asad: revealing ‘secondary handicap’?

I had decided, during the break from visiting in Ramadan that I would try to use a different method to engage Asad on my return, as the observation technique alone did not always provide opportunities to learn about Asad and his interests. I decided to take along some pens and paper, to see if this might interest Asad⁴⁵. On the sixth visit, Asad showed some initial reluctance, but then he eagerly started to draw:

Asad carefully took a black pen and began drawing. With slow and deliberate movements, he drew first a round head and some big eyes. The picture was symmetrical and neat. He drew what seemed to be two arms emerging from the neck and then added two similar shapes below for the legs, adding round feet at the bottom. Then he added two arms sticking out from the upper V-shape. He drew some hair above the head and what looked like some whiskers from the side of the face. (6:3)

I asked him some clarifying questions while he drew and learnt that the picture he had drawn was of himself with a beard; he Makaton-signed the same, the sign for ‘man’, to make his point to me. For Asad, it seemed important to him to be seen as a growing, maturing young man⁴⁶, aspiring to adult status.

Asad then fetched his college bag and took out an exercise book, in which I saw he had covered several pages with closely written letters, none of which seemed to form words. I recalled feeling a little surprised at the amount of effort he must have exerted in doing

⁴⁴ Learning disabled people are often considered exempt from the need to fast during Ramadan (MWSC, 2006) so his achievement in this area is considerable.

⁴⁵ Observation on its own was not an ideal technique with which to research Asad’s life as he was more mobile and independent than the other young people in the study. Drawing was used to create a less formal space in which it was possible to learn about Asad.

⁴⁶ Beards are compulsory for Muslim men according to some sources (Inter-Islam website, 2008).

this work and how it exposed his cognitive difficulties so clearly. He attempted then to copy out his name and his mother took an interest in what he was doing:

She immediately noticed a mistake and said 'no, you spell it ASAD'. He looked a little perturbed but didn't try to change it. Mrs Begum seemed very conscious of his mistake and she wrote it out for him again on another piece of paper, spelling the letters out to Asad. (6:4)

I noticed feeling very uncomfortable about Mrs Begum's correction of her son and that Asad seemed to be cut-off and defended from his mother's criticism, as though he was used to this kind of encounter when his mother sought to correct him⁴⁷. I remembered other encounters between Asad and his mother, when he had turned the tables by suggesting his mother was 'stupid' or 'crazy', as though he was projecting these feelings back onto her:

He saw his mother and motioned with his finger rotating near his head that she was 'crazy'. Both mum and dad told him off for this, shushing him. Asad laughed and did it again, to be scolded lightly again. (5:4)

It seemed difficult for Mrs Begum to tolerate Asad's problems with learning and the atmosphere felt tense and angry in the room. Asad dealt with these feelings a few minutes later, by emphasising his wish for a mobile phone and a car; symbols it seemed of his wished-for escape into adulthood. Asad also indicated to his father on a later visit, his wish to travel independently on a planned visit back to his old school:

'He wants to get to school without me. What about mum, Ama?' Mr Mohammed said, 'he thinks he can travel on his own' and 'no you go with me, I take you.' (6:5)

⁴⁷Sinason (1992) identified the notion of 'secondary handicap' and how 'stupidity' can be a defence made use of when learning disabled people feel criticised and blamed, rather than emotionally contained.

I asked Mr Mohammed, somewhat provocatively, whether he thought that Asad would ever become able to travel independently?

Mr Mohammed said 'maybe, in the long, long term.' Then he went on; 'at school, they said he'll never be able to travel independently; he's not safe' (6:5)

I noticed and recorded at this point, the sight of Asad flicking through a catalogue, looking a little bored and I began to wonder just how much stimulation and interest he had in his life at home.

11. Learning more about Asad

In the last two visits, Asad continued to do some drawings in my company, each of which showed views of himself and his interests. He seemed to want me to take the pictures away with me, shoving them towards my bag. In one case, on visit seven, Asad drew his favourite food, only for his Dad to use this as a way to remind his son of which foods he was permitted and which not:

This time, he drew Coke, samosas, chips, fish and sweet corn. 'Your favourite food Asad?' I asked. His dad said 'he can have these at college. I tell him "no chicken or beef, it's not halal". Fish, pizza and chips, OK.' Asad took out some yellow to colour the sweet corn. He signed his upper lip for ketchup, but he lost interest in the drawing and passed it to me to put in my bag. (7:4)

Mr Mohammed and Mrs Begum continued to show their pride in Asad's conventional achievements however, when their son had collected some certificates for attending courses within school during his last year there. I was not quite sure about how Mrs Begum viewed the certificates however, noting during the observation that I picked-up a degree of amusement from her, as though she did not think the certificates worth much:

I said 'Asad's certificates, you must be proud' to her and she smiled, but I felt almost attempting to get me to collude with her. I felt maybe she thought they were silly or meaningless (or was this my own countertransference?) I have felt this way before with her, that sometimes she looks at me to check out how seriously I think about Asad, as though either she is nervous that I think he's silly or stupid or that she thinks he is and she is trying to share this with me. (7:3)

As I noted, this might be my own countertransference, but I felt there were enough hints over the weeks that Mrs Begum wanted to be able to air her feelings that Asad was not clever and that this was a difficult thing for her and the family to cope with. Making use of me as an observer in the home, she seemed to want to let me know of her feelings on this issue.

12. Concluding the observations of Asad and his family and expectations of obedience

On my last visit, I noticed that once more my bag seemed to form a bridge, or a communication between us:

Asad pointed at my bag, noticing it was not my regular work bag, but a different smaller one. He seemed less disapproving than he usually is about my back pack. I said 'yes, it's different' (8:2)

This seemed to be a way of Asad showing me that he noticed things about me, a point which reminded me of Miller's (1998) case study on the somewhat fluid nature of the transference between Beth, who also had Down's syndrome, and her therapist. It was as though Asad, like Beth, struggled at times with notions of difference and sameness. Asad soon went to fetch his bag, as though to make a very concrete identification with me. While bringing his bag, there was a small event which provided further information on the relationship between Asad and his parents; a hint that the polite, well disciplined

young man may have been subjected to physical chastisement as part of the way in which his parents maintained his obedient demeanour:

Asad got up to fetch his bag. As he did, he signed something about dirty shoes, (rubbing his face for dirty and pointing at his shoes). His dad laughed and said Asad had come in yesterday from outside with very dirty shoes. 'He brought mud all over the carpet'. Asad quickly signed a slap on his cheek, pointing and verbalising at his dad and I understood very well what had happened when dad got angry yesterday. Mr Mohammed seemed embarrassed and laughed awkwardly (8:2)

Reflecting on this incident of muddy feet on the carpet I wondered whether this might be thought about as Asad displaying 'typical' adolescent behaviour (disappointing, defiant and careless). The difference here is that Asad's cognitive difficulties will make such 'typical' behaviour more complex to deal with for the parents. Due to his learning disability, similarly 'thoughtless' behaviours might be expected to recur and the prospect of these ever being resolved into a fully 'adult', 'mindful' way of behaving might be limited. The anger the father expressed might have therefore been an unconscious allusion to the chronic, exhausting nature of caring for a son with learning disabilities as much as it was a conscious reference to the mess.

Although I was speculating on this issue, it suggested to me also that it was a difficult business for the parents to permit Asad to make mistakes and to get dirty⁴⁸. Maintaining Asad as obedient, controlled and clean perhaps helped the parents in coping with feelings of shame, associated with their son's disability. While distressing, it was a useful piece of information that I picked-up at this point, incidentally indicating that as a research technique, observation can perhaps gain access to the life experiences of young, 'hard to research' members of society in a manner that other, more traditional approaches might miss.

⁴⁸ There were parallels to the experience of observing Billy in the first set of visits.

13. Saying goodbye and wishful resolutions to complex problems

During this last visit, I reminded Asad that I was to say goodbye to him that day and I noted that he seemed a little confused by this information. He went on to create some drawings, telling me more about him and his state of mind at this time. Firstly, he carefully drew a square, indicating and signing that it was a swimming pool. Then he said, quite clearly after I had asked if he liked swimming, 'and football' while he pulled at the Liverpool football club T-shirt he was wearing. Then we had an exchange where I did not fully understand what he was trying to tell me, as he pointed at the television, saying 'broken'. Perhaps he was telling me about not being able to see something on television when he wanted to (as the set evidently was not broken) or about being told it was broken to stop him asking to view it, rather as parents sometimes do to stop much younger children asking for something prohibited. It may also have said something about Asad's attempt to take-in the information once more, that I was saying goodbye to him today and that perhaps this made him feel sad; broken-up.

Asad went on to draw himself, in tracksuit and trainers and with large ears. I acknowledged what he had drawn, that he liked these clothes and also that I thought he knew he could hear well. Asad might have wanted to remind me that though his ability to express himself verbally was limited, he could hear and perhaps understand more than it seemed. Asad went on to draw me, adding my eye colour and therefore indicating that he was himself an observer, capable of noticing things.

On finishing the observation visits with each family, I brought a present to thank the young people and their families for allowing me to spend time with them. In Asad's case, I had managed to find him a Liverpool football shirt. Asad was thrilled with the present:

Asad couldn't express himself as clearly as he wanted to. He came over to me and 'gave me five' by slapping his hand down on mine. His eyes were full of excitement and pleasure. (8:5)

While in my own culture, such a gift might be understood as a simple thank you for the time and care the family had given to me, it seemed that it was not quite the same for Asad's family. They needed to reciprocate and I initially felt guilty at causing them to feel this. There may have been other associations too:

Asad bounced back in and slapped my hand, saying thank you in an excited way again. I smiled and said 'that's fine' to him. I wondered if I'd done the wrong thing, as it might have seemed a bit over the top. Also, his exuberance was greater than I've seen previously and it seemed what his parents are often trying to dampen down. Asad took my hand and touched my ring again and his own hand and his ear lobes. His parents laughed and it seemed to be that he was so excited that he wanted to marry me. (8:6)

Mrs Begum disappeared to re-emerge a few minutes later with a small jewellery box containing some pretty earrings as a present for me. I felt rather awkward and embarrassed at this, as though there was a wish that the exchange of gifts might indeed represent some kind of tie between me and Asad. There was a manic, magical feeling in the air as his exuberance filled the room, yet I felt quite panicked and wanted to escape. While I felt uncomfortable, I took a little time to reflect on this feeling and I realised that perhaps Asad had had few experiences like this; of feeling special with presents that he really liked bought for him. Also, his parents had expressed the view in an earlier visit that at some point they hoped a partner might be found for Asad, that: 'we don't know what happens tomorrow.' (4:6)

I felt as though I was picking up clear communications from the family. First, it appeared that Asad took great pleasure from being made to feel special. Second, it seemed that his parents as they did with their other children, were preoccupied with concerned about how they could make their vulnerable son's future secure. While I do not suppose that they saw me as a possible partner for their son, something special and unanticipated might arise, they seemed to hope, which would solve the dilemma of what to do with Asad⁴⁹. I

⁴⁹ Recent investigations by the Forced Marriage Unit (as reported in *Community Care* 28.8.08) highlight concerns about severely learning disabled young people, who lack full mental capacity, becoming subject to arranged marriages in the South East Asian community. While it is not suggested Asad is at risk in this

left feeling sad that I would not be visiting again and puzzled as to what the future held for Asad.

14. Learning from the observation experience

As with the first two settings visited, this observation sequence offered insight into the life of another family which was living with the experience of severe learning disability and again, it was not always a comfortable experience for me or the family. From one perspective, family-based observation limited what I could learn about Asad who in keeping with other older adolescents of his age led a significant amount of his life outside the family setting. I did discover however, that there were strong emotional bonds and expectations of Asad within his extended family which were different to those I had experienced in the other families. The opportunity to observe Asad as a learning disabled young man dealing with the tensions of balancing his home life and his wish for a more independent social life was therefore a valuable one.

I found that my role as observer took a very different form in Asad's family from that in the earlier observations. Whereas I had been made use of in a very active manner in the Brown family and as more of a listener or container in the Anderson family, my visits to Asad's family were characterised more by formality, control and distance. I found it difficult to know whether Asad would be at home even when I carefully pre-arranged visits as sometimes his father would take him out having forgotten I was coming. When I did visit I was treated as a guest, seated in the front room and offered tea and cakes. It would have been very inappropriate of me to have attempted to move around the family home during my visits there, as I did in the other families to differing degrees.

These experiences needed to be thought about in relation to the cultural distance between myself as a white female researcher and the family. Asad's household was more carefully demarcated between public and private spaces than the other family homes I visited for one thing. Also for a Bangladeshi family, my role as an informal female

way, this work indicates that it is not unrealistic to imagine that Asad might be expected to marry in the future.

observer of family life presented a different set of challenges than for the other white British families. My relationship with Asad was less formal than that I experienced with his parents and perhaps this transgressed cultural and religious norms which divide male and female worlds quite distinctly. Conscious and unconscious tensions between Asad, his parents and me (perhaps as I was identified in the parents' minds with the outside world) were apparent during the observation sequence and thinking about these informed the research.

Signs of Asad's embodied adolescent development were evident through the observation experience and there were many examples of the parents taking pride in his achievements as he moved from school to college and he managed the strictures of Ramadan fasting. At times, Asad achieved 'subject' status in a manner only touched upon by the other, more disabled young people researched.

There seemed to be a central dilemma facing Asad and his parents, which I observed over the weeks of visiting. Asad had a very clear view of himself as a developing young man who looked forward to enjoying an adult status in the family and in his community, aspiring to having a car, a mobile phone and other markers of adulthood that he had identified. Yet Asad's parents were very reluctant to see him as potentially more independent and indeed some of his expectations did appear unrealistic given the extent of his learning disabilities. The parents had a tendency to limit Asad's opportunities to learn how to travel on his own and they were unwilling to let him take any risks. In some ways, this seemed to be not untypical of the kind of issues facing non-disabled adolescents as they practice separating from their parents. Yet this situation was underpinned by the parents' anxiety as they really did not see Asad as potentially adult⁵⁰.

Through observing, I found that the parents denigrated their son unconsciously, projecting their anxiety onto him, and that his father was angry and genuinely perplexed about what the future held for Asad. These feelings seemed to oscillate with a more

⁵⁰ Schools and colleges would usually offer, as part of their curriculum, travel training and life skills for learning disabled teenagers to increase levels of independence, though in my social work experience it is often a source of anxiety for parents as in Asad's case.

idealised, almost magical view of Asad; that a woman would appear to marry him and thus resolve the difficult issues of who might care for him once his parents died and how to meet his sexuality needs. Although only unconsciously expressed, there were times when I felt that the parents might have associated me with these thoughts. The defence mechanisms of projection and idealisation seemed therefore to be in place within the family as with the other families observed. Shame was also evident and the parents wrestled between feeling this emotion and acknowledging of the damage done to Asad by his disability and an additional life-threatening illness which he had experienced as a very young child.

As an observer, I found that yet again I was tempted into overstepping my role as I tried to help the parents with their distress (on one occasion offering Makaton signs translated into Bengali). Through acting in this way and finding that it did not help, I became able to reflect that the emotions involved were less easily resolved. I was then more capable of acknowledging and containing the parents' sadness. The parents appeared to make good use of the time I spent observing Asad and his family, to think through their feelings about his and their predicament.

I found that I needed to adapt the observation method while visiting Asad and his family as the formal circumstances of my time with them restricted the possibility of me observing spontaneous behaviour and interactions in the home. Making use of drawing was helpful, as it provided an intermediary, non-verbal space for Asad to express himself and importantly we were able to communicate by use of this.

Chapter Six

The Davis Family

1. Introduction

Contact with the Davis family was arranged, as in the earlier observations, by a worker from a voluntary agency who was in contact with local disabled children and their families. As in the previous observation of Asad, visits to Carly and her family involved my researching in a cross-cultural context, or partially so as she was of mixed parentage Chinese and white British ethnicity. The parents are of a similar social class and profession to me however and perhaps, because I have close relatives who are of South-east Asian ethnicity, I found that during this observational experience I felt more closely identified with this family than the others. Observing the Davis family felt at times extremely painful and distressing, with thoughts about emotional damage and impairment appearing close to the surface from the start.

2. Meeting the Family: boundary setting

When preparing to visit the Davis's for the first time, just as with the other families, I speculated on how the family might be viewing my arrival as a researcher within the privacy of their family home and on whether any particular motivation might lie behind their decision to allow me in. When I did arrive, I found that Richard Davis adopted a kindly, altruistic attitude towards my wish to research Carly and her family and that as an academic himself he empathised with my wish to complete my studies and he was helping me with this. Sally was more cautious about my arrival in the house, often appearing a little shy and reserved. She was able to verbalise her ambivalence to my presence during the first visit, commenting humorously that her husband, now retired, was missing his work as a doctoral supervisor. Sally suggested:

That's the only reason he'd let you come to do the research!' (1:3)

Richard and Sally were confident in their interactions with me and they were the most able of the parents I met during the observational visits to take charge consciously of when and how they would allow me to visit, planning and thinking ahead as we went along. As will emerge during the account of my visits to Carly and her family the experience of observing was at times distressing, for me and more importantly for the parents and possibly therefore for Carly herself, as she is so dependent on her parents for her care. The ability of parents to provide the high level of physical and emotional care required by their severely learning disabled children, as I have discovered during this research, appears to be closely connected to the emotional availability of parents, so it would not have been ethical to try to persuade the family to admit me to the home more than they felt able and happy to manage. For this reason and also because of a death in the Davis extended family during the time I was visiting, I curtailed the original plan from visiting weekly over a six month period, to five months and we arranged some spaces between visits according to the wishes of the parents⁵¹.

As the weeks went by Sally and Carly together often formed the focus of my observations and during most of my visits, which took place at the end of a weekday afternoon, Sally would be feeding her daughter her evening meal. Sally had to bear the brunt of my presence and as the feeding process turned out to be an emotionally charged, stressful experience I could understand her initial ambivalence towards the observational nature of the research and the notion of being watched. We therefore adapted the pattern of visits half-way through, so that I could observe at times before and after feeding. This enabled me to see some other activities that Carly took part in at home and it also relieved the stress for Sally of being observed.

⁵¹ I visited them nine times altogether.

3. Meeting Carly

a. Jumping emotional hurdles

On my first visit, I noticed that the semi-detached house appeared neat and anonymous and that it was ‘well insulated from the outside world’ (1:1). Richard Davis greeted me at the door and immediately introduced me to his daughter Carly, whose bedroom was to the right of the front door. I saw that the bedroom, like Billy’s in the first observation, had been specially adapted with a bathroom en suite and a tracking hoist fitted to the ceiling. As with the Anderson family therefore, the disabled family member necessarily took-up much of the space on one side of the ground floor of the house and the rest of the living space downstairs was a little cramped:

Richard said ‘here is Carly. She’s just having a lie down, playing with some toys’. I quickly put my bags down... and I went into the room, following Richard. Lying on the bed was a girl in a bright, flowery skirt. Carly was turned away from us and she was twisting and pulling some toys tied to the side of the bed. There were cot-sides to keep her from falling and Carly seemed fairly relaxed, kicking about a bit. I noticed that she seemed quite long in stature and her hair was lengthy and mid-brown in colour. Richard said ‘here she is. You see she won’t be able to talk to you’ (1:1).

