Title: Emotion and relatedness as aspects of severely learning disabled adolescents’ identities: contributions from ‘practice-near’ social work research

Abstract

This paper considers social and personal/individual approaches to researching severely learning disabled adolescents’ identities; suggesting that vital components of emotionality and relatedness are largely missing from research and consequently from literature informing social care professionals. This leaves untapped, rich information and communication resources for research which may improve understandings of the experiences of a socially excluded group of young people. A psychosocial view of adolescent identity development, ‘subjectivation’, offers a way forward and a case study on ‘Billy’, drawn from a ‘practice-near’ observational study, helps to illustrate this. Observation allows the researcher to be sensitive to the subtle ways in which severely learning disabled young people’s identities are constructed, often with a sense of fragility and uncertainty. Continuities of experience between the young people and the rest of the adolescent community may be seen, but also the impact of living with impairment can be thought about in relation to the particular psychosocial circumstances of each young person. Knowledge of these processes enhances social work practice by encouraging workers to be sensitive to, and healthily curious about, the multiple ways in which severely learning disabled young people’s identities are shaped in relationship with those around them and the wider social field.

Key Words

Social work, identity, adolescence, severe learning disability, psychosocial, relationship
Introduction

This paper considers social and personal/individual approaches to researching severely learning disabled adolescents’ identities, suggesting that vital components of emotionality and relatedness are largely missing from research and consequently from literature informing social care professionals. This leaves untapped a rich information and communication resource for research which may improve understandings of the experiences of a socially excluded group of young people. A contemporary psychosocial view of adolescent identity development, ‘subjectivation’, is proposed as a way forward. This theory considers how subjectivity develops in adolescence through inclusion of developing bodily conditions, relatedness with others and the social world, and personal emotions.

The paper commences with a brief critical commentary on themes in contemporary research on young learning disabled people’s identities and a case is made for adopting a psychosocial perspective. A model, derived from the four developmental domains described by the concept of subjectivation, is then applied to data obtained from a qualitative, observational study carried out with severely learning disabled young people in the context of their family lives, to provide an illustrative case study focusing on one of the young people, Billy. The technique of observation allows the researcher to be sensitive to the subtle ways in which severely learning disabled young people’s identities are constructed, often with a sense of fragility and uncertainty. Viewed in terms of relationship with significant others (parents, siblings, carers and outside agencies) some of the complexities of young people’s lives begin to emerge. Continuities of experience between the young people and the rest of the adolescent community may be seen, but also the impact of living with impairment can be thought about in relation to the particular psychosocial circumstances of each young person. These findings are informative for children and young people’s social care practice; not because they formulate rules to be followed, but instead they encourage practitioners to be sensitive to, and healthily curious about, the multiple ways in which severely learning disabled young people’s identities are shaped in relationship with those around them.
1. Setting the context: research on learning disability and identity

Severely learning disabled adolescents are more likely than most to be subject to the care and decision-making of others, due to cognitive impairment and lack of voice (often both literally and figuratively). Parents, carers and practitioners wrestle daily with the issue of how to ensure these young people’s wishes and feelings are central to planning their care to ensure wellbeing; professionals following the principles enshrined in policy and guidance (DH 1989; 2000; 2001; DfES & HM Treasury 2007) and more recent policy driving forward personalisation through provision of individually held budgets for families of disabled children (DfE 2011). More remains to be done however, to explore the identities of severely