Already at this opening moment of the observation, Richard let me know that Carly would not be able to talk, as though he was unsure if I understood the nature and extent of her impairments and to get over the potentially painful experience of watching me gradually coming to understand this. I reflected later on the impact of stigma on the family and ideas about the link between trauma and the ‘discovery’ of impairment for parents of disabled children (Klauber 1998). There may be a repetition of these feelings of trauma when meeting professionals, Klauber suggests from her clinical practice and I guessed that Richard was guarding against this on meeting me. I made sure to say hello to Carly so that I could show that I was not perturbed by meeting her and that I could

contain any anxiety I might feel on meeting someone who had significant impairments⁵². Later on in the visit, Richard once more alluded to the extent of Carly's impairments, suggesting that I might find it preferable to visit families where the child's disability was less profound:

There are other girls at school' he said, 'who are much more vocal than Carly'. He named a couple of girls. 'They have Down's syndrome and could probably tell you more than Carly'. (1:7)

There may be several ways of understanding the father's response to my arrival in the home. First it may be that he was simply checking with me whether I understood the full extent of Carly's impairments, in case I had planned to interview her. Another possibility is that he may have felt some ambivalence about her; was she 'worth' researching? I reassured him by saying that I particularly wanted to know about the experiences of adolescents who are unable to communicate verbally and who have severe learning disabilities. This question of whether Carly's experiences were worth researching seemed to be thought about further when Richard and Sally pondered on whether Carly could feel pain:

Occasionally, Carly would pick up her right arm and bash it down on the side of the tray. Richard, noticing this, said that 'Carly seems to have a very low, or is it a high threshold of pain?' Sally answered for him 'high- she doesn't feel it if she bashes herself'. Richard said, 'yes that's right' and he showed her arm, by lifting it at the wrist, while Carly pulled it away and bashed it again (1:5)

The parents seemed able to share with me some uncertainty not just about how much their daughter could feel and experience physically, but also emotionally. Questions about the degree to which Carly could feel and how to interpret her emotional state

⁵² This was reminiscent of my first meeting with Daniel's mother Kate, when I picked up her anxiety about my seeing Daniel for the first time and I defended myself from noticing his 'odd' autistic presentation. I made a comment earlier about the dangers of social workers or researchers defending in this way in terms of thinking about how this might limit their usefulness to families in this situation.

appeared as a theme through the observations. As time went on, the experience of observing Carly reminded me of the earlier observations of Daniel in the second family observed, a young person who was on the autistic spectrum. It will be remembered that Daniel's mother devoted a great deal of energy and concern towards imaginatively 'entering' her son's mind, tirelessly updating herself on how he was interpreting and reacting towards events going on around him, so that she could predict and avoid difficult behaviours that he might otherwise display. Sally, I found, was particularly adept at this practice with Carly whose moods often seemed to dictate the emotional temperature of the home.

b. Observing Carly

Soon after I arrived on the first visit, Carly was brought by her mother into the kitchen, to have her evening meal. I watched from a distance, while Sally slowly and carefully made use of equipment to lift and carry her daughter into the kitchen:

Carly appeared in the gloom of the corridor outside the kitchen. I could see her form being lifted by the hoist, up and into the chair- a light wood, movable arm chair with padding, a kind of indoor wheelchair-cum-armchair. She had her back to me and her mum, having taken time over the manoeuvre to keep Carly safe, eventually wheeled her into the kitchen. (1:4)

Richard again forewarned me about how things would be when observing Carly, particularly now that she was about to be fed:

Richard explained that giving Carly her tea could be 'a difficult matter. Carly sometimes refuses to eat, till Sally gets cross with her. She sometimes manages to hold things up while she refuses to eat, even if the thing she's preventing is something she'd like to do, like going out somewhere', he said. (1:4)

In this way, Richard was providing me with important information about Carly. First, he was suggesting that her moods could change and that these moods could be 'difficult'. He was implying also that these moods needed to be understood in relation to Carly's intellectual impairments, because sometimes, though she did not understand that she was doing it, her refusal to eat was preventing her from doing something she would enjoy. Lastly though, there is the suggestion that Carly might have some volition in this process; that her refusal to eat was not just due to her intellectual impairment, but that she might be deliberately holding things up, provoking her mother to 'get cross' with her. Richard was also showing me that he had applied a researcher's logical thinking to considering how his daughter perceives the world around her and this was really very helpful to me.

This information reveals the complexity for parents (and professionals) of untangling and interpreting the needs of severely learning disabled young people. Not only does the impact of intellectual difficulties on the young person's awareness of the choices available to them need to be considered, but also there is a possibility that mood may be affected by neurological impairment⁵³. In these case studies, adolescents with severe learning disabilities have of course been found to have emotional interaction and relationship with their caregivers, so patterns in these relationships will clearly impact upon their response to the circumstances they are presented with. Lastly, the physical and hormonal changes of adolescence impact on disabled children as much as non-disabled children and these can also lead to unpredictable mood changes.

It took some time to arrange Carly in the right position to eat, but I was able to see her now:

Carly had her head down, flopped in front of her, her body propped by soft 'brick' shapes which her mother had gently wedged to her side to get a good upright posture for her. Carly looked up, her eyes a little glazed. She's a pretty girl and she had her mid-length

⁵³ Neurological aspects of Angelman Syndrome are briefly described in the appendix

brown hair tied back with clips a little untidily, but nicely. Carly's even, soft facial features mix those of her parents and the syndrome she was born with.

Carly lifted her eyes to take me in briefly. She seemed to find it difficult to support her head for long and perhaps she was tired or relaxed which meant she allowed her head to fall forward again. Her parents encouraged her to look up and this time she held her head up and seemed to look at me for some time, engaged by my face which was new to her. I spoke encouragingly to her; 'hello Carly. I'm Helen, I've come to see you'. (1:5)

4. Feeding Carly: an opportunity for emotional interaction between mother and daughter

During my first visit to the family, several important aspects of Carly's life came across to me, themes which were repeated, developed and refined during the months I visited her. What I learnt at first about her and her family, revolved mostly around the experience of watching Carly being fed her evening meal by her mother, as this was a lengthy activity which often took most of the hour of my visit. From this first observation, two main strands emerged quickly. Firstly, that the difficult feeding routine for Carly was managed expertly by Sally, as the mother performed a precise and intricate set of care practices. Secondly, feeding seemed to provide a focal space for emotional contact to take place between Carly and her mother primarily, but involving her father too in a supporting role.

On this first visit, I had the opportunity to begin to see and to appreciate the carefully organised feeding routine during which mother and teenage child wrestled over the essential task of eating. Sally and I had to find a way to allow me to watch, while not impacting negatively on Carly's routine. On this first visit (as I will describe) I stepped back at one stage out of tactfulness and respect, as I was concerned that I was making things more difficult for them⁵⁴.

⁵⁴ As with the previous family observations, I had to find a way to observe; an appropriate stance for the family to manage my presence.

I noticed first that there was a certain amount of anxiety in the air in anticipation of the feeding. Mr Davis had already warned me that Sally might have to 'get angry' with Carly in order to persuade her to eat. This feeling of anger and aggression was already manifesting itself in the room as Carly rapped her hard wooden toys on the tray fixed in front of her to which they were tied.

Carly chose a toy and bashed it against the wood of the tray, making a hard, wooden sound. Sally seemed concerned she would hit someone with it (me) saying 'be careful Carly' to her, thus warning me not to get my head too close. Carly repeated the play, getting some satisfaction from the bashing. Occasionally, Carly would pick up her right arm and bash it down on the side of the tray. (1:5)

There was concern here that Carly might harm me or herself with this hard, banging play. Carly's physical strength and size as a teenager had to be reckoned with. As if to counteract this tough, aggressive mood that seemed to be in the air, Sally tried to 'sweeten' the atmosphere, by presenting her with small pieces of doughnut, to coax and persuade her daughter to eat:

Carly allowed her mother to pop the doughnut pieces in. She looked up at her mother slightly, opening her mouth a little, as though showing her mother she was allowing this, but to keep her on her guard a little. About three of these went down, with Carly chewing with some difficulty, then swallowing. (1:6)

As soon as Sally started to offer savoury food, however, Carly refused this and asserted her wishes very clearly:

Sally began to offer some mashed rice, potatoes, veg and meat, in spoonfuls. Carly clamped her mouth shut, looking as though she was chewing her lower lip (1:6).

At this point, with a stressful, confrontational feeling to the encounter between mother and child, I decided to remove myself from the situation. I had been standing to Carly's side and I suggested that it might be better if I sit down at the kitchen table, a little away from the two of them. It felt too much to observe at this moment. Sally said nothing, but the emotional atmosphere was tense and it felt as though I was persecuting the mother by watching Carly refuse the nutrients she was providing so that Carly could survive. Eventually I noticed that Sally had coaxed Carly into eating:

Sally managed over the next twenty minutes or more, with extreme precision and care, to encourage Carly to eat her tea. She held a small syringe of water in one hand and the spoon of food in the other (a good spoonful of the mashed food) and managed to grab Carly's attention by engaging her with talk, to gradually eat the food. I could see from where I was that with gentle coaxing and persistence, the food went in, mouthful by mouthful. (1:6)

5. Carly's social world and professionals involved in her care

While Sally gently persuaded Carly to eat, I took my attention away a little from mother and daughter and talked to Mr Davis, who also offered occasional encouragement to his daughter, supporting his wife from a distance. Richard started to tell me about his daughter:

Richard said that Carly is 'very sociable. She enjoys being with people and she is good at picking up on emotions' (1:7)

Richard continued by telling me about the different social activities Carly takes part in and this led him to think about the disappointing role professionals had so far played in her life. First, health services had not provided flexibility about when Carly should be offered physiotherapy; treatment she required to prevent the worsening of scoliosis (spine curvature). Physiotherapy was offered only in term-time, as though she did not need it in

holiday time too! When they engaged in a letter-writing campaign to have this changed, the health managers tried to shame the parents:

'Then they showed me letters we'd written to and fro and they made us look like we were being unreasonable for asking. Very patronising in tone' Richard said (1:7).

Richard described how he had worked hard to encourage the educational professionals to develop new ways of working, as there was frustration that they did not appreciate the complexity of Carly's needs. This culminated in the parents drafting Carly's Statement of Special Educational Needs themselves. SEN statements were at this time usually written only by professionals, so their action was aimed at challenging professional orthodoxy in quite a powerful manner. There was disappointment too with school, who sometimes send Carly home having not eaten anything during the day, as she is 'ravenous' on returning home.

Social services also came in for criticism as Richard described the lengths he had travelled to master the art of 'getting what Carly needs' from them:

'You have to expect a battle and to know your rights. I usually write to the head of social services, to her boss and to the boss of the council, suggesting I might contact the relevant minister if necessary. You then expect the usual round of letters explaining why you can't have what you ask for and you then take them on till they end up agreeing'.
(1:8)

Challenges to prevailing professional practice do need to be made by parents and carers as services frequently fall short of what families need in a practical sense⁵⁵.

Contemporary welfare organisations are required to consult with parents, ensuring that decent services are provided for families living in very stressful circumstances. The emotional content of Richard's account of his dealings with service-providing agencies and professionals however, should not be lost sight of either. His description of the

⁵⁵ Recent social policy and campaign groups are attempting to deal with this problem (DfES & DH 2004; 2007; Every Disabled Child Matters, 2008)

'battle' that must be fought and the dogged determination to hang-on until things come right, mirror some of the practical and emotional difficulties faced by parents who are providing care for their children with severe learning disabilities. The process of feeding Carly already at this stage seemed a battle of wills between parent and child and the parents have to show incredible persistence and containment of their own feelings in order to achieve the required outcome. These contained, angry feelings aroused by Carly I conjectured, then become projected onto the professional group, amplifying the emotional volume of the complaint. The tone of Richard's complaints reminded me a little of Maggie's anger about harm she felt had been done to her son Billy in the first family observed.

In his account, Richard seemed prickly on the subject of the health department officials' handling of Carly's case, when he mentioned how his letters were brought out during a meeting. The parents have had to make themselves vulnerable to professionals, by the act of asking for help; a potentially demeaning process given this is a middle-class family who seem to value their independence and who have their own professional status. Having their correspondence waved in their faces is like a double insult; it feels like being condemned for being too needy and then publicly ridiculed and exposed to shame in the process⁵⁶.

6. Care practices

a. Understanding the feeding routine

On the second visit, Sally allowed me to watch the feeding routine and while it may have been difficult for her to have me there, she seemed to have engaged with the idea of observation and with me as an observer. She helpfully and speedily filled me in on the events of the day and the preceding week, so I would understand the context of the meal.

⁵⁶ Sennett (2003) has looked at how some of these dilemmas affect those in receipt of welfare services in contemporary society, suggesting that great sensitivity to these emotions is required by professional workers who are trying to help.

Carly had been sick over the weekend, but seemed better this morning which was a Monday and a school day. The parents described the difficult task they had in trying and eventually failing to get her onto the school bus that morning:

'The bus was late as it had broken down' Richard explained. Sally said 'so we got her on the bus and she was sick. It happens quite a lot' she explained, 'Carly is often sick in the mornings'. Then they had tried Carly back on the bus and she was sick again. (2:1)

Given that Carly's wheelchair had to be chair-lifted onto the bus and carefully fixed in place, and that she had to be cleaned up twice, I realised that this episode must have exhausting and disappointing for her parents and tiring for Carly too. Now that the day had passed, Sally was however assertive and clear that it was time for Carly to eat.

'Well girly' she said to Carly, 'shall we try some food in a minute?'. Her tone was direct and kindly, with an air of the suggestion that the issue of feeding might not be a straightforward one. (2:1)

b. Feeding: getting started

Sally herself, seemed to take up an observational stance with Carly as she commenced the feeding routine. She looked closely at her daughter and provided her with spoken and physical prompts to remind her that it was nearly time to eat. Sally provided a narrative to her actions:

Sally made more tentative remarks to Carly. 'Are you ready for some food now? We'll start in a minute Carly', again forewarning her daughter. Carly was still bashing the toys on the tray in an absent way, not seeming to watch what her hands were doing, feeling the sensation of the movement. (2:3)

Sally went on to brush Carly's hair as she always does before feeding her daughter⁵⁷. Carly winced slightly in discomfort as her hair was pulled and her mother apologised gently. Sally moved slightly so that I could see what was happening and she continued to provide Carly with verbal prompts that she was soon to eat. The atmosphere was fairly tense and I felt that I would like to be standing further away, not witnessing the feeding. Sally tried Carly with a drink:

'Let's see how this is Carly. Here's something to drink' Sally said as she offered Carly her beaker. Carly firmly closed her lips, so the liquid dribbled down her chin. Sally said 'you don't want any?' to her and tried again. Again, Carly wouldn't take it in. Sally stood back a moment and stroked Carly's hair. 'Eh girly? How about a drink?' She then picked up the bowl of dessert and tried a spoon of the custard and apple at Carly's lips. Carly clamped her mouth shut, refusing the pudding. (2:4)

Carly seemed uncomfortable and miserable, her head dropping down. Sally continued to coax and persuade her daughter and I came to feel extremely uncomfortable myself:

The spoon rested on Carly's clamped-shut lips and I noticed that she projected her lower lip in an exaggerated pout, to make really sure that no food would get in. For a moment, I felt as though I wanted to prise open Carly's mouth and to force the food in, even if the action would hurt or distress her. Sally stood back patiently however, though perhaps the feelings I experienced cannot be far from her parents' minds on occasion. I wondered how much emotional distancing must go on, to be able to carry this caring out task in a kindly way. (2:4)

Richard then stepped in, encouraging and persuading his daughter to eat, kissing her cheek, gently rubbing her hand and laughing a little, as if in an attempt to lighten the atmosphere. I noticed however, that neither parent was willing to give in:

⁵⁷ An action described by Sally as providing 'an object of reference' for a learning disabled person

Sally laughed and said 'are you asleep Carly?' She seemed to have drifted off. Neither parent seemed overly sympathetic or acceptant that this was the end of the matter. (2:4)

The atmosphere continued to feel tense and anxious. Carly became distressed:

She screwed her face up and started to cry out, angry and desperate. (2:5)

I noticed that it seemed as though both Sally and myself were both observers, vigilant and trying to make sense of Carly's emotional world. Sally was empathic, considering Carly's distress and the impossibility for her of expressing her wishes and feelings in any other way:

'It's your way of taking control isn't it? You don't have another way'. Sally lent over and gave Carly a kiss. (2:5)

Nevertheless, Sally remained firm that Carly had to try to eat something, for fear that her daughter would wake in the night as it seems has happened before, hungry and in need of feeding.

The process had taken perhaps half an hour and Carly had taken almost no food. I was beginning to feel a little sick watching and felt anxious about how much persuasion Carly seemed to need to have to eat. I doubted whether she would ever eat again. Carly seemed very strong and determined; so was her mother. (2:5)

With no apparent explanation, except that she had been worn-down by her mother's determined attitude, Carly suddenly began to take the food and drink. She accepted the beaker and Sally took this as a sign to commence feeding. The mother worked with both hands, skilfully to administer small spoonfuls of food with one hand and drinks from a beaker from the other hand. She also slipped in a couple of syringes of medication while feeding, presumably so that Carly would not taste the medication. I noticed how strange it seemed for a teenage girl, of good size and weight to be fed with a weaning spoon:

Carly now seemed acquiescent and Sally was more relaxed, coaxing and encouraging her daughter. I noticed that the only 'well done's' were coming from Richard, who occasionally stood by and gave Carly a kiss or a stroke of the head during this. Sally was workmanlike over the feeding. She gave time and space, but stuck doggedly to the task of getting the food into her daughter. (2:5)

As I came to the end of my visit, I realised that I had over-run my time. It had felt as though I could not leave until I had witnessed Sally completing the feeding. Perhaps I was colluding with a feeling of Sally being judged; that to be seen as a good parent, she had to succeed at this difficult task and I wanted to witness this? On the other hand, I felt as though I was there to offer support too; to be another person who might encourage Carly to eat. As I left, I noticed that Carly herself seemed exhausted and compliant, as though the fight had gone out of her:

Carly seemed fairly expressionless, accepting the food without complaint. (2:6)

c. Further observations of feeding Carly and anger contained

Sally allowed me to observe Carly around her tea-time over the next few weeks and it felt as though we had managed to find an accommodation to my observing and Carly and Sally carrying on with their routine. I was able to see a similar pattern to the feeding; that Carly would initially put up some resistance but that eventually she would accept the need to eat and the food would be ingested. During the third visit, I noted that Carly seemed tired and that there was little pleasure involved in her feeding:

Her chewing was almost imperceptible, but somehow she managed to swallow, not conveying the feeling of hunger to me at all. (3:3)

Sally was able to persist however and she seemed keen to help me to understand Carly and her world, engaging me in discussions about Carly's social activities at a drama club

and about the role of food in the family. Sally explained to me that she prepares fresh food for Carly and that she usually provides her with Chinese-influenced dishes; what Sally described as ‘her own’ food. This seemed important for Sally, enabling a link to be maintained with Carly’s Chinese heritage and her family who all lived abroad.

During the fifth visit, I once more observed a difficult feeding session between Carly and her mother and while the atmosphere was tense, there was also real anger in the air. I noticed a slightly aggressive side to Richard’s play with Carly:

I felt a though there was a slightly hard edge to the play as he ‘grrr’d’ when tickling her (5:2)

Carly also seemed cross, shouting out as her mother brushed her hair:

She moved her head and arms about quite vigorously and began to vocalise, angry sounds, crying out (5:3)

Carly held out for some twenty minutes before eating this time and I found myself unconsciously drawn in, wanting to eat ‘for her’. Sally had offered me some sweet Chinese porridge to taste at the beginning of my visit and although I could have refused this offer I was interested and curious, so accepted, overstepping my observer role. When Carly resisted her parents’ attempts to feed her, I found myself wanting to eat:

After each try, Sally would stop and stand back for a minute. Then dad had a go, trying to slip in another piece of mango. That was refused too. Carly was cross and at times tearful. She frowned and rolled her head to one side as she cried. I felt terrible watching, particularly as I found myself at one point spooning food, the dessert, into my own mouth, sipping tea as well (5:3).

I found myself drawn-in to the events I was observing, trying to compensate for Carly’s refusal to eat by showing Sally that at least someone appreciated her efforts! I did learn

to think more carefully before accepting offers of food from this experience, as I reflected that it might be telling me something about professionals and the wish to make reparation when faced with distressing circumstances in families they work with⁵⁸.

During this mealtime, the parents seemed to move between allowing Carly to relax for a moment and then persisting and trying again with the feeding. At one stage, Richard expressed frustration. He had switched on a music channel on the television in the kitchen, which was playing opera music. Two tenors, one of whom was blind, sang out:

Richard said 'look Carly. He's blind and he can sing. Why can't you eat?' (5:4)

Eventually the tension broke and Carly once more seemed to place herself in her mother's hands, accepting the food.

Unravelling the cause of Carly's behaviour is a complex matter: which aspects of her feeding refusal are brought about by neurologically based damage caused by the presence of Angelman syndrome and which might be caused by her own personal emotional responses to her impairments and her living situation? The manner in which Carly refuses food, with anger, determination and a clamped-shut mouth, hints at the possibility she is able to exert and communicate feelings about her situation and her difficulties, including perhaps her dependent relationship with her parents and carers (expression of which is not unusual for any teenager). An exploration of Carly's emotional life is very speculative, but psychotherapists writing on the issue of eating problems offer an interesting additional perspective. Williams (1998: 79) looks at how young people with eating disorders can be seen to be rejecting of more than just food; their rejection 'extending at times so widely that it might be referred to as a 'no entry' system of

⁵⁸ I had been aware over the years of my social work practice of my own tendency and that of those I had supervised to find it difficult to leave disabled children's families we had been visiting without offering a service of some kind to them, even when the parents had not asked for one. This might indicate a need for practitioners to learn to reflect more in order to process the feelings involved in their interactions with stressed service users, rather than simply trying to make things better in a superficial manner.

defences'. In her hypothesis, such young people are at times responding to parents who project their unconscious anxieties excessively into them⁵⁹.

It has already been said that parents of learning disabled children are likely to experience a great deal of anxiety, which if unprocessed may be projected onto the child (or onto others within or outside the household as in the Anderson's case described earlier). Some kind of cycle may be at work in Carly's case therefore: she feels frustration at the limitations placed on her by her impairments, the impact of neurological damage contributing to her mood or affect leading to her refusing behaviour. Her parents have the dilemma then that they know she has to eat and their understandable feelings of anger at her refusal, mixed with other anxieties which are projected into Carly, may make it feel to Carly as though they are overly assertive, even attacking in their approach to feeding her. This in turn is likely to lead to her blocking their attempts further. It would be wrong to blame the parents for their part in this, as it would be hard to know whether these dynamics really do lie behind Carly's behaviour. On the other hand it does indicate a role for professional support to provide parents with a way to talk through their perceptions of what might be happening and practical assistance to give regular respite from the stresses of caring in such difficult circumstance⁶⁰.

Returning to the visit, perhaps because the atmosphere had been particularly tense and the unconscious wish to do harm to their intransigent daughter might have been around, the parents seemed to be thinking about times when Carly had hurt herself through accidents in the past. Richard described to me that once Carly had broken her nose when she fell from a bed in a hotel and another time, she broke her leg at school. The second accident had happened when Carly was having an aromatherapy massage and the teacher, while hearing a crack, did not notice that Carly had sustained a fracture as she did not seem

⁵⁹ She describes one young patient she worked with as having been 'used, almost always unconsciously, by one or both of his parents as a *receptacle* of their projection, *their* own unmetabolised feelings or 'ghosts' (Frailberg, 1975)' (Williams 1998:95).

⁶⁰ This professional role can be thought of in terms of 'relationship based practice' for social workers (Wilson et al 2008). More is said about this in chapter 7

distressed. The parents told of their frustration with the hospital where staff had refused to X-ray Carly's leg, despite the parents' certainty that something was wrong with her.

At the end of this visit we discussed the idea of my visiting at a time when Carly was not having her feeding session. This seemed sensible as it is possible that my presence was not making the challenging task of feeding any easier. Having an observer may be helpful at some times, but if the reflection it brings about for parents feels punishing and blaming as may have been the case with the complex emotional dynamics around Carly's refusal to eat as described earlier, then it was better for me to withdraw. We decided that I should visit before or after her feeding time in future weeks, where this was possible.

7. Adolescence: Carly's physical and sexual development

During the fourth visit, one other theme which emerged was that of Carly's growing body. I noticed at the beginning of the visit that Carly seemed too big for her chair:

I noticed how long Carly's legs are, popping-off the rest at the base of the wheelchair from time to time, as though she was out-growing the seat. (4:1)

Sally also seemed to notice this at the end of the visit:

Sally said 'we'll have to change your chair, look the tray's a bit tight' as she patted Carly's tummy. Carly did look as though she was out-growing the chair, her legs dangling off the foot plate from time to time, mum placing them back. (4:6)

During the sixth visit, the matter of Carly's growing body, her developing sexuality and the difficulty of holding this in mind while providing care for her as a young person with significant learning disabilities seemed to come to the fore. After tea that day, as he usually did, Richard carried Carly into the living room for some play time before bed:

Richard sat back with his daughter on his lap, explaining that they might sit like this for half an hour or for two hours, depending on how tired Carly was. He pulled over some toys and began to play with Carly. There were some familiar characters; the monkey and caterpillar brightly coloured toys, with squeaks and rattles and mirrors. Richard took a rattly toy, introducing it by name and shook it in her ear, laughing as he did this. Carly smiled a little. Then he took a squeaky toy and suddenly began squeaking it not too far from her ear. Carly jumped in surprise. Then she smiled and pulled her head down as if in response to being tickled round her ears. Carly seemed to enjoy this interaction. (6:4)

During the play however, Carly pushed her hands down the front of her trousers, evidently playing with her genitals, perhaps rather in the way a younger child might do. Richard was matter of fact about this, commenting that it was difficult to pull out Carly's hands once she had pushed them in her trousers. Afterwards, I noted:

The incongruence of Carly's lying on her dad's lap, being entertained with by baby toys while masturbating was rather striking. Dad, it appeared, put Carly's teenager sexual activity or the possibility of its existence, out of his mind. (6:5)

Once more, the complexity of the parents' role in managing the different aspects of Carly's needs came across. Carly had need of intimate personal care from her parents, for feeding, toileting and bathing and these occasional moments when her actual age and sexual maturity became obvious to the observer highlighted the difficult role the parents face as they are providing this intimate care well beyond the stage at which a non-disabled young person would need assistance. It could also be seen, as for both Daniel and Asad in earlier observations that Carly's sexual development could not always be hidden from view and there was potential for the family to experience shame as her sexuality was demonstrated in a public manner.

8. Parents' resilience

When I visited for the sixth time, I had a chance to see the parents' resilience as carers. I had been puzzled during the earlier sessions by just how the couple managed to keep going while Carly seemed sometimes so resistant to feeding and to their attempts to nurture her. We had timed this visit so that Carly would be finishing her meal when I arrived and it seemed to be going well:

Sally seemed fairly relaxed and in control of the process of feeding. She passed Carly mouthfuls of savoury food, with small blocks of pear and some pastry chopped into small pieces. I came over to stand in front, but to the side of Carly. Sally spoke encouragingly to Carly, who was more animated than I'd seen her for a while. (6:1)

There seemed to be a synchronicity to the eating, with Carly and her mother responding sensitively to each other and the atmosphere was calm and relaxed. Sally offered Carly some chocolate, as a treat once she had finished her meal. Carly's mood suddenly changed then:

She suddenly began to laugh. Her face contorted with the laughter, which seemed a little crazy and hysterical. The mood in the room seemed not to connect with Carly's laughing and it felt awkward. (6:2)

Immediately after this, Carly began to retch and she soon vomited-up the meal she had just consumed. I noticed that both Sally and Richard responded calmly, cleaning her up as the vomiting ceased. I asked if I could help and Richard responded:

'We just follow normal procedure' he said with a sigh, as he helped to wipe up the mess. Sally mopped Carly, cleaning up her tray, her clothes and emptying the bib which was by now full. The mood felt pretty despairing. I thought about all the effort Sally made to make appetising food for Carly and about how hard it was to interest her in the act of eating, then for all of this to be puked out. Sally didn't speak, except to say 'I'll wipe you

Carly' and 'is that all of it?' to her. She spoke kindly, but she seemed a little flat and sad. (6:3)

I was left wanting an explanation for Carly's sickness, but the parents seemed resigned and acceptant and neither questioned the other on what the cause might be. I remembered that they had told me on an earlier visit that Carly is often sick, so I assumed that this was indeed a normal occurrence for them to deal with. While the parents cleaned her up, Carly began to push her fingers into her mouth:

Carly tried to put her fingers inside her mouth and Sally noticed quickly, pulling her hands down. 'No, don't hurt yourself Carly' she said. Then, when the action was repeated, 'Don't make yourself sick Carly', Sally said, again pulling down her hands (6:4)

The suggestion that Carly might deliberately be causing herself to be sick was difficult for me as an observer to contemplate and I wondered how the parents coped with this thought and the anger that I assumed a carer might feel in response to this provocative behaviour, however unconscious it was. What happened next seemed to point up the couple's resilience and their ability to contain and to manage any feelings aroused by Carly's difficult and challenging behaviour. It seemed that Richard simply flipped-over the feelings of despair which had been around a moment before, converting these into a buoyant, almost joyful mood:

Richard lifted Carly from her chair with a flurry and a bright 'here we go', carrying her to the living room (6:4)

Sally meanwhile had been given a little time to herself to clean-up in the kitchen. I wondered whether there was an emotional cost to the couple of coping with these events. Both parents however seemed in this case to be able to apply a thoughtful, rational approach to the events, bracketing their ability to make full sense of Carly's behaviour

and thus containing frustration and despair⁶¹. This provides evidence of their ability to contain and support each other through such distressing aspects of their caring roles.

9. Time to reflect: ‘social death’ or a different life-course?

Later during this sixth visit, while we sat together in the living room, Sally and Richard reminisced about the role of the church in their family life. They had always attended the local church, their son Ivan going to Sunday school and later Carly accompanying her family. They stopped attending when some of the older church goers complained about the noises Carly made once the hymns had finished and people were praying quietly. She liked to join in with the singing, but did not understand when to be quiet. Richard mused on this, saying that the church members still remember Carly by sending her some flowers every few weeks. I noted my own feelings of anger about this and how:

It made me think of people mourning someone who’s dead. (6:5)

Without more information it would be wrong however to make assumptions about what had happened here. Perhaps the family had indeed experienced stigma and a kind of ‘social death’ as I was feeling when I heard this story. The congregation of the local church had excluded the family, but perhaps the parents had in fact chosen to withdraw, finding Carly’s behaviour difficult too. The church-goers may have been assuaging their guilt by giving Carly flowers regularly, but this might also have been to show that they had not forgotten her or her family; a more caring, inclusive set of reasons for their actions. I noticed that in the telling of this story the couple could recall these events without rancour and I wondered then whether they had managed in some sense to grieve the impact of Carly’s disability both on her and on the family, even though its impact was to move them out of the mainstream of local life. As they described these events there

⁶¹ Perlesz (in Flaskas 2002:60) is described as seeing hope and despair co-existing in families coping with significant illness and disability, implying that one does not have to become stuck with either emotion, but rather one might move between both feelings.

was a sense of the years passing by, of a family's life lived apart from the community around them and perhaps a little regret about this.

10. Later observations of Carly and her family: coping with damage

There was a gap of six weeks before the next visits as Sally's mother, who lived in South East Asia and who had been seriously ill for many months, suddenly took a turn for the worse and died. The couple had been able to get Carly an emergency place in a residential respite unit for five days to enable Sally to go to the funeral and I visited after her return. I was struck by how constrained the couple are by the availability of this resource and just how little time Sally had been able to spend with her mother in her last months, although it would be hard anyway for her to leave her daughter in the care of others.

I arrived before Sally was due to give Carly her evening meal and was able to spend time with Carly as she played and relaxed on her bed. Richard remained with me and I noticed that he seemed in a fairly cheerful mood:

Carly's head faced away me and I said 'hello Carly' feeling the need to raise my mood to be jollier and brighter. Richard was talking with a slightly enforced brightness and I began to meet his tone, speaking more loudly and at a higher pitch than before (7:1)

I found myself resonating with Richard's rather manic, jolly mood, which was reinforced by loud music playing in Carly's room.

I'd noticed the music playing as I first went into Carly's bedroom. It was 'Beautiful' by James Blunt and it was switched on fairly loudly, the hi-fi on a nearby chest of drawers. The music is quite uplifting which also accounted for my mood shifting. Richard seemed in a positive, up-beat mood himself, perhaps making the effort to welcome me and for me

to see Carly in this light. I was aware that the music made it difficult to focus on Carly and remembered that there is usually music playing around Carly. I wondered if the music helped the parents to manage when the care tasks become tiring and frustrating, a way of managing cutting off at times. (7:2)

While I was with Carly I experienced a feeling of panic, wondering how I was going to pass the hour of my observation. It was then that I began to acknowledge some of what it felt like to be with her at that moment. I sensed her vulnerability and I felt anxiety at being with someone with such significant impairments. Also there was a fear that I might be left with her and worst of all, a questioning of the validity of her very existence:

I suddenly noticed how disabled she is; a fourteen year old lying in a large bed with cot sides, with fingers that don't work and baby toys around her, pulling and banging those toys. I spoke gently to her as I stood to the side of her bed, noticing the soft quilt placed over the raised side of the bed protectively in case she threw her hand over in that direction. The bed looked like a giant baby's cot, padded and safe. 'How are you getting on there? Have you got tangled up?' I wondered if the tone of my voice would mean much to Carly. I lent over to gently try to disentangle her fingers from the fabric holding the toys. Once free, I handed the toys again to her and she again grabbed them and bashed them about, rather as she does when sitting on her chair. Carly did not look at me in a way which made me feel she registered my presence; instead she seemed self-absorbed.

I stood by, saying a few words from time to time about what she was doing, as though narrating. Carly carried on playing. I felt aware of the need to relax and to lose any sense of expectation while with Carly. Reflecting on this later, I wondered if some of this feeling was about the pointlessness and disappointment of Carly's life, when viewed from one perspective. It seems difficult even to write this down and to stay with the feeling of hopelessness, to admit to those feelings. It must be difficult to be positive when the rewards of caring for a child seem so limited; hence the distracting music which takes charge of ones mood. (7:3)

My experience of Carly I believe is informative, as it mixes consideration of the feelings aroused by being with her with thoughts about how I then managed those feelings. It is a large assumption to make that the parents might experience a similar range of feelings, as I have to acknowledge my own counter-transference which undoubtedly clouds the account. Also, the parents' emotional bond and their love for their daughter would affect their ability to manage their feelings towards her. The process I went through however of calming myself, containing my anxiety and adjusting to having a very limited expectation of what Carly might offer to me in return for my care and attention, does seem to mirror some of what I had witnessed in the couple.

Relationships between children and their parents operate in both directions, children reciprocating to parents and carers for the love and attention they receive, enabling parents to feel good about what they are able to offer thereby encouraging them to continue to care. I wondered how it must be to love and care for someone whose disability is so severe that it is difficult for them to reciprocate and the patience and attention parents offer may be repaid in small, micro-level developmental responses over long periods of time⁶². In Carly's case, her behaviour could be challenging and provoking, bringing out angry and exasperated responses in her parents. Later on in the visit, I noticed that Carly offered me a smile and this gave a clue as to how the family cope:

She looked up at me, giving me a clear look, which opened up into a smile. I responded, 'that's a nice smile Carly' (7:4)

Despite the undoubted difficulties and challenges of providing care for Carly, her ability to light-up in this way indicates that she does have the ability to reciprocate, making those around her feel good about being with her. This seemed very important and

⁶²This thought can be extended into the wider arena of considering how children's development is now subject to continual scrutiny and assessment as encouraged by the government's agenda within schools and in social policy more generally. How might individual families, where disabled children are unable to conform to requirements, feel about this?

significant, enabling me as an observer to see how the household functions and how the parents maintain their resilience.

11. Final thoughts: taking things one day at a time

In the final two visits, there were some further examples of the couple's ability to contain Carly. Sally was able to help Carly through a difficult, stuck moment in her feeding, to calmly accept the need to eat:

Carly's demeanour changed. She was calmer and at last getting what she needed. She seemed so much less disabled. Her eyes rested on her mother, whose back was facing her as she worked at the counter to get the food ready quick enough for Carly (8:4)

One thing that seemed to sustain the couple was the thought of having some short breaks away from home and their caring responsibilities and they described their plans for the following year, as all the breaks had to be planned many months in advance to fit in with the respite unit's availability.

On my final visit, the couple told me about an accident that Carly had in the previous week, when she fell from her chair as her father had very briefly left her without any kind of restraining belt.

He had just taken her tray away for one second and turned away, when she fell forward onto the floor. Richard moved round and showed me the mark on the kitchen floor where Carly's glasses struck. I cringed thinking that she must have hit the ground with some force. Sally quickly added, with a look at me, that Richard had turned away from Carly while she wasn't secured in the chair- it was his fault. I felt a little surprised at this discussion, particularly as Richard was describing this event in a fairly jovial fashion. (9:2)

Although Sally blamed Richard for this, there was no real feeling of anger in the air and I was struck by the contrast between these parents' view of an accident befalling their daughter and Maggie's view of Billy's accident in the observations of the first family, the Andersons. In Billy's case it will be remembered that he fell from his bed while a paid carer's back was turned and Maggie spent many weeks angry and trying to seek justice for her son. Sally and Richard seemed more able, between them, to accept that such accidents may happen on occasion⁶³.

In my last observation of Carly, I witnessed her feeding one more time and the skilful manner in which Sally proceeded. I noticed for the first time, perhaps because of the limited time available in which Carly's mood would permit her mother to feed her that Sally went about this task in a fairly mechanical way:

Today Carly choked on her food. Sally didn't lean down and commiserate with Carly. Instead, she quickly turned to her side to put down her feeding implements (spoon, cup or what ever it was) and tended to Carly in a slightly mechanical way. 'Has it gone down now girly?' she would ask before quickly returning to pick up the spoon again (9:3)

This slightly 'hard' approach to feeding was mirrored by what I noticed to be a fairly controlling attitude towards Carly, who was not permitted to experiment with her food or to make any kind of mess:

Carly wasn't allowed to touch the food with her hands to explore it at all; it just went straight into her mouth. I wondered whether this act of control by her mother was to do with some kind of horror of the mess of Carly's feeding or because Carly's poor co-ordination might mean that she really wouldn't get any useful nutrition from the experience. At any rate, she has never been allowed to explore food, or to make mess with it, during my visits. (9:4)

⁶³ Had I been concerned that the parents had been neglectful in their care of Carly, I would have had to act here as a responsible researcher and as a registered social worker. The parents were very attentive to Carly's physical state and she appeared well.

I remembered that Billy in the first family observed had also not been allowed to touch any food with his hands and thought about the worry about dirt that Maggie had expressed.

12. Saying goodbye

Finishing my visits to the Davis family was difficult. They had been very welcoming of me despite having many difficulties to cope with, not least a major close family bereavement. The experience of having an observer with them was not always helpful to them as arguably it had been for some of the other families I visited, as I believe the reflection it encouraged brought out painful, distressing feelings for them. They were able to tell me once more about some trips they hoped to make in the next year, so that they might have a break from caring and these holidays seemed to give them a hope of some genuine respite. I was struck in my observations of the Davis's however, by the lack of discussion about their hopes for Carly in the future. The parents in the other three families I had observed had all at some time been able to voice thoughts about what they might expect for their disabled teenager's adult future. While it might just have been that the couple did not want to share these thoughts with me, I left wondering how they viewed Carly's future:

Carly had her fingers back in her mouth and then tried to push the teething ring into her mouth at the same time. Both mum and dad laughed and dad said 'you can't get both in at the same time Carly!' They seemed a little embarrassed by her 'stupidity' about this, but I felt encouraged- as though she was trying to orally satisfy herself and that she might learn something as a consequence of her 'mistake'. This made me think how stuck the situation seems with little hope of learning and things getting better. I wanted to ask about the future, but didn't voice this. What did the couple plan for their future and for Carly? (9:5)

13. Learning from the observation experience

The opportunity to observe Carly in her family home presented me with a valuable research experience. The parents were doing an impressive job in providing excellent care and a good quality of life for their daughter and I was able to come to an understanding, through observing, of some of the factors which contributed to their resilience and their capabilities.

On entering the home I found that the parents, perhaps because of their educational backgrounds, had already given some thought to having me there as a researcher and to helping me to see what was going on. They were clear about when and how much of their family life they would allow me to observe and this made it easier for me to quickly focus on issues of interest. In a sense, they were protective and containing towards me, gently letting me know of the significance of Carly's impairments before I met her and forewarning me of her difficulties.

Through observing the fine detail of Carly and her mother's interaction at feeding time, it was possible to see how their relationship played out and to speculate on how Carly might have been using her refusal to eat as a way of expressing her feelings; her response to the stresses of experiencing her impairments and to her parents' difficulties in this area, which resulted in their projecting anxious feelings into her. Also the parents way of coping with the uncertainty of not knowing why Carly behaved as she did was informative, as on occasion having applied rational thought to her reactions, they allowed her just 'to be' without the need to ruminate endlessly on the meaning behind her behaviour⁶⁴.

The exposed nature of the feelings which emerged during the observation, meant that it was right that I step back from observing when it was too raw and we negotiated spacing and altering when I might visit, so as not to amplify the parents' difficulties. The use of

⁶⁴ This contrasted greatly with the Anderson family, where rumination on what Billy might or might not be feeling at any time tended to preoccupy the parents.

an infant observation style of approach to researching Carly's experience was very appropriate and a rich source of data. The way in which they managed me through the observations, illustrated the parents' high level of competence in working together to care for Carly which was not an easy matter when caring for someone with a high level of practical and emotional care needs. This ability to work in unity as a couple was untypical of the families I observed, where often conflict was apparent.

While observing, I had the opportunity to experience and to reflect on some of the difficult to own feelings encountered when being with someone with severe learning disabilities; questions about the limitations and purposelessness of life, the arduous nature of caring in these circumstances and thoughts about the defences which are needed at times to cope. From this however, it was also possible to learn that, rather as with young children, parents can make good use of small but significant reciprocal acts by severely learning disabled young people to enable them to keep going and to feel good about caring.

When thinking about the necessary defences needed to facilitate caring in difficult circumstances, I was also able to understand the hyper-sensitivity of the parents to professionals who worked with them and the vital importance that professionals understand the emotional dimensions of their roles. These were highly competent, rational parents who were very well able to think about their daughter's needs and to approach agencies with reasonable requests for help. Not every encounter with professionals had been positive and containing, showing that ways in which professionals respond to the parents' requests for help are as significant as the implications of funding limitations to them.

Chapter Seven

‘Trying Transitions’: A Discussion of the Study’s Findings and their Significance for Policy, Practice and Research

1. Introduction:

This study proposes that the identity development of severely learning disabled young people might best be understood by drawing on a psychosocial approach to research; one which emphasises the emotional and relational dimensions of identity, as these have tended to be underplayed in existing studies. A methodology derived from psychoanalytically informed infant observation was employed because this afforded a good opportunity to capture the complex relationships, experiences and emotions of this difficult to reach group of young people. During the presentation of the four family case studies in subsequent chapters, an array of issues and themes emerged concerning the identity development of the learning disabled young people. These will now be distilled and reflected upon further in order to gain an understanding of the young people’s experience.

This chapter will commence by proposing a psychosocial model of adolescent development, which helps to account for the shaping of identity by highlighting four key domains: internal, personal, external and social domains. The young people in each case study will be looked at in relation to the research questions set out at the end of chapter one which address the quality of subjectivation experienced by the young people; that is the process of gaining ownership of the body, mind and drives (internal and personal domains). After this the young people will be thought about in relation to those immediately around them (parents, siblings and carers) as well as in relation to the influences of wider social processes (external and social domains). The main finding of this section is that the subject status of the young people in the study is itself impaired by

the experience of severe learning disability, though in different ways according to the nature of that disability and the context in which the young people are living.

Following on, a second strand of the findings from the case studies will be examined emerging from the discussion on subjectivation; the role played by defence mechanisms employed by family members. A relational mapping exercise is undertaken for each young person and their family, considering the role of defence mechanisms employed by parent/carers and the young people's state of 'becoming a subject'. This leads on to the implications of the findings for social policy, practice and research and finally, to the use of infant observation methodology as a tool to research the identity development of severely learning disabled young people in the context of their family lives. While limitations are acknowledged, it is argued that the method has much to offer in providing a sensitive and respectful approach which enables new, useful knowledge to be uncovered about the lives and experiences of this disenfranchised group of young people.

2. Subjectivity, identity & change in adolescents with severe learning disabilities: shaping a psychosocial model of adolescent identity

A range of models describing normative adolescent development were introduced earlier (Erikson 1963; Cahn 1998; Kennedy 2000; Waddell 2002)⁶⁵. These models present some dilemmas however when considered in the light of the experience of those with severe learning disabilities. Questions arise as to whether or not it is meaningful to apply normative models of human development, those which see the developing subject at their centre, to young people with such severe impairments. Can it be said that a person with severe learning disabilities has the experience of a subjectivity which is comparable to those without such disabilities? Read et al (2006:168) citing Riddell (1998) acknowledge this difficulty, but suggest that as transition to adulthood is so closely linked to the assignment of social rights and obligations, disabled people must be considered as eligible adult subjects and offered adult services and choices 'unless a case can be made

⁶⁵ In chapter one there is a discussion about the different approaches to understanding adolescence; firstly as a transition and secondly and more contemporarily, as process.

specifically to the contrary'. Yet if it is simply suggested that severely learning disabled people's lives are the same as those of non-intellectually impaired people, surely some of the complexity and detail of people's lives (as well as those of their families and carers) will be lost or glossed-over in an attempt to deny real experiences (Dartington, Miller & Gwynne 1981)?

Thinking of adolescence as a relational process is a central premise of this study. To recap on what was said in chapter one on normative development, adolescence has been described as a bringing together of both internal and external worlds of the young people; the psyche is seen as moving through a developmental process discussed in terms of the notion of 'becoming a subject' (Kennedy 2000) while at the same time changes in the adolescent's body and physical state occur as well as changes in relationship to the outside social world. By identifying and naming these components of adolescent development, it becomes possible to consider each of the young people in the study in relation to these. It may be that a modification of the principles of normative development is necessary to help make sense of a particular young person's development. Should this be the case, then the knowledge gained may be useful in saying something about others with comparable disabilities and their families.

The components of adolescent development seen from a psychosocial approach may be illustrated thus:

Internal (objects, psyche)

External (objects, family, carers)

Personal (physical, embodied)

Social (school, professionals, society, policy)

In this psychosocial model of adolescence, a sense of balance is required between the different components for a young person to move towards a state where they may be considered a 'subject'. In normative circumstances for example, under the 'personal'

domain, an adolescent would develop physically, through puberty towards gaining a more adult, sexually mature body. At the same time the psyche continues its process of differentiation, the young person in a continuing, yet changing relationship with their external objects. As the young person develops physically, this impacts on how they are seen and experienced unconsciously by those external objects and by the society around them. There is a process of oscillation between these internally generated, physical and emotional changes within the individual and the external objects. The wider social world also sets the frame by way of designing official social policy as well as defining ‘unofficial’ social prejudices and attitudes which impact upon the developing individual positively or negatively.

When thinking about learning disabled young people’s lives these four components will also be detected, but there might be some key differences in the manner in which they are expressed. The existence of a severe learning disability is likely to impact upon how the young person is experienced emotionally by their close family carers (external objects) but also therefore it will impact upon how they experience themselves (their internal objects)⁶⁶. The degree of cognitive impairment will also affect the young person’s potential to notice and to experience themselves and those around them.

Constituting the ‘personal’ domain described above, the young person’s embodied self (that of a developing adolescent possibly with particular physical impairments) also impacts upon the internal and external object relations. The co-existence of signs of an impaired, dependent body with a sexually maturing presence may be expected to add complexity to the relationship between parent-carers and disabled young person. In addition to this, the fourth component (the social domain) provides the wider frame within which familial relationships are set.

⁶⁶ Discussed earlier in Chapter One was Stern (1998) on early infant-parent relating. These ideas were linked with those of Sinason (1986, 1992) on secondary handicap and Simpson on defence mechanisms (2004, 2005) as they set out to characterise the particular emotional dynamics of learning disabled children’s relationships with their parents.

Explicit social policy and implicit socially-held prejudices and attitudes about disability may be expected in turn to contribute to the expression of the learning disabled adolescent's development. Complexity is added to the 'social' domain by considering the state of flux of adult identity in late modern society (Thomson et al 2004; Jones 2006) and notions related to the rise of individualism and the shaping of the 'project of the self' (Giddens 1991). It is conceivable that these will influence how the young people view themselves, how their parents view them, but also in turn how the parents have come to think of their own identity. The impact of caring for highly dependent children within the context of late modern society which promotes independence as an idealised state can be thought about in this light.

Through close examination of the case study material developed from observations of the four young people in this project, the contrasting ways in which their subjectivities are formed and expressed can be characterised and the next sections will look at this. In Billy's case for example, while the four different components are all in place, his impairments have a distinct effect on the quality of relating between his external and internal objects. It is possible to describe Billy, as a fragile, partially-formed subject.

3. 'Becoming a Subject': the experiences of the young people in the study

a. Billy: a fragile and partial subject

Considering Billy as a psychosocial subject, a place to start is by looking at his physical, embodied self (his 'personal' domain) and what this might tell about his internal world, before moving on to see how Billy related to those in the external and social dimensions.

During my first meeting with Billy it was possible to see that he was a physically developed adolescent of fourteen years, who closely resembled the other family members. Billy's severe physical disabilities restricted his mobility and much of the household space was taken over with specialist equipment needed to move him safely and to keep him comfortable. It was observed that Billy was developing normal physical features of adolescence, for example his voice was heard to have deepened and he was

growing in height⁶⁷. For his parents however, signs and indications of his developing physicality and sexuality were not readily thought about or discussed in my experience. Thoughts that he might soon have to shave or that he at one stage had a 'girlfriend' at school were not dwelt upon by the parents. This indicated to me that it could be difficult for the parents to hold together the ideas that Billy was both very disabled and dependent, yet he also inhabited a developing, adolescent body.

Alongside this notion of a developing body then, is the stronger, foreground image of a disabled body. Billy's body also showed signs both of the attempts to rectify his impairments and curative attempts to make his physical condition more comfortable. His body was scarred by operations on his spine, his kidney and to fit the peg to make feeding straight into his stomach possible.

Despite the way in which Billy's impairments seemed to take centre stage, he was able at times to assert his physical presence on others and this moves the discussion towards thinking about Billy's development in the domain of external objects. In the fourth visit for example, I noticed that he was able to command attention and respect through nodding, communicating feelings with his eyes and through vocalising assertively. These physical, embodied expressions of Billy's suggested to me that he was able to have transient and partial moments of subjectivity analogous to the states of mind thought about in terms of normative adolescent development, though more fragile and illusive⁶⁸. Billy's parents, in my experience, worked hard to build on such moments, exerting quite some effort in the attempt to ascertain their son's views and feelings. There were many accounts in the observation records of both Maggie and Tim leaning closely into Billy's face, clearly enunciating questions to him which might have a 'yes' or 'no' answer to be indicated by Billy showing a change in his eyes. It was however difficult to ascertain truly how much Billy was able to comprehend and to communicate as the parents were often unsure of the content of his responses.

⁶⁷ These details are described in chapter three

⁶⁸ Although I am speculating on this point, the fact that I noticed feeling his irritation during the fourth observation visit would seem to support this view.

There were times when I was observing, that I doubted Billy as a thinking, emotionally-experiencing subject. Billy was often tired from the exertions of his busy school day when I was there and it was not uncommon for him to fall asleep while I was visiting in the late afternoons. The impairments associated with cerebral palsy were exhausting for him to live with and as he was unable to communicate at home except by use of his eyes which registered understanding and connectedness at some moments, it seemed that often Billy would simply 'shut-down'. At school, I had been told by the parents, Billy sometimes made use of a switch to provide a pre-recorded statement; 'good morning' or a yes or no response. This was not made use of at home, so it was difficult for me to attempt to assess the degree of Billy's communicational abilities. I did wonder whether the lack of electronic communication aids at home was due to their not being offered, or to the parents' view that they were not helpful as they were not convinced that Billy could fully comprehend their questions.

Communication between Billy and his parents was difficult and uneven and it was hard to decide whether his cognitive difficulties were solely responsible for this or whether both Billy and his parents had given up the attempt to understand each other with the use of assisted communication aids because of the sheer effort involved on both sides. It seemed that he was able to show some feelings but that in my experience there was a high degree of uncertainty about the degree to which these could be understood⁶⁹.

The parents ascribed meaning to Billy's communications and demeanour at times, but this appeared to be contingent and malleable according to the circumstances at a given moment. For example, Maggie would describe Billy's attitude towards his sister Catherine in such a way as to affirm his older sibling status; he might be described as being irritated with her if she was being difficult and demanding, or he might be described as a protective older brother. While these were examples of positive, relationship-enhancing ascriptions of meaning to Billy's communications and behaviours, there were other times when his status as a subjective, feeling individual was down-

⁶⁹ Had I interviewed Billy's teachers at school, I might have gained a fuller assessment of his intellectual and communicational abilities. I was interested however, in how his parents experienced him and what this meant for relationships within the family, so did not pursue this avenue.

played. One account concerned Billy's protest at having a hospital procedure carried out to test his kidney function (visit 13). Maggie described how Billy would have to be held down while this was carried out without an anaesthetic. This raised for me the thought that adults and carers might at times have to discount the possibility of Billy's status as a conscious subject. It suggested that while time and care were devoted to trying to understand Billy's feelings and wishes, limits were placed on this.

It would seem that if Billy's subjectivity was transient and partial in nature, his parents were left with space into which their thoughts and fantasies about him might be placed. Where normative adolescent development might entail experimentation with peer relationships, to broaden the field of emotional experience, Billy was reliant on relationships largely with the field of his family (relationships with others at school may have been significant but they were out of the scope of this study). Billy's limitations in terms of understanding, feeling and communicational capacity placed the parents in a difficult and confusing position with unconscious anxieties about what was contained in his internal, unconscious world⁷⁰. There seemed to be times when the parents projected greater meaning into his behaviours and his feelings than was warranted and there were other times when his subjectivity was discounted altogether. These thoughts would suggest that Maggie and Tim's own development, as middle aged adult people engaged in parenting under complex circumstances, was itself affected by the caring responsibilities they faced.

The next element to be considered is the 'social' domain which forms a part of the adolescent developmental model described above. Giddens' (1991) ideas on the self and

⁷⁰ As for example in visit 12, I noted afterwards: *Billy was still calling and 'whahhing' away next to me and it was really difficult to disentangle his communications. From time to time you'd feel clear what it was he was wanting you to pick up and at other times, happiness and smiles disintegrated into a grimace and a moan with little division. The emotions seemed to range about as though Billy didn't know what he was feeling. It was hard to try to piece things together (12:7)*

identity in late modern society are relevant here⁷¹. Relating these ideas to the families in this study, Billy's parents have had to develop a high degree of expertise in managing his care, which involves sophisticated nursing tasks as well as providing loving parental care. The 'privatisation' of this care within the family also has an impact, as the risk is then present that they become isolated; solely responsible without the support of a containing welfare state. The only alternative to the family is often seen as its polar opposite, institutional care; a frightening, potentially harmful prospect for vulnerable young people such as Billy. Pressurised by the notion therefore that they must cope or face the shame that goes with 'failure', there appears little opportunity for the parents to receive meaningful help in the current situation.

Prospects for the future were also concerning to the parents as they described the worrying experience of hearing from the 'transition' worker on the limited choices facing Billy as a young adult. They learnt at a meeting with professionals that they needed to campaign for Billy to leave home as a young adult of nineteen years, because if they waited till he was twenty five years old the local authority 'won't consider it' (visit 12). This runs very much counter to the aims of current policy and practice in this area (DH 2008) and without researching further on this specific topic, it is not possible to check whether such restrictions would be in place on the range of choices facing Billy as an adult in need of services. The concerns raised by the parents do however suggest that 'personalisation' of social care may have its limitations in situations where service users or their carers are not able assertively to state their claim for support (Burke & Williams 2008; Shakespeare 2006).

If development during adolescence involves a move towards acquiring subject status within a psychosocial frame, Billy may be thought about as a fragile and partial subject. The parents could be observed in their interaction with him as attempting to make sense of Billy's inner world and this was a perplexing, emotionally draining task for them.

⁷¹ As described earlier in chapter one, Giddens (1991) suggests that with the rise of individualism people are seen as needing to develop expertise in managing the 'project of the self'. Also he puts forward that social processes tend to be sequestering away unpleasant experiences (and perhaps the experience of severe learning disability might be categorised as such by many).

They appeared to project capability and agency into Billy and at other times to project the idea of him as an empty, non-feeling or experiencing being. The stress they experience as parent-carers, it has been suggested, has been added to by the 'privatisation' of the family; a place where they are expected to provide expert care, isolated from the support of the welfare state. These themes will be developed further later when the role of defence mechanisms and blame are considered in relation to the family. For now though, it will be useful to compare Billy's development to the other young people in the study, firstly to Daniel.

b. Daniel: an unruly, un-integrated and resistant subject

For Daniel, a very different patterning emerges when a psychosocial model of adolescent development is thought about. Beginning, as with Billy, by looking at the 'personal' domain of his physical, embodied self, I found that Daniel was eleven years old and was in the early stages of puberty. His appearance was that of a younger child, with his soft facial features and longish, mop-like hair. On the seventeenth visit however, I noticed that he seemed very much like a teenager in his apparent mood and behaviour as he roused himself to go downstairs. While this felt to me like 'teenage-type' behaviour and body language, it might have been more a case of an 'autistic-type' of demeanour. There could be a sense with Daniel, of a flat and emotion-free presentation and into this it was possible to project many of ones own assumptions about what he might be feeling.

Daniel expressed sexual excitement and arousal as he engaged in genital rubbing while playing at water flicking. While this might be an aspect of early adolescent sexuality, it also seemed linked to the rest of the sense-stimulating behaviour he exhibited. Daniel's experience of himself and the world around him appeared centred on his heightened senses. His impairment of autism seemed to be leading him towards a fascination with the minutiae of physical and sensory experience and as such it was an extremely 'embodied' experience. Daniel, given the opportunity, would lose himself in repetitive, sense-stimulating action, almost as though he had surrendered his mind to his body. The physical changes of puberty and adolescence, through which Daniel was moving,

contributed and added further stimulation to the physical, embodied sensations with which he was already preoccupied.

The next aspect of Daniel to consider is his external object relations. As an observer I fell into the category of an external object and I found that being with Daniel sometimes it was possible to experience a sense of 'psychic merger' with him. It appeared that through autism, his identity and sense of self was impaired and un-integrated, lost as it appeared to be in the bodily experience of physical sensation. This was added-to by the feeling that one had while with him of his omnipotence and omnipresence as it was possible to feel quite controlled by him. Through the experience of observing Daniel it became evident that it was important to make a stand with him, to differentiate oneself from him.

Ian, the father, spent less time at home than his wife Kate, but he was clear that it was important to 'stand up' to Daniel and he provided some leadership within the family in this area. Ian wished to put an end to Daniel stripping his clothes off in the garden showing that he was mindful of the need to be aware of his son's chronological age now that he was nearing adolescence. Noticing Daniel's behaviour and defining some boundaries seemed particularly important as this contributed to Daniel developing some more purposive, social behaviour. It was interesting that once Daniel was confronted with the need to do something more purposeful (or at least to put a stop to repetitive play such as water flicking) he often appeared dull and flat in mood and though competent, his impairment would appear obvious.

Daniel's identity development in relation to wider society can then be thought about in connection to his behaviour. Comparing the 'artistry' with which Daniel engaged in water flicking with his more 'amateurish' attempts to join in with playing football or on the trampoline, it is possible to see why autistic features may become romanticised in popular culture; as though the autistic person is freed from social convention to pursue

their wildest dreams in a way more socially constrained individuals cannot⁷². For parents this is might be a particular problem as they detect real talent in an aspect of their autistic son's functioning (though perhaps in an obscure aspect of this) and it is perhaps sad to have to call a halt to activities in which their son can lose themselves so blissfully, yet mindlessly. In this way, there might be seen to be polarised views held in wider society about autism and what it represents. Social policy and practice guidance tends more towards the need to shape and control autistic children's behaviours by moving towards early assessment and diagnosis of autism and by pathway planning and behavioural interventions (DH 2004), but as Moore (2004) shows, there can be ambivalence from a parent's point of view at approaches which give primacy to behaviour management.

As in Billy's case, Daniel's parents are in the position of managing care of their son in the private setting of their family, a task which demands a high degree of expertise given his considerable needs. Daniel's family are however seemingly better equipped to carry out this task for two reasons. First, Kate is a teacher who has experience of working with children with special needs, knowledge which she displayed when for example talking to me about the behaviour modification plans that she attempted to carry out with Daniel at home. Second, the family were better off than Billy's and they were in a position to purchase the services of 'mother's help'. Sharon was a very supportive and capable employee, able seamlessly to take over from Kate when she was needed. The family also purchased additional residential respite care for Daniel from a private centre at considerable cost, enabling them to have more time away from him than would be available to a less well off family, dependent only on what a local authority would fund for them as part of a care plan⁷³.

In conclusion, for Daniel it seemed as though the parents had to encourage and cajole their son to adopt a subject status, manifested in his case by his socially acceptable

⁷² Charlotte Moore's (2004) writing on her own experience of raising two sons with autism examines some of these issues from a parent's perspective as discussed in chapter four.

⁷³ In my own social work practice I am unaware of other circumstances where families have purchased their own residential respite care in addition to the state funded package, although I am sure this happens. The costs over a number of weeks would run in the thousands of pounds. I concluded that Daniel's family were actually quite wealthy, though of course there would be things they were not able to do because of choosing to spend their money in this way.

behaviour, as he appeared to have little interest or inclination towards this end, his interests and proclivities directing him towards bodily, sensory-stimulating activity. I was surprised by his capability at adopting regular, more socially competent behaviour once this was expected of him. Considering the social domain and its impact on Daniel's development, Ian seemed to stand for the outside world and the need to ensure Daniel could learn to behave in a socially acceptable manner. The family also seemed better equipped than other less wealthy families to have genuine breaks from their caring tasks with Daniel, as they were able to orchestrate effective respite services within their own home, from both public and private resources.

c. Asad: a frustrated, controlled and unknowing subject

Starting with a look at his personal, embodied adolescent self, Asad was fairly small in stature with the familiar facial features of Down's syndrome. He was physically mobile and active, expressing an interest in sports and wearing clothing typical of his age group; football shirts and tracksuit bottoms. Although shy when I first met him, I found him sociable, friendly and polite; except when he became exasperated by one of his parents, usually his mother. As a young man just reaching sixteen years of age, Asad appeared to be fully physically developed for his age with facial hair growth and a deep adult voice. In many ways Asad presented as a regular teenager irrespective of impairments associated with Down's syndrome.

Along with the facial characteristics of Down's syndrome, there were two other features which drew attention to an embodied self marked out by health problems and disability. First, Asad had scarring on one side of his head, a result of a life-threatening bout of childhood cancer. This scarring served to remind Asad's parents daily of his traumatic early life. Second, Asad's communication difficulties led to his adopting sign-supported language which incorporated Makaton signs, Bengali and English. This made for a complicated matrix of communication which was expressed in a very bodily, dramatic fashion, as Asad enthusiastically tried to gain other people's understanding. The mix of his communication difficulties and his cognitive impairments presented some

complications for him and for his parents, as it seemed that they did not always understand each other clearly.

As the oldest of those visited and the person who was least intellectually impaired, there were many examples of Asad as a young person who had a strong sense of himself as a developing subject. He had a clear wish for an 'adult' identity and this was expressed through his signing for material objects and possessions to which he aspired; mobile phone, car and money. Asad therefore expressed his view of himself and his aspirations in a grounded, materialistic sense, perhaps reflecting a very solid, determined internal view of himself as a young man to whom certain respect and possessions were due.

Turning to Asad's external objects and how they responded to his grounded, embodied view of himself as an adult subject, I found that his parents were not always sympathetic to his view of himself. Following one of Asad's assertions about his material aspirations in adulthood, for example, they laughed in an awkward, embarrassed manner, following this with a despairing reference to his limited potential for ever achieving a degree of independence.⁷⁴ The parents' ambivalence towards the idea of their son as having an adult subject status and the difficulty Asad faced in achieving this will be looked at later. Before this however, it is important to reflect on the social environment in which Asad found himself.

As a young man leaving school, the social domain of adolescent development was of particular significance. It was said earlier that the social world in which young people live imposes certain attitudes and values which impact upon their internal, personal and external objects. One significant element of Asad's social world was that represented by the further education college which he joined while I was observing him.

The curriculum at the college emphasised Asad's need to develop skills for independent living (travel training and cooking were mentioned). His parents however appeared ambivalent about his acquiring these skills and they described how they had gone to some lengths to prevent Asad from learning to travel more independently. This they did by

⁷⁴ Details of this are to be found in chapter five.

campaigning for council funding to taxi him to and from college each day in preference to his having to learn to take a public bus. Risk was a key concern for the parents. The outside world presented many fears to them and they were not prepared to allow their son out of the home area without his being accompanied at all times.

One aspect of the risk the parents felt attuned to in regard to Asad might have been to do with fears of racist attack, particularly given anti-Muslim feeling abroad in British society at the time of the observations. I do think there was more to it than this however as the parents seemed aware of the unevenness of their views on helping their son to become more of an independent subject; in fact this issue seemed to cause them distress (literally 'a headache' for Asad's mother in visit four). Asad's difficulties in speaking became the focus of the problem for his mother. I conjectured that it was perhaps his cognitive difficulties which were more of a concern to his parents, yet this did not appear to be discussed so openly. Mr Mohammed seemed to emphasise Asad's achievements, for example his school certificates, while it appeared to me Mrs Begum found his learning disabilities difficult not to denigrate. Asad contributed to this parental split, by dismissing his mother's worries for him by 'swatting' her away from him. This picture was further complicated it seemed by the memories of Asad's life-threatening illness as a young child, which were never far from the surface particularly for his father. Not all elements of adult subject status were however out of Asad's reach. While he had been reluctant beforehand, Asad's parents proudly announced to me that he had kept the Ramadan fast. This symbol of adult identity, which was important to the parents, was achieved by Asad and he was praised and he received respect for this.

In all, there was a mixed picture for Asad in terms of his developing subject status. He appeared to have a view of himself as a competent, proud young man, but the parents did not feel able simply to support this view of his identity because of the worry they felt for their son, as a vulnerable person with a severe learning disability. They held him back in a protected, younger child position at times, making him 'subject to' their parental control, occasionally even resorting to physical chastisement to keep him in line, as was suggested towards the end of the case study.

I conjectured that it was exhausting and despairing for them to maintain this caring role, as both parents used my presence as an observer to express some of their feelings about Asad's dependency on them and their fears for the future. There was, I thought, a magical hope that someone would appear in the future to marry Asad and to take care of him. They were fearful of the future when they would no longer be able to care for him and perhaps they suspected that though they had offered, Asad's siblings might not after all be willing to take him in. The dilemma of how Asad's sexuality needs might be met therefore seemed intrinsic to this plan for marriage, although not mentioned directly.

Considering some concluding thoughts about Asad's developing subjectivity, it appeared that he had a strong sense of his own identity, but that this was limited by his simplified view of adulthood as a state when he might have certain marked-out material possessions. In this, Asad was not so dissimilar from some non-disabled young people entering adulthood. As Jones (2006:9) shows:

It is very clear from research young people may share among themselves sets of aspirations (such as for a good job, good income, house, family and car), but they do not have a common set of methods (or even sense of method) for achieving these.

Like many of his age-group Asad had ideas of where he wanted to be, but not how to get there.

In contrast to the situations facing the first two young people described, Billy and Daniel, Asad's family seemed less directly affected by individualising and privatising forces of late modernity, with the pressures these bring for parents to become experts in their children's care in the isolated circumstances of their homes. The Mohammed family adhered strongly to the religious and cultural practices of the Bangladeshi community in relation to their care of Asad, relying on the extended family generally and when times were really hard (as when he was seriously ill as a young child). Asad's parents, in

common with this view, do seem to struggle with the idea inherent in the social model of disability approach that independence is necessarily a good thing⁷⁵. Asad is clear he would like more independence than his parents are willing to allow, an aspect of his identity which contact with mainstream British society at college would be supporting through its emphasis on self-help skills such as travel training. In this way, Asad and his parents are struggling in opposite directions, in common perhaps with many families from more collectivist, family orientated cultures than the mainstream British, individualistic culture.

d. Carly: an unformed and unknowable subject

Commencing with her personal domain (her embodied, physical self) I found Carly to be of mixed Chinese and white British heritage and fourteen years old at the beginning of the observations. I noted in my first observation that she appeared to be tall for her age, her hair was long and that she wore pretty, feminine clothing. She showed the secondary sexual characteristics of breast development expected for her age group showing her to be progressing through puberty. Carly was the most disabled young person that I visited during the study, Angelman syndrome having brought about severe learning disability as well as significant physical impairment. She was a wheelchair user and like Billy in the first family, Carly's home was adapted to ensure that she could be moved safely about from her downstairs bedroom/bathroom to the kitchen and living room areas.

From observing Carly, it seemed to me that there were moments in which her individual subjectivity and selfhood emerged. These were fleeting however and more than any other of the young people, I was left with doubt as to the extent to which she was able to make sense of the world around her. I had learnt that Angelman syndrome could affect Carly's emotional presentation, with hysterical laughter one manifestation of the neurological impact of the condition. Therefore it was difficult for me as an observer,

⁷⁵ Bywaters et al (2003) have suggested from their research into Southeast Asian families with disabled children, living in the United Kingdom, that many remain unaware of the prevalent values of the disability rights movement, for example the idea that disability is a social construct. Read (2006) cites research by Hussain, Atkin and Ahmad (2002) which shows that South Asian parents and young people do not share the same aspiration for independence that white families are said to.

accurately to un-pick her emotional state, though her mother's agreement to allow me to observe while she fed Carly enabled me to identify patterns which emerged over time and to begin to see how the parents understood their daughter.

Although there were significant cognitive difficulties faced by Carly, she presented as a young person who experienced a wide range of moods and embodied physical and sensory experiences. I observed her on the first visit, to enjoy holding and banging hard wooden objects on her wheelchair tray for example. There was a sense of Carly bashing-away to get something out of her system, to express some hard and angry feelings. Certainly her mother seemed aware of this, warning me to keep out of her way! She was also observed to bash her arm on the tray and this led to questions from the parents about just how much Carly could feel or sense pain.

Carly appeared, like Daniel, to experience her world in a very embodied, sensory way. One example of this was evident in visit six when Carly engaged in genital stimulation responding to the new physical sensations experienced with her changing adolescent body. Carly was sitting on her father Richard's lap when this was happening and I remember noticing how the sexual undertones of the moment were banished necessarily from mind in a kind of distancing or denial process. So parents have to 'disaggregate' parts of their teenage learning disabled child (in this case the body from the mind) in order to care for them with sensitivity to the varying levels of physical, emotional and sexual development they require. Some of Carly's behaviours may also have been giving her the experience of pain, such as when she bashed her arm on a hard wooden surface. This sensory stimulation was something she seemed to want to repeat.

Some of the self-stimulating activity engaged in by Carly had the potential to be self-harming in nature. Carly's parents described a difficult episode during my second visit when they had taken her on and off the school bus several times that day to clean her up after she had vomited, only to give up in the end, keeping her off school for the day. It appeared that it was not always a simple matter for the parents to distinguish occasions when a sickness episode was brought about by a specific infection from those which

represented self-inflicted, stimulatory activity. For example, on the sixth visit, I observed Carly pushing her fingers far into her mouth and the parents seemed aware that she might make herself sick.

This introduces the theme of just how much volition lay behind Carly's behaviour and what the behaviour meant to her parents as her 'external objects'. Having volition or control over her own choice of actions, might imply that Carly enjoyed a degree of subjectivity; a characteristic of developing adolescent identity. Sally and Richard, rather like Billy's parents, appeared uncertain as to the extent of their daughter's subjectivity. As in the first family, the Andersons, it seemed that uncertainty in this area led to the parents speculations as to what their daughter was experiencing. On the one hand, the parents projected feelings into their daughter about her wilfulness⁷⁶, but on the other there were examples, as with Billy, of the parents 'switching off' to the possibility that Carly might be subjectively experiencing⁷⁷.

A distinction could be drawn between the ways in which the parents in the Davis family seemed to be dealing with the uncertainty of Carly's status as a subject as compared to the other families. In Daniel's case the parents seemed to be struggling with how to encourage their son to become a subject, while in Asad's case the parents were trying to control and limit his ability to develop as a subject. Billy's situation had more in common with Carly's as he was felt to have a partial and fragile subjectivity. Yet in Carly's situation, the parents appeared more willing than Billy's parents to accept that there were limitations on how much they could know or come to understand their daughter's sense of her own identity. They seemed to draw a line, accepting that they could not know what was motivating her behaviours at times; whether these were driven

⁷⁶ Richard had let me know in the first visit for example, that Carly was capable of withholding co-operation, even when it was not in her interests to do so, thus implying that he was aware of a 'bloody minded' streak in Carly's personality. The discussion of Carly's food refusal in the case study also suggests that she may have been asserting her wish to reject overwhelming unconscious projections from her parents.

⁷⁷ To illustrate this point, the parents seemed to stop attempting to understand or to apply meaning to Carly's behaviour in the sixth visit, when she vomited-up her meal, so laboriously fed her spoon-by-spoon over the previous hour.

by the desire for sensory stimulation or more conscious decision making and subjectivity. In this way, Richard and Sally did not seem to project their unconscious anxieties so actively onto Carly's psyche in the way I had seen with Billy for example.

It was indicated to me that the parents were living with the sense that their daughter was an unformed and unknowable subject as I became aware of feelings of despair during the observation experience. I felt for a moment the purposelessness of Carly's existence and I felt aware of the arduous nature of the caring task for Sally and Richard⁷⁸. It appeared to me, while trying to reflect closely on this experience, that the couple managed these difficult emotions by limiting their expectations for Carly and for themselves. The parents seemed able to be resilient partly because they had faced the worst reality of the damage done to Carly by her impairments, while being able to enjoy her presence for the moments when she could reciprocate with positive feelings (as when I experienced her smiling at me). This enabled them to reflect clearly on their situation and to see how others in the wider social world viewed them, without the level of blaming I had seen in Billy's family for example.

It appeared to me that recognition of the reality of their situation as carers for Carly brought feelings of despair, but it also made them resilient as they were able to stake a claim for reasonable support from the social agencies which were there to help them in their caring role. The couple was therefore able to recognise their own needs for time away from their caring role too and the importance of regular and reliable respite breaks seemed vital once I was able to consider this.

The situation of the family, as with Billy's and Daniel's mentioned earlier, again seemed to be that caring for Carly, whose needs are considerable, was undertaken in the very privatised domain of the family, sequestered away from the mainstream. The parents have developed a high degree of technical expertise in providing the care Carly requires, but there is little sense that from the wider social welfare system that the parents feel

⁷⁸ This is described in some depth in chapter six

‘cared for’ as carers. A story is told of struggle with the professionals for every aspect of Carly’s needs to be met⁷⁹.

A very positive aspect of Carly’s social life was the school she attended, offering her as it did a wide range of stimulating activities⁸⁰. As with the other young people observed, school seemed to perform an important role, enabling her to have a lively, stimulating experience, with teachers and staff able to hold her interest in a manner which was sustaining both to her and to the family.

Carly’s adolescent development took a different form to those of the other young people observed. Her impairments were significant and she engaged in self-stimulating, sensory activities, some of which could be described as self-harming in nature. While Daniel could be seen also to enjoy sensory activities in a very embodied fashion, he was able at times to be drawn from this level of consciousness to a more socially engaged state of relating to others around him. In Carly’s case, it was harder to discern just how far she was able consciously to relate to those around her. The parents, who appeared fairly isolated and at times despairing, occasionally tired of the attempt to make sense of their daughter’s responses, making her, to an extent, an unknowable and unformed subject.

e. Summary of findings relating to the formation of subjectivity

i. Living with the reality of partially formed subjectivities

It is a key finding of this project that the young people observed were all found to have identities which were significantly affected by the experience of severe learning disability. Each young person displayed a different form of impairment in the development of a subject status when thought about in relation to the psychosocial model of adolescence set out. Billy revealed a partial and fragile subjectivity as he moved

⁷⁹ For example Carly’s overnight breaks had to be planned a year ahead in order to ensure a place was available in the over-subscribed respite centre.

⁸⁰ In visit six, Richard allowed me to look at some photos of Carly at school which had been prepared for her last school review meeting.

between more conscious, engaged states of mind in which his feelings were discernable, to times when he was cut-off and less knowable to his parents. Daniel seemed to resist the process of becoming a subject, preferring to lose himself in bodily sensation and repetition. For Asad, a stronger subjectivity emerged, but one which was attached firmly and simply to concrete and material manifestations of an adult identity. Lastly, Carly was able to communicate powerful emotions, yet she remained partially unknowable to her parents due in part to her cognitive difficulties which led her, rather like Daniel, to appear immersed by bodily sensation.

When the social domain of adolescent identity development was considered in relation to the young people and their families, each was found to be affected in different ways by the individualising tendencies of late modern society, with class and culture playing a major role. Asad's family remained firmly connected to the more collectivist values of Bangladeshi culture and while Asad had aspirations to greater independence, this goal had a different meaning for his family than for the others. Billy's family, who were from a working class background, were closest to this patterning, as his parents expressed upset that he could not make a slow and gradual transition of dependence onto others in his young adulthood. The services on offer, so they had been told, were not able to manage such a gentle transition. Billy's family and particularly those of Carly and Daniel were characterised by their more privatised form. Parents in all the families had developed great expertise in recognising and meeting the needs of their learning disabled child, often carrying out technical, nursing and behavioural management programmes which are far beyond normative parental roles and expectations. The parents of the two young people with the most severe learning and physical disabilities (Carly and Billy) seemed most isolated and although they were both in receipt of support from welfare services they described their relationships with professionals in terms of their need to battle and to campaign to get what was needed for their child; in other words they did not appear to experience what was on offer from the state as containing, supportive or emotionally engaged with them in their caring roles. Daniel's parents were unusual in that they were better off which appeared to enable them to have greater control over the support they received, mixing as they did private and state funded support.

ii. Disrupting simplistic dualities: dependent and independent identities

The young learning disabled people involved in the study were found to have incomplete development as subjects. However if we draw on what is known about normative identity development, 'incompleteness' can also be seen to feature. A significant proportion of young adults remain in close, often dependent states with their parents for longer than was traditionally thought (Jones 2006; Thomson et al 2004) and as has been suggested, we all remain only partially located in adult subjectivity (Cahn 1998).

Through the previous analysis of the case studies and of emergent ideas on the development of subjectivity in the young people observed, there were key findings which disrupt a simplistic split between notions of dependence and independence. Such ideas therefore show the experiences of learning disabled young people as continuous with the mainstream population, supporting the notion that identity is not as fixed as might be thought. By way of illustration, there were significant examples in the case studies of parents and siblings being in receipt of warmth and emotional contact which emanated directly from the disabled young people⁸¹. In this sense then, love and care are shared within the family and do not flow only from the carer to the cared-for person (Olsen & Clark 2003), but in many different directions; ideas about just who is dependent on whom are up for discussion.

While there are greater continuities between them than might have been thought, it would be wrong and over-simplified to say there were no factors which differentiated the families in the study from families without learning disabled members. There are very significant additional caring tasks both physical and emotional for the parents and siblings concerned in these families, where cognitive and physical impairments in the young people impacted upon them in such a way as to influence their capacity and potential for learning and development in the future.

⁸¹ Billy and both of his parents in the first case study shared warm, close contact with each other. Daniel in the second case study responded positively to his brothers' wish to play with him. Asad in the third case study took a responsible, avuncular role with Samir. By simply offering me a smile, Carly in the fourth case study enabled me to feel warmly towards her.

Different models and ideas have been expressed to account for the response of families to having a child with a learning disability and often these incorporate notions of loss and bereavement; loss of the wished-for child and attempts to adjust to current realities (Emmanuel 1997; Rafael-Leff 1993, in Bloom 2005; Simpson 2004; 2005)⁸². This sense of loss may also be projected forward in time by parents too, as they consider how they may be placed in a role as ‘perpetual parents’ (Todd & Shearn 1996) well after they had imagined they might move on from this state as their child might have been expected to leave home.

These models imply that it is necessary for the parents of severely learning disabled young people to mourn and to cope with a situation of ‘chronic grief’ in their everyday lives. It is of interest, in terms of the opportunity offered to an emotionally-engaged observer, to consider the mechanisms which make living with such complex feelings possible. There were many chances during the observations, to notice and record the apparent impact upon those surrounding the young learning disabled person of living with significant learning disability in the family. In particular, a variety of defence mechanisms were in use in the families and it is to this subject that the discussion now moves.

4. Considering the role of defence mechanisms in the families observed: coping with complex, long-term dependency

My intention on commencing this research was to enter the field of the families concerned, to observe and to engage emotionally with the conscious and unconscious experiences of the young learning disabled people and the others in their households in order to learn about those young people and their adolescent development. Through my previous work experience with disabled children, I knew that often there were powerful emotions at work within the families. As a professional, I and others I knew had often been at the receiving end of intense feelings from family members and it seemed that the

⁸² These ideas were looked at in terms of ‘primary disappointment’ in chapter one

role of professional as a 'container' for such feelings was an important one, although I found this was not often talked about in any official textbooks available to social workers. It was with these thoughts and memories that I commenced the observations of the families.

When considering the emotional landscape of the families observed, the description offered earlier in the case studies and the discussion of these particular elements here, is anchored by ideas from the theory and practice of psychoanalytic psychotherapy; particularly those of Klein in her development of the notion of the mechanisms of defence. The existence of defence mechanisms in the families should not be seen as pathologising; in psychoanalytic thinking these mechanisms form an essential component of human emotional functioning and as such they would make an appearance in most people, some of the time. They can in this way be seen as protective, enabling people to cope with deep seated anxieties intrinsic to the human condition. As Jacobs (2004:104) puts it, defences:

...serve a definite and, in some ways, positive purpose because they protect people either against feelings which are too strong and threaten to overwhelm them or others, or against the self-criticism of a punitive and persecutory super-ego...

Simpson's (2004; 2005) perspective, as detailed in chapter one, is that in the families he has worked with who were referred for therapeutic help, there is a tendency for these mechanisms to make an appearance because of the particular constellation of emotional responses that seem common to parents facing the stress of the discovery of learning disability in their child. Considering the role of the defences in the families who took part in the research project and who were not in a state of crisis but were living normally with their severely learning disabled adolescent, may then give a clue as to the development and usage of effective coping mechanisms in families with learning disabled young family members more generally.

a. Theorising blame and idealisation

i. Defining terms

One of the common features of the four families observed was that of the conscious and unconscious expression of the emotion of blame. The tendency to blame others is closely linked within psychoanalytic thinking with the notion of projection. For Laplanche and Pontalis (1973:349) although projection is shown to have a variety of meanings in psychology more broadly, within psychoanalysis, it can be defined as:

...operation whereby qualities, feelings, wishes or even 'objects', which the subject refuses to recognise or rejects in himself, are expelled from the self and located in another person or thing.

Klein's (1952) explanation of projection is that it constitutes one of the primitive defence mechanism, made use of in the first months of life and then in different forms as the person matures⁸³. Simpson's (2004; 2005) formulation of the impact of learning disability suggests that for parents, impairment or disfigurement in their offspring can arouse immense unconscious anxieties. There may be unconscious guilt for causing the disability and anger and shame associated with these feelings which are so socially unacceptable for a parent to express. Parents' mixed feelings towards their disabled child in many ways mirror the unconscious ambivalence of a wider society, which simultaneously both normalises antenatal testing and screening-out of impaired fetuses while offering radical medical interventions to keep extremely damaged babies alive at all costs; then later on, while extensive social policies are geared towards improving the life chances of disabled people (for example the Disability Discrimination Act 2005 and Valuing People, DH 2001) many families find the actual support on offer very inadequate (EDCM; DfES & HM Treasury 2007). Living in the late modern context of a society which purports itself to be humane and liberal perhaps inevitably involves such

⁸³ There was an account of the defence mechanisms involved in the paranoid schizoid and depressive positions in chapter one, along with discussion of the importance of parental containment.

contradictions and ambivalences and this constitutes the wider context or environment occupied by the observed families. Parents may remain extremely sensitised to the subject of disability or difference in society, immediately feeling projected upon or re-traumatised when in contact with professionals concerned with their disabled child (Klauber 1998).

ii. Experiencing blaming and idealisation in the families including the impact on siblings

One of the most powerful experiences of blaming or projection in the observed families occurred during the visits to Billy and his family, after he fell from his bed when with his agency carers. Billy's mother Maggie understandably felt angry and blaming of the carers who she felt would not own-up afterwards about what had happened. I too found myself feeling angry with them and with the professionals who did not seem to take the episode seriously. During a later visit, when I observed that Billy was left unsupported and at risk of falling from his seat on the sofa, I felt as though I was the only one at that moment thinking about Billy's vulnerable position and conjectured that intermingled with conscious anger for the carers, Maggie was revealing unconscious negative feelings about Billy.

During later visits, when Maggie was unable to leave alone the theme of her bad feelings towards the carers, it felt to me as though a wound was being picked at and kept open and raw. It seemed as though damage had been done both to Billy by his impairment of cerebral palsy and to her through experiencing and re-experiencing the trauma of discovering his impairment. The emotions involved seemed to be ruminated on, without any hope of resolution, in a form of 'repetition compulsion'⁸⁴. The relatively powerless paid carers were blamed and denigrated, as though they were merely 'hands' paid to help out, not members of a caring family system who might share in feeling responsibility and

⁸⁴ Laplanche & Pontalis (1973:78) draw from Freud's *Beyond the Pleasure Principle* (1920) to describe repetition compulsion as 'an ungovernable process originating in the unconscious...the subject deliberately places himself in distressing situations, thereby repeating an old experience' but without insight into its origins.

attachment. They then become associated in Maggie's mind with other professionals who failed to recognise the damage done; perhaps the damage of this current incident and that of the disability Billy was born with becoming unconsciously mixed in Maggie's mind.

As has been described earlier, caring for a young, non-verbal infant can be a reciprocal arrangement where the child signals feelings and the parent attempts to make sense of these, offering containing, responsive support and nurture (Klein 1952; Stern 1998). Billy however has long passed by a stage of infancy, yet he still requires sensitivity and the emotional attunement of his care givers. As he is not always able to respond by clearly signalling his feelings of love or distress the parents face the exhausting and confusing task of imagining his feelings for him to fill some of the gaps.

My observations of Billy and his family suggested that his parents were involved in this process of imagining and worrying for much of the time. This seemed to leave them in an anxious state of mind, feeling like inadequate parents. Simpson (2004:73) describes the way in which the defence mechanisms used by parents to ward off feelings of chronic depression form part of a 'melancholic state' which 'often hangs like a black cloud over the relationship between the parents'; a relationship which is at particular risk of failure, perhaps as in Maggie and Tim's case, 'through the weight of guilt and shame' which is unconsciously experienced. I conjectured that Catherine, the next eldest child, became the recipient of some of these negative feelings. Billy, who was so vulnerable and difficult to feel cross with, was therefore idealised as the 'good' child, while Catherine became the 'bad' and ungrateful one. This finding therefore helps to explain the range of experiences of siblings of disabled children which research has previously uncovered and which was briefly reviewed in chapter one.

Asad's situation is also illustrative of the ambivalent feelings which can arise in families where severe learning disability is present. In his case, the parents were able to voice very positive feelings towards their son and his achievements, tempered by a tendency to over-protect him for fear that an accident would befall him. The emergence of over-

protecting and idealising feelings for Asad may have been masking unconscious negative feelings towards their son; feelings which were not acceptable to voice. As in Billy's family there was much rumination by parents over Asad's situation. For Asad there was a question of how his dependency needs might be reconciled with his undoubted potential to achieve a state of greater independence; arguably leaving him rather stuck and without plans for the future.

iii. Despair, depression and resilience

It has been said earlier that Carly's parents showed some similar emotional responses to caring for their daughter to Billy's parents, but that there seemed a key difference. Richard and Sally appeared to draw a line with Carly, coming to a point when they tacitly agreed between them that there was no way of knowing what thought or meaning lay behind their daughter's behaviour at times. While in Billy and Asad's families, anxiety was projected (as angry or idealising feelings) into others within and without the family, the Davis' appeared to me to have more moments of despair, when they accepted the full impact of Carly's impairments and as an observer I experienced the rawness of these feelings (as described in chapter six).

It did seem to me that the couple, while experiencing despair at times, also had moments when they could ensure that they had breaks from caring without being overwhelmed with the feelings of guilt which seemed to prevent Billy's parents from having time away from him. Perhaps in this case, the capacity to feel despair is therefore related to a form of resilience; a recognition that one cannot be everything to one's child and that others outside the family should play their part too.

iv. Projective identification and denial

I was struck during the observations of Daniel by his father's parting comment to me: '*You don't know what Daniel has done to us*' as he described him as a '*tinder box*' ready to go off at any time (visit 17). While he had been cautious of me as a researcher in the

private sphere of his family home, Ian made sure I heard his view of his son before I left. This view highlighted Daniel's destructive potential and the delicate manner in which he had to be handled. Ambivalent feelings towards Daniel were expressed quite openly by his brothers who while they were observed once or twice during my visits playing with him, were also able to give voice to their hatred towards him, as detailed in the case study.

Kate, Daniel's mother, was devoted to the care of all her children, but it seemed that Daniel took up much of her time and her emotional capacity making it a struggle to balance everyone's needs fairly. Daniel's impairment in relating, stemming from his autism, seemed to me as an observer to be impacting upon his potential to 'object relate' as he attempted to merge psychically with those who he was close to. Daniel's use of projective identification was therefore different to normative, non-autistic functioning as he struggled against separating, differentiating developmental processes. One could feel quite bullied by him in his omnipotent attempt to get you to do his bidding; almost as though he saw your body and you yourself as an extension of his.

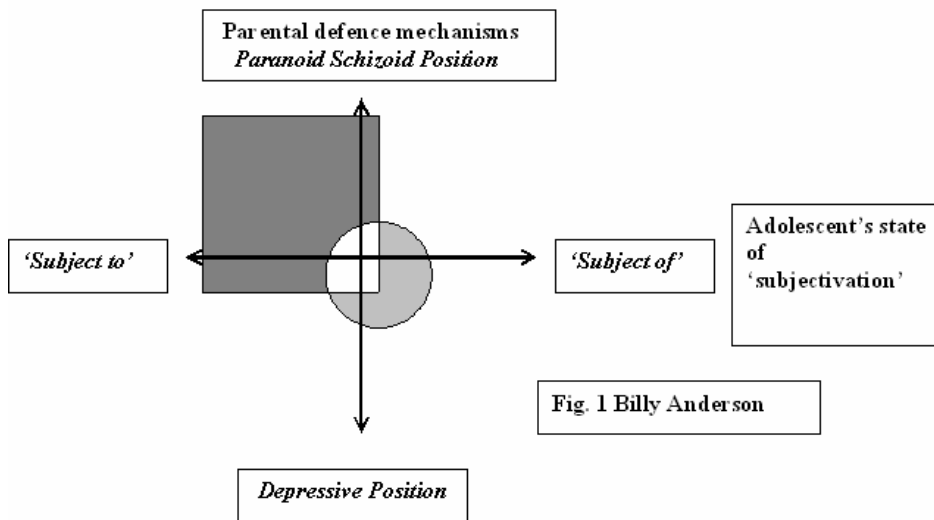
Given that feelings of guilt are said to be easily aroused in parents of disabled children (Simpson 2004) the temptation is often for parents to give in and to enable the eccentric, often obsessional behaviour to continue. By experiencing this form of projective identification with Daniel, one could mindlessly carry out his bidding. In a conscious sense then, denial is used by a parent to justify this; giving into him is the best way to an easier life. Ian, as an outsider to this close mother-son relationship, took an important role in suggesting that it was not acceptable for Daniel to continue this behaviour. He called a halt to Daniel's nakedness and to his blissful pursuance of repetitive, mindless behaviours. It was therefore necessary and helpful that he noticed the patterning of Daniel's relating and its impact on others, to enable change to take place.

5. Bringing together the notion of ‘becoming a subject’ and the defence mechanisms used by parents as ways of coping: relational maps

During the observations of the young people in relationship with others in their families, the development of case studies in the previous chapters and the discussion in the first part of this chapter, it has been possible to characterise both the young people’s subjectivity and the ways in which their parents employed defence mechanisms to manage the feelings which arose in the everyday task of caring. In the following, tentative suggestions will be made as to how these two features come together in relation to each of the young people in the study. These features have been mapped onto an axis to provide a picture, a relational image of each family. While these pictures offer a representation of relationships within the families, they also begin to highlight areas which professionals and systems of support might consider in their work with families with these kinds of caring responsibilities.

Billy Anderson

First, Billy Anderson (in figure 1) was described as a ‘fragile and partial subject’. On the vertical axis, movement between the two positions described by Melanie Klein (1952) the paranoid schizoid and depressive position is illustrated. In Billy’s case, his parent and main carer Maggie tends to employ projection as a means of dealing with anxiety, a feature of the paranoid schizoid position, with a resulting difficulty in achieving a more realistic, reflective state of mind about Billy’s impairments and the caring responsibilities she faces, including being able usefully to receive support. On the horizontal axis, is Billy’s movement between being ‘subject to’ and ‘subject of’ the internal and external aspects of the developing self in the process of ‘subjectivation’.



He was described as having a limited potential to achieve a subject status because of the degree of his impairments. The circle on the diagram represents the optimal area that the young people might achieve; that is enjoying a more whole sense of themselves as a subject, within a relationship of care with their parent and those assisting them (family and wider social welfare systems) which is characterised by acceptance. For Billy however it is not simply the case that the family view his potential to become independent as an ideal. Like Asad's family, the parents (who were of white working class British background) were ambivalent towards the idea of Billy moving away from him as a young adult and wanted this to be a more gradual process that the services seemed prepared to offer.⁸⁵

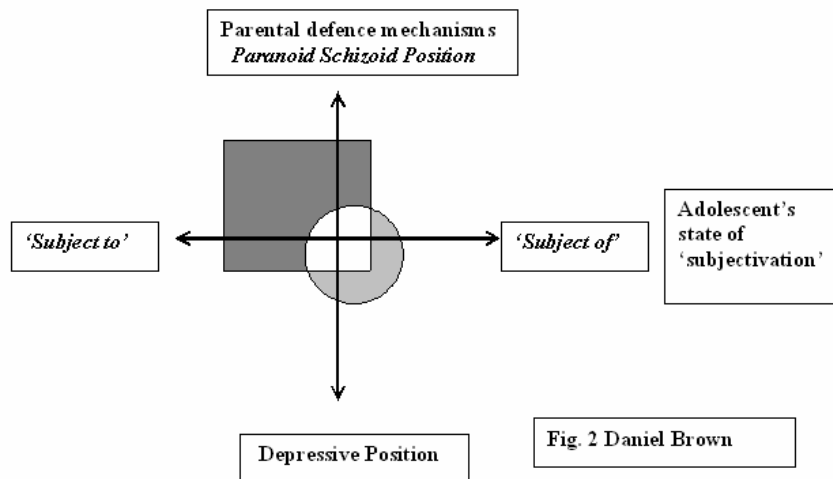
In Billy's case, the 'relational map' highlights the shape of a square, falling in the upper left quadrant of the axis. An aim of work with the family might therefore be to help move Billy and his family towards the lower right quadrant for more of the time. Clearly his potential to achieve an independent subject status is likely to be limited by his impairment, but the 'heat' of relationships within the family might be cooled somewhat if his parents were enabled to engage meaningfully with professional support which is both practical and emotional in nature. The diagram is not intended to blame the family or to

⁸⁵ This point was made earlier in this chapter where the meaning of independence for the different families was discussed in relation to the subjectivities of the young people.

suggest that finding solutions is all their responsibility; it is there merely to point out the areas which might be worked at by those in a network of care around Billy towards both enabling him to achieve his potential while his parents' and carers can feel well supported.

Daniel Brown

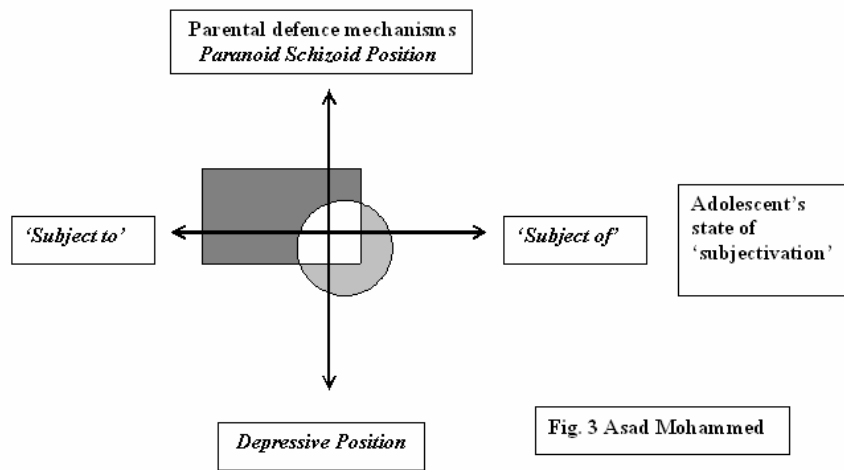
Daniel Brown was described as an 'unruly, un-integrated and resistant subject' (figure 2). In Daniel's case, his parents too were seen to project anxieties into those around them, although arguably this had a beneficial effect as they used me as observer to work out what they felt about their son's behaviour. Daniel was shown to have a greater capacity to become a subject capable of displaying more socially acceptable behaviour when his father intervened. For this reason, a rectangle is shown, which moves over further towards the lower right quadrant than was the case in Billy's above. Work with Daniel and his family might then continue to build on the parents' capacity to use professional support to reflect on their circumstances and to help find solutions to supporting their son in becoming more of a 'subject' in his own right.



Asad Mohammed

The third case study described Asad and his family and he was described as a 'frustrated, controlled and unknowing subject' (figure 3). He, like Daniel, has a greater potential to

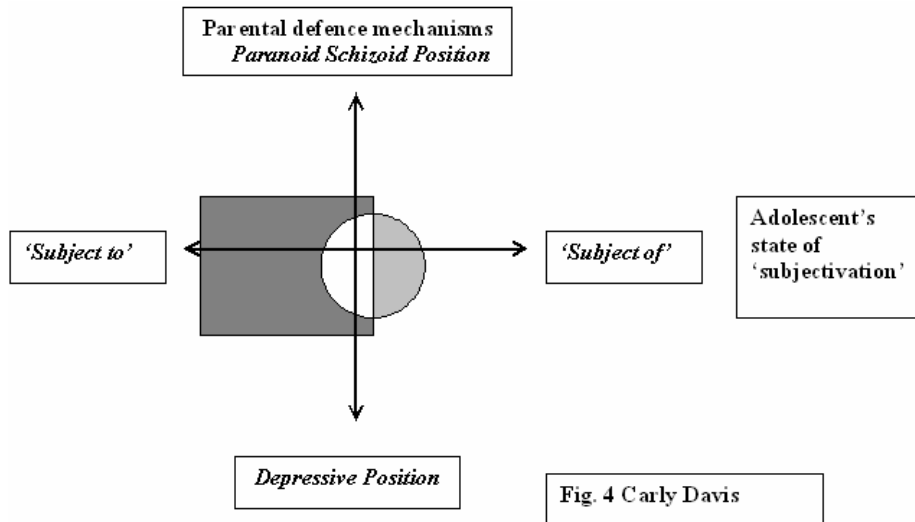
be a subject and though his parents, in the same way as the other parents so far discussed, project angry as well as idealising feelings into him and into others around him, they also managed to make use of the observer to make sense of some of their feelings about their son. This work might be built upon by professional support to encourage the parents to reflect further on the difficulties they and their son face, with an appropriate network of services to help. As with Billy and his family, there is not a simple wish for Asad to be independent of the family as this seems not in keeping with Bangladeshi cultural values. Opening up a discussion in this area might be helpful for Asad however, as it would be a way of showing his parents the conflicting ideals of Bangladeshi culture and the mainstream British culture to which Asad is exposed.



Carly Davis

The final case study concerned Carly Davis and her family (figure 4). Carly was described as an 'unformed and unknowable subject' She, like Billy, has a limited potential to achieve a subject status largely due to her severe cognitive difficulties. In the diagram the relational map highlights an area on the left hand side. Unlike Billy's situation however, her parents have been described as more able to accept the limitations of Carly's impairments and they appeared less prone to project idealising or negative feelings onto Carly or other family members. They also appear able to articulate their needs in terms of the support they need in caring for Carly very clearly. In their case,

professional engagement and appropriate advocacy might enable them to move back from the more despairing moments of the depressive position, nearer to the middle of the axis. Provision of a more generous, flexible package of respite care in the context of a supportive, engaged professional relationship would also help them with these issues.



6. Implications of the findings for social work practice and social policy

a. Considering Transition

The notion of adolescence as ‘transition’ came into being, to ensure that young learning disabled people’s experiences were understood in terms of the life changes that go with adolescence. In this way, instead of viewing learning disabled people’s lives as stagnant and without a sense of connection with others in the community, professionals and policy makers applied the template of ‘transition’ thus encapsulating the notion of movement towards a more adult, independent life stage. With this change in thinking, service planning gradually took on board the need to think about people’s lives in the round, including the need to plan for leisure and social activities as well as education and care (Valuing People, DH 2001; DH 2008; Williams 2006; Morris 1999).

Various aspects of policy and practice (including social, educational, employment and leisure opportunities) incorporate the idea of transition planning in the services available to learning disabled young people. A significant moment in service planning is that of the 14+ Review of Special Educational Needs (DfES 2001). To this meeting, key personnel are invited whose job it is to plan with the young person and their parents for the next life stage of the young person; into later adolescence and beyond. Upon the eighteenth birthday, social policy and statute impacting on learning disabled young people changes overnight as the provisions of the Children Act (DH 1989) make way for those under the NHS & Community Care Act (DH 1990) and recent moves towards the 'personalisation' of social care (DH 2008). Often with the aid of 'transitions workers' employed by welfare agencies, young people and their families have to navigate the complex task of making links with new services. These are styled around the notion of the young learning disabled person as an autonomous adult in their own right; family carers now more peripheral to the service planning and provision than was the case under 'Child in Need' legislation (Section 17 Children Act 1989)⁸⁶.

It might be supposed, given the complex range of factors impacting both upon the young person concerned and their parent-carers, that the idea of transition during adolescence and then sudden transformation from child to adult status at eighteen years of age, such as that which is incorporated in social policy and practice, is a difficult one to imagine for families of learning disabled young people. In the observed families, the concept of adolescent change tended to be focused mostly, where it was mentioned at all, around thoughts of the young person's physical development. The notion of adolescence as a time of emotional differentiation and separation and of sexual maturation was alluded to hardly at all (although Asad's case might be thought of as an exception).

⁸⁶ Aiming High for Disabled Children (DfES & HM Treasury 2007) recently began to un-pick some of the policy and practice complexities of transition to adult services for disabled children. By seeking examples of good practice nationally, the idea of 'transition teams' and 'transition champions' are recommended along with plans to improve inter-agency work, information for parents and overall planning. While no solutions are offered around the problem of the 'leap' into adult services, there is a welcome emphasis on person-centred planning for young people from 14 years on and the need to recognise that 'transition occurs at the appropriate time for the individual rather than at a specific point in time for all young people' (ibid: 41)

Recognition in transition planning therefore needs to be given to parents in terms of the care they offer the young person, not just physically but also emotionally. While such levels of involvement by parents might sometimes be labelled pejoratively by professionals as ‘enmeshment’ or over-involvement, it needs to be remembered that unusually strong emotional connections exist between learning disabled young people and their parents for very real and understandable reasons. To be critical of a parent who finds it hard to let go of their severely learning disabled son or daughter, would therefore risk the professional denying the reality of the strength of emotional bonds and the incomplete subject status of the young person too. This may be a real area of difference between young people with severe physical disabilities for whom provision of aids and adaptations may enable them to live more independently⁸⁷ and those who have severe learning disabilities who are likely to be extremely emotionally as well as physically dependent on their parents and carers. A sense of balance is required then, when professionals plan for independent living for young severely learning disabled people. The need for parents of young adults to remain closely emotionally involved (or perhaps the opposite, as they decide to ‘switch-off’ their feelings of parental responsibility) with their offspring is likely.

The interplay of the many factors which come together to form a severely learning disabled young person’s identity would suggest that planning transition services for young adults is therefore a complex task and one which should be carried out bearing all of these in mind. From this study, it can be seen that emotional bonds play a greater part than might previously allowed for. In addition to this however, broader psychosocial influences need also to be considered amounting to what Giddens (1991) describes as people’s ‘dispositions’. For some of the families in the study, dependency issues are not necessarily viewed entirely negatively, culture and social class having a mediating influence. Both Asad’s family and Billy’s do not therefore have a straightforward, perhaps more middle class British set of values which would lead them to aspire to their learning disabled adolescent living independently from them. The need to plan in a

⁸⁷ Morris (1999) describes how one group of young people with cerebral palsy (citing Spastics Society 1978) suggested it was their parents who needed counselling to help with issues relating to disability in adolescence, not them.

flexible manner is indicated, without the 'all or nothing' approach which seemed to characterise the transition to adult services that parents in this study had come across.

b. The Social Model of Disability criticised and implications for social work practice with severely learning disabled teenagers

i. The Social Model of Disability as 'horticulture'?

It appears that for the severely learning disabled young people in this study the development of subjectivity, such as that which is seen as the goal of normative adolescent development, is incomplete. This finding would seem to confirm the work of psychoanalytically informed researchers and practitioners who have stressed that the presence of a learning disability can have an impact on the development of personality. This might be, as Sinason (1986; 1992) showed, directly through the impact of cognitive impairment (as seemed illustrated clearly by Carly's case study) or it might also be as a response to how a learning disabled person is treated by those around them through secondary handicap (which Asad's case study reveals at least to some extent).

Such an approach to thinking about learning disability; that it has such fundamental influence on the sense of self; is a difficult one to take hold of. How is it possible to think about cognitive impairment and its impact positively when to have such an identity is so devalued in mainstream society and by learning disabled people themselves (Beart 2005; Harris 1995)? In a society which values individualism and independence to such an extent that these terms become synonymous with successful development, how is it possible to think about those who will always remain dependent on the care of others to some degree or another (Irwin 2001)?

I would suggest that the use of denial which has been described in relation to the observed families can also become employed strongly by professionals working in the field, by policy makers and academics when dealing with these uncomfortable feelings. Professionals may therefore deny the dependency needs of young learning disabled

people, led by policy makers who stress the social model of disability as the value base for working with those young people (Assessment Framework, DH 2000; Middleton 1996). The social model has as already been described, faced criticism for failing to take into account the mixed feelings that go with learning disability, along with other experiences of impairment (Morris 1992; Marks 1999; Shakespeare 2006). To an extent then, professionals and others who deny these difficulties, risk following the 'horticultural model' (Dartington et al 1981) which idealises learning disability.

Perhaps what is going on here on a wider societal level is a process of splitting. Learning disability is so unconsciously feared and hated that those feelings are split off, allowing only idealising, and positive feelings to flow towards those with impairments. While it is no bad thing to think positively about those who are vulnerable in society, the danger is that the negative aspects risk becoming hidden and unconscious. In this new model, families become idealised as the 'right' place for severely learning disabled children to grow up, rather than institutions. This cannot be argued against. Yet if families are isolated ('individualised') and left to cope with enormous demands alone and without social welfare institutions sharing this with them, they are likely to fail or at least to buckle under the strain. In the observed families, the negative impact upon relationships between others in the families could be seen. Siblings in both the Brown and Anderson families were seen to be under stress as were the parental couples in these families as well as the Davis'. The Mohammed's showed greater resilience in this regard, calling as they did on the help of their extended family in caring.

In a practical and technical sense, it is possible to suggest from this study that the existing value base for social work practice with severely learning disabled young people might be built upon to create a psychosocial approach. In this way the criticism which social workers operating in this area often face, that they lack the required communication skills to interpret disabled children's wishes (Morris 2002) might be, at least in part, tackled.⁸⁸

⁸⁸ Woodcock and Tregaskis (2008) have recently tried to address this area combining a social model and social work approach to considering the stresses faced by families caring for disabled children. They highlight useful points for professionals (listening to parents and containing feelings) but their approach still does not look beneath the surface in terms of intra-family emotional responses to disability.

While for social workers, the Framework for Assessment of Children in Need and their Families (DH 2000) provides an outline of relevant areas to consider while assessing severely learning disabled young people, as it has been possible to show here, identity formation can be seen to be founded on several components which it does not fully explore. In order to go beyond a superficial understanding of the teenager concerned, it might be possible to employ these ideas to improve the quality of social work assessments and this is an area to be explored next.

ii. Thoughts on assessing identity needs with severely learning disabled teenagers: areas to include

In order to adopt a psychosocial approach, as in this study, several components of the teenager's developing identity or subjectivity would need to be considered. Firstly the assessment would need to give due weight to the young person's embodied physical self. Included here would be knowledge of the young person's physical development, including pubertal changes and the impact of any physical impairment. The probability that physical embodied aspects of the young person's identity will be of particular importance should be considered, given that sense-stimulating behaviour is likely to be present and there may be a range of responses by care-givers to this. Is this permissible or shameful for example, if it draws attention to a young person's sexual development?

Secondly, a young person's capacity to engage in communicating their emotions (to 'object relate') might be included. In this study, young people's varying cognitive difficulties had quite an impact on the degree to which they were able to communicate in an emotional way with their care-givers. Asad was relatively able in this regard, while Carly was less so, Billy falling between the two of them. Daniel's autism provided an atypical example of object relating; another variation.

In turn, the external object's response to the young person's emotional communications will also have an impact upon their identity development. How well is the external object

(often a parent-carer or perhaps a sibling) able to persist in tuning-in emotionally when the young person is not able to process emotions normatively? If it is hard work emotionally for carers as well as physically, what is the fall-out for the rest of the family, including siblings and partners? What is the parent-carer's attitude towards their well-being and their own need for rest and recuperation? Are they able to imagine time away from the young person and what does their attachment style reveal (Howe 2006)?

Lastly, the wider social frame can be included in the assessment. How do factors such as class and culture impact upon family views on the needs and aspirations of the young person and do these favour the notion of increased independence or not? Is the young person able to benefit from lively educational and leisure activities, so as to reduce social exclusion? Is local, regular and good quality respite provision available (including the opportunity for over-night stays)?

iii. Techniques:

Clearly a mixture of techniques can be drawn upon to develop a social work assessment of a severely learning disabled young person. These would include using any kind of electronic or manual communication system they might employ and working with someone who knows them well to 'interpret' the young person's responses.

From this study, it can also be added that putting aside time to do emotionally engaged observation of the young person with their parent-carer and with other key people in their social network is an invaluable component of the assessment process. It has been shown that much is communicated between parents and children in a non-verbal, unconscious fashion, but also that gaps in this can be stressful for carers as well as young people to manage. It was conjectured that a range of possible strategies or defence mechanisms might be employed to deal with the particular circumstances which can arise when the possibilities for emotional engagement are affected by cognitive impairment. Working with the defences then requires a particular approach to practice, which will be looked at next.

iv. Working with emotions: relationship based practice

One of the findings of this study was that in common with everyone else, parents of severely learning disabled young people employ defence mechanisms as a means of dealing with difficult unconscious emotions involved in caring. It is suggested here that understanding parents' emotional reactions and responses to learning disability is a key component of the professional role. The families in the study have shown a great capacity to deal with the practical and emotional stresses of caring, but it is clear that they all needed in different ways to receive support from outside welfare agencies to enable them to keep going; to keep them resilient.

It was shown that the process of blaming others, resulting from the use of projection as a defence mechanism, is quite normal for families under such stresses. Agencies whose task it is to support severely learning disabled young people and their families therefore need to be aware of the vital function they play in helping the family. This help has to be, just as the caring role is too, both practical and emotional in nature. From a practical point of view, families need a good range of services to provide parents and siblings with a well earned rest (as outlined in campaigns led by 'Every Disabled Child Matters') in addition to stimulating activities for the young people themselves.

Turning to the emotional function of welfare agencies, an equally important role is to be played as social care personnel help to care for the carers⁸⁹. A parent-carer who is rested and emotionally contained by support from professional agencies and other support networks, is in a better position to stay resilient and coping. This professional work may well incorporate some element of more traditional casework or relationship based practice by social workers (Howe, 1998; Harrison & Ruch, 2007; Wilson et al, 2008) or perhaps more formal counselling or psychotherapy if severe difficulties are faced in managing the emotions of caring.

⁸⁹ Waddell (1989) gives a helpful description of the professional stance to be taken by a social worker in her exploration of the idea of 'serving' rather than 'servicing' clients.

Ian Craib's (1998) work on mourning is useful to refer to here as he rails against formulaic responses by professionals to individual's grief reactions; the cases he describes are those who are recently bereaved. Craib is critical of the traditional division of the grieving process into mourning, which is seen as following a predictable, 'healthy' process, and melancholia which is not. Freud, Craib shows, saw mourning as a process by which an individual socially withdraws, concentrating energy on the lost one. Gradually, with repeated reality testing, feelings are withdrawn or de-catheted from the lost one until eventually a new love object can be found. By contrast, melancholia is seen as pathological. The mourner identifies with the person they have lost and directs criticism and anger felt for them, back at themselves. Hostility is then directed at the self instead of the loved one. The idea that many parents of learning disabled young people are experiencing this kind of melancholia was described earlier (Simpson 2004; 2005) and a similar understanding has been applied to the experiences of parents and close family members of people with severe and enduring mental health problems (Jones 2002).

Craib's perspective is helpful however, as he suggests that by drawing on the ideas of Melanie Klein, the ambivalent feelings involved in complex grief reactions can be seen to be the same as any other form of personality pathology and not necessarily particularly to do with any prescribed grieving process. This shifting of perspective then enables therapy and professional practice to focus on the particular and individual characteristics of someone's grief reactions. This work should be 'authentic' Craib argues and this may mean that the patient or client chooses not to move on in their mourning. It may be acceptable that the person does not want to achieve happiness and creativity and in terms of the professional role: 'we can help the person to suffer' (Craib: 166). These ideas can apply to the situation of the families researched in this project. They help show that professionals should be wary of trying magically to improve the situations of families when parents are caring for children for whom they have understandably ambivalent feelings. The opportunity to have an emotionally receptive observer in many cases helped the parents to reflect on their relationships with their learning disabled adolescent and others within the family. This containing function is arguably a forgotten, but vitally

important aspect of the professional role which often allowed painful feelings to surface, but sometimes also small movements and change occurred in helpful ways.

In rare and extreme circumstances, child protection situations can arise if such emotions are not actively worked with or are not containable, as the parent's unconscious feelings of hatred can be acted out onto the child directly through physical abuse or through more unconscious emotional abuse or neglect. Given the relatively high incidence of child abuse experienced by disabled children compared to the non-disabled population (Miller 2002) an awareness of and training in how to work with the emotional dynamics of caring would seem particularly relevant for practitioners. Areas to be covered would include complex grief reactions and how common defence mechanisms can be manifested. Looking at the particular area of working with adolescents with severe learning disabilities, practitioners also need to have knowledge of normative models of adolescent development such as have been explored in this study, so that the young service user's own development can be understood in this light.

v. Working with systems, networks and organisations

The contemporary context for social work practice with disabled children and their families, in common with all childcare work in England and Wales, is for agencies to work in an integrated fashion. That is, since the arrival of the Children Act (DfES & DH 2004) services for all children are to be provided in a joined-up form as organisational boundaries and budgets are broken down into new, larger structures or networks. This has enabled the development of new Children's Trusts in some local authorities, where education and social care agencies have often amalgamated under one management structure and in some cases health agencies have also joined. Where management structures have remained separate, there is a duty to plan jointly and to provide services in an integrated fashion.

Another strand of child care policy and practice to impact upon work with disabled children and their families is Every Child Matters (DfES 2004). This statutory guidance

sets out common goals to be achieved for all children in England and Wales with a number of attendant practice and organisational implications. One particular area which had already been impacting on social work practice with disabled children and their families is that of the establishment of a 'lead professional' when Child in Need assessments are to be carried out under Section 17 Children Act (DH 1989). Families with disabled children and campaign groups have long asked for the development of the key worker role (DfES & DH 2004; DfES & DH 2003) for professionals working in this area. The aim of this is for one professional to take a lead in planning and co-ordinating services from the usually wide range involved in providing care for a disabled child, particularly in the early days following diagnosis. While it is hard to criticise social policy which has better integrated service provision as its aim, some have shown that there can be negative repercussions if the new forms of 'network organisation' are not managed in a thoughtful manner (Cooper and Dartington 2004). Applying this to the context of working with severely learning disabled teenagers, there are some issues worth considering in relation to the findings of this study.

It has already been suggested that the parent-carers in this study, who were often under considerable emotional and physical stress, appeared to benefit from experiences of emotional containment. Containment was offered by partners, paid carers, other family members, professionals and others in the social and emotional network (including myself as observer at times). Being held in the mind of another and having ones distressed feelings managed and 'digested' seemed to strengthen and support parents in their caring tasks. Given the strength of the defence mechanisms which appear to have been at work within all of the families observed, particularly the defences of denial, projection and idealisation, it is likely that professionals in the key worker or 'lead professional' role are often going to need considerable support themselves to work through these feelings with the parent-carers they are assigned.

While networks incorporating numerous relevant parties around the disabled child may form a vital working milieu for integrated service provision and emotional containment for parent-carers, organisational structures are still needed to provide a wider sense of

containment (or leadership) for practitioners and parent-carers. Placing too much responsibility on the shoulders of one professional, placed low-down in the organisational hierarchy, or far away on the other side of the network, is unlikely to enable them to practice in a containing manner.

On a related point, many agency carers who are bought-in to provide personal care for severely disabled young people have low status and an isolated position at the fringes of the network and this can be concerning. In Billy's case I witnessed over ten different carers visiting him through the six months I was observing and there were many times when the care was more of a hindrance than a help (see chapter three). In great contrast to this was the private carer, Sharon, employed by Daniel's family. She was able to provide such continuity of care that I once saw her take some cooking utensils from Daniel's mother's hands to complete a cooking task, neither she nor Kate having to say a word! Clearly much is to be learnt about what constitutes genuinely helpful paid care and also to discover how these low status workers can be supported too; to feel positive about their important role and a valued member of the nexus of care around the young person. More also needs to be done to make the option of taking Direct Payments from the local authority more straightforward, so that parent-carers can be enabled to find and employ their own private carers who best suit their needs, in a guilt-free manner, just as Daniel's mother Kate seemed able to. Wilson et al's work (2008: 32) highlights that the modern welfare state, with its emphasis on choice and access to opportunity leads to 'the "reconstruction" of the once "dependent" client of social services or patient of the health service into an autonomous customer who can make choices in the health and care marketplace'⁹⁰. This research has shown that whether it is through the influence of parent-carers' different class or ethnic and cultural backgrounds or simply more to do with their personalities, some are more able to make use of the available choices than others.

⁹⁰ The Commission of Social Care Inspection December 2005 (cited in DfES & HMT 2007: 41) illustrates this aspiration, by stating that 'people's expectations of social care are changing. In future, people will expect social care that enables them to live independently, that gives them choices, that are high quality and that leave them in control. For children, social care must support them and their families to make the most of their educational and life chances'.

In conclusion to this section on the implications of the study for social work practice and social policy, it is worth perhaps remembering the speed with which change has come about in professional attitudes and in wider society towards learning disabled people. It is only a matter of years ago that the large institutions began to close and that parents have been given the real choice to care for their severely learning disabled child at home, within their family instead of incarcerating them in one of the old mental handicap hospitals. It may be the case that the full implications of these changes for the young people themselves, their parents and families as well as for professionals involved in their care have not yet been thought-through fully. The families in this study were all coping well with the care of the young disabled family member, yet it may be a useful function to keep an adapted model of 'the institution' in mind in order to ensure that a proper, containing network of support is offered families for as long as they need it. Institutions were often reprehensible places, warehouses or dustbins for those forgotten and hidden from the rest of society. On the other-hand, a 'virtual institution' or network whose purpose it is to keep service users and their families and carers in mind, enabling them to opt in or out as they see fit with services provided as needed, could provide a good supportive model of professional care.

7. Reflections on psychoanalytically informed observation as a research tool, conclusions and new areas for research and practice

Returning to methodological issues, there were a number of reasons for adapting infant observation approach as a tool to carry out the research aims of this study. To begin with, as it was proposed that identity should be thought about as a psychosocial concept, the methodology was intended to explore an ambitious series of research questions (set out at the end of chapter one) capable of exploring the inner and outer relational ('psychosocial') aspects of identity as experienced by young severely learning disabled people. Traditional approaches to researching disability and childhood were seen as flawed as they depend on a 'thin' conception of the self and of identity; a view which minimises the emotionality and subjectivity involved. The debates which were uncovered, in childhood and disability research, were found to be preoccupied with rights

and ethics-based issues. In both childhood and disability research, academics are perplexed by how to research young people who are not fully constituted adult 'agents' in their own right; how should one communicate with young people to obtain consent (particularly when they have severe cognitive difficulties) and how should one make inferences about the information gleaned? Interesting though some of these issues are, focusing overly on rights and ethics detracts from what should be a more central concern of researchers; that is learning about people's lives in such a way that they will benefit.

Infant observation in its original form is used to sensitise therapists to the emotional and relational worlds of others, through developing their understanding of the workings of unconscious communications (Bick 1964). Given that psychoanalytic psychotherapists have emphasised the emotional intelligence 'left intact' in many learning disabled young people (Sinason 1986; 1992) it was thought that by using infant observation methods, it would be possible to gain access to emotionality and subjective experience of this group of young people. The method, it was hoped, would enable a 'beyond language' approach to research, in which the observer uses their own reflexivity to attempt to explore and to characterise the emotional experience of those observed in relation to their carers and families.

The reflexivity involved in observation of this kind is, I believe, its unique contribution to research. As an observer, I negotiated my entry to the families carefully and thoughtfully followed Bick's (1964) advice about the need to allow the parents to 'fit me in' to the household in the way they thought best. The approach involved making oneself as observer quite vulnerable to the emotional under-currents within families. The observer can become deeply involved in the emotional world of the family quickly, particularly when the family concerned is living in stressful circumstances and they have a need, perhaps an unconscious one, to communicate something of their experiences of this life

to others. The observer's use of self has to be sophisticated as boundary issues present themselves frequently⁹¹.

In the case studies, I have written as honestly as I can about the experiences I had with the young people and their families, including instances where I felt embarrassed, exposed or even used unconsciously by the families. These experiences often provided important insights into the emotional dynamics of the families and so rather than dismissing these moments, I tried hard to reflect on what was going on in order to make sense of things. Hunt (1989) looks at the importance of the transformation of role in psychoanalytically informed participant observation, suggesting that overstepping or changing ones role enables learning to take place in the research context. She discusses research in which 'transformation was particularly important because it facilitated empathetic understanding of the subjects' world of meaning' (ibid: 43). I needed help to think these instances through and so I would suggest that supervision and support of a researcher carrying out this kind of 'practice near' project is very necessary. Previous practice experience helped too, as this facilitates the capacity to contain and to stay with difficult feelings and situations which can arise rather than panicking or unconsciously retaliating.

Research which uses this form of observation presents the opportunity for ethical (by which I mean sensitive and respectful) practice that goes beyond a static, one-off appreciation of the issues. In order to maintain the observation relationship with the families, I had constantly to keep my role and stance in mind. In this context, ethical researching is a dynamic, developing set of concepts. There were times when I stepped back from observing when it became too uncomfortable for the parents (as in the Davis family) or for the young people, if they required privacy (such as when they might be receiving personal care or their behaviour warranted me giving them space). Following these practices enabled me to research in the intimate, private field of family life in a

⁹¹ Examples of this are when parents left their children with me (as in the Brown family) or when the young people's behaviour presented me with anxiety (when for example the young people displayed sexualised behaviour).

respectful manner and to investigate difficult yet vitally important issues of relevance to a disenfranchised group in society.

In terms of evaluating the method, observation was largely successful in enabling me to do what is rarely achieved; that is to place the severely learning disabled young person in the very centre of the picture. The method enabled the gradual emergence of different aspects of the young people's personalities and emotions over time, so the research could focus on their experience and then build upon this by looking at patterns of relationships within the families in micro-detail. Through observing, it became possible over time to begin to attempt to untangle some of the complicated threads that make up the identities of the young people observed; formulating ideas about the influence of the impairment itself, the child's personality and their social and emotional worlds, the role parents and siblings have in 'constructing' and giving meaning to the young person's identity and also difficulties and stresses experienced by the families which seemed significant. My observations at times ran counter to what other family members told me about the young disabled people, therefore providing a new and unique understanding of the research subjects' experiences.

In other dimensions, observation was not always so successful. In Asad's case for example, I found that it was a less appropriate methodology as he was an active young man who had to sit in a rather formal way with me during my visits. I found there was little room to manoeuvre as an observer so in the end we decided to use drawings as a way of helping us to communicate with each other in a more conscious way. Given his age and the fact that Asad was less severely learning disabled than the other young people, it might have been preferable to have negotiated that I observe him at a youth club or another more social setting. Having said this, Asad did not appear to attend many social activities apart from his Further Education College so observing him within his family home, including learning about his occasional frustrations with his parents, was a useful exercise.

One other limitation of this form of observation was that the data available to me was really only what came up during the observation hour. I did not interview the families formally, so pieced together knowledge of their wider networks only if these topics emerged during the session. Parents did tend to offer me information, but I had no way of checking the detail they provided (for example about what supports they were receiving from formal agencies). While this limitation should be taken seriously, I strongly believe that the observation method allowed a different quality and depth of learning than would have been available to me through more traditional methods of researching; interviewing and so on. On many occasions I actually had to dampen down what parents and family members were communicating to me, in my effort to make sense of the observation hour and so as not to be overwhelmed with information. From this perspective the method was not limiting, it was quite the opposite and as such it has something useful to contribute to researching 'hard to reach' and non-verbal members of society. Analysing the observations at a later date was a complex matter as there are many, many strands of experience which have to be explored, discussed and reflected upon and choices made about what to exclude. From this process however speculative findings can be presented, compared and generalised in such a way as to generate new knowledge about this rarely researched group of young people.

Taking the method forward: new areas for research and practice

In terms of my own learning from acting both in the past as a practitioner who has worked with severely learning disabled young people and their families and now as an observer-researcher, the importance of finding space to reflect and stay with the complex and difficult emotions involved in caring seems vital. Psychoanalytically informed observation has, it seems to me, the potential to reach out in two directions; both as a method to facilitate researching those who are non-verbal and whose views are not often included, as well as offering a tool for practitioners, with which they may be helped to uncover experiences and feelings of 'hard to reach' service users and their families, giving clues for the future about new ways of working in situations of long term need and dependency.

Considering first its potential for practice, Rustin (2006) highlights that infant observation method has therapeutic potential, describing work carried out in France where observation of young infants at risk has been extended beyond its traditional 'passive' role. A regular and reliable observer, who provides kindly attention to parents and child, has been found helpful and supportive; facilitating the development of the parents' ability to reflect on the child and the emotions aroused by the need to provide care. In the current study, there were examples too of parents finding the presence of an observer helpful, the reflective space opened up to re-think emotions and relationships of care and dependency in the families. Whether this kind of attention is paid by research assistants or as part of the relationship-based practice approach made use of by social workers and social care professionals described earlier, it would seem well advised as a method to inform practice with this group of young people and their families.

Thinking finally about the research potential of infant observation methodology, here too it has much to offer in the future. It is widely accepted that the numbers of severely learning and physically disabled adults are likely to increase in the future (DfES & HMT 2007) as are the numbers of the oldest cohort of elderly people, with the consequent rise in numbers of those experiencing dementia and chronic health difficulties associated with ageing (DH 2008). Questions of how to offer appropriate care and support to those vulnerable and dependent people as well as those closely involved in caring for them are becoming more pressing. In particular, the theme of what constitutes good, effective paid carer support requires further exploration as this was found to be so variable in this study; some initial clues offered as to the reasons for this. The observation techniques made use of in this study have therefore been found to be fruitful and it is recommended they should be employed further in the future. This study has shown that psychoanalytically informed observation provides a vital part of the researcher's repertoire and that it is uniquely placed to help uncover the subjective experiences and emotions of those who are highly dependent; dependent not only on individual carers, but also on wider social policy and welfare services for their well being.

Appendix

The Four Families Introduced

The case studies in chapters three to six are built around observations of four families. Brief biographical details on the young people and their families are provided here.

The Anderson Family⁹²

Billy is fourteen years old at the beginning of my visits to the family. He lives at home with his mother Maggie and his two younger siblings Catherine (ten) and Sean (six). Billy's father Tim is divorced from Maggie, but he still visits at least three days a week after school to provide childcare for the children. The family are white, working class British. Tim works as a milkman and Maggie is a full-time carer for the children.

The family lives in a housing association home, in a low-rise estate on the outskirts of a large southern English city. On arriving in the home, it is possible to see that the entire right-hand side of the ground floor of the house is adapted to provide Billy with an accessible bedroom and bathroom, furnished with a hospital-style bed (with cot-sides and a raising and lowering facility) and tracking hoist on the ceiling to enable him to be transported to the bathroom easily and safely. By contrast the living room and kitchen on the other side of the ground floor is a little cramped, although it has to provide space for the other four family members during the day. I was struck by the amount of physical space Billy needed to take-up within the house and the clinical or hospital 'feel' that his equipment brought to the home.

Billy has complex disabilities including cerebral palsy (spastic quadriplegia) severe learning disabilities, very restricted physical mobility and feeding difficulties. He also

⁹² Pseudonyms are used in the writing to ensure anonymity.

has some physical health problems related to kidney damage. Billy had a major operation some years ago, to correct his spinal curvature (scoliosis). He is not able to speak and he has a limited ability to communicate his wishes through some nodding and indicating his feelings with his eyes, though the parents do appear to find it difficult to interpret Billy's wishes and feelings. At school Billy makes use, at times, of a switch system. Messages are recorded on his behalf and he can strike the switch to make his message heard by those around him. I did not see the parents make use of this or a similar system at home.

Billy requires help to carry out all aspects of his daily routine. From the practical tasks of feeding, dressing, washing, toileting and moving from space to space in his wheelchair to social and leisure activities, he is largely dependent upon the care of others. Billy attends a local secondary school for severely learning disabled children, but otherwise receives care at home from his family. Pairs of council-funded carers visit twice daily to help with his practical needs (bathing, dressing and so on) Billy requiring two as he has to be carefully lifted due to problems with his back and kidneys. Billy has no regular overnight respite care arrangement, although he does usually go away from his family for a few days holiday in the summer school break. He has a local authority social worker who I did not meet while visiting the family.

The Brown Family

Daniel is an eleven year old white British boy at the time of the study, who lives with three brothers Peter, Andrew and John (twelve, ten and six years respectively) and his parents Kate and Ian. Kate gave up her teaching career to be a full-time carer for the children several years before and Ian works as a business man.

The family has their own, fairly large semi-detached house, in the suburbs of an English city. The house has been extended in every possible direction, to increase the space available to the family and there is a good sized garden at the back. It is on a moderately busy road in a residential area. The children each have their own bedrooms and there is a

large open-plan living area on the ground floor. In contrast to Billy's home, Daniel's did not need to have major adaptations or building work to meet his needs. The emphasis instead appeared to be on maximising living space within the house and securing the doors, windows and the fences around the garden to prevent Daniel from escaping.

The diagnosis of Autistic Spectrum Disorder was made when Daniel was three years old. He started special school at the nursery stage and as this research was commencing, he was preparing to transfer to a local secondary school for children with severe learning disabilities which has a unit for children with ASD.

Daniel has no speech and his autism takes a fairly 'classical' form, with the triad of impairments 'in social behaviour, impairments in communication, and the presence of stereotyped, repetitive behaviours' (Lewis 2003:248, describing the work of Wing 1976). He goes for short respite breaks at a local residential centre, every six weeks or so. Daniel's parents have recently located another residential centre which they pay for privately, where he goes for occasional stays during holiday periods, enabling the family to go away without him. Daniel attends some out of school play activities; otherwise he is at home with his family throughout the week. Daniel and his family receive support from a local authority social worker, who I did not meet during the research period.

The Mohammed Family

Mr Mohammed and Mrs Begum are from Bangladesh, having lived in Britain for over thirty years. The couple are in their middle fifties and Asad is their youngest of five children who is soon to have his sixteenth birthday at the beginning of the study. One older brother in his thirties lives with his own family elsewhere in the city while two other brothers live in the house, one of whom is married with two young children. Asad's seventeen year old sister lives at home too. The maternal grandmother also stayed in the home, although later on during my phase of visiting the family she returned to Bangladesh to live with other family members, having been here for many years; an illustration of the close bonds which remain between family members in Britain and

Bangladesh. In all then, there were ten members of the extended family living within the home; a surprising fact as the house they occupied was not substantial in size.

The family home is a housing association maisonette, in a row of modern properties set in an inner city area. The home did not require any special adaptations to accommodate Asad's needs. Nearby are large commercial buildings, supermarkets and offices. There is a pleasant and well maintained children's play park opposite the home, with a quiet paved area between.

Asad was a physically able young man just nearing sixteen years at the beginning of the observations, with Down's syndrome. His cognitive and communication difficulties meant that he was defined as having severe learning difficulties. He is however the most intellectually able of all the young people observed. Asad communicates using a matrix of spoken language, sign and gesture, including English and Bengali words supported by use of Makaton signing. I often found it difficult to understand his communications and it is the combination of Asad's learning disabilities with his language problems that make his needs complex.

At the beginning of the observation sequence, which lasted over a six month period, Asad was soon to leave the school he had attended for eleven years for a further education college where he was to study for the next few years. The college Asad was to attend had a curriculum which had been developed to accommodate the needs of young people with severe learning disabilities. Asad's father informed me that there were a number of Bangladeshi young people there so his son would be, he felt, amongst those who understood his needs. While I was visiting therefore, it was possible to learn about how the family and Asad in particular coped with the transition from school to a more adult-orientated college setting.

Asad did not make use of overnight respite services, although his father informed me that they sometimes travelled away for a week in the summer as part of a family holiday scheme for disabled young people from the Asian community. I heard that Asad

sometimes took part in evening leisure activities run by a society for learning disabled teenagers, though he did not appear to do this while I was visiting him over a six month period.

The Davis Family

Richard and Sally Davis are a married couple, in their sixties and fifties respectively at the beginning of the study, living at home with their daughter Carly (fourteen) and an older son, Ivan (twenty-two). Richard, who is a white British man, had recently retired from an academic post teaching in the sciences. Sally, a woman of South East Asian, Chinese ethnicity, is a qualified teacher who gave up work some years ago to care full-time for Carly.

The family lives in their own suburban home on a busy road on the outskirts of a southern British town. The house is neat, anonymous and well insulated from the outside world. Carly's specially adapted downstairs bedroom provides her with a bathroom en suite and a tracking hoist fitted to the ceiling for ease of transferring her from one place to another. Carly's room, like Billy's, takes up much of the space on one side of the ground floor of the house:

Carly, who is of mixed parentage, has Angelman Syndrome, which is a neuro-developmental condition characterised by severe learning disability, jerky movements and seizures. The condition is caused by genetic abnormalities of the same part of chromosome 15, often caused by a small deletion and it is unusual to find more than one family member affected. Children with Angelman have facial characteristics of a broad, smiling mouth, eyes that are deep set and a prominent chin ('Contact a Family' 2008). In common with other children with Angelman, Carly is unable to communicate verbally and she has severely restricted physical mobility. She relies on a wheelchair to move around and her parents make use of hoists and other equipment at home to transfer her from her bed to her chair or bath. Although children with Angelman are said to be of sociable, happy demeanour, the condition can also involve children being overactive and

excitable, with outbursts of inappropriate giggling and there can be difficulties sleeping at night (ibid).

Carly attends a local secondary school for children with severe learning disabilities and she attends various clubs and social activities after school on several evenings of the week. She has a carer to help in the mornings before school and Carly goes for approximately thirty-five nights of respite care away from home each year in a local residential respite care centre.

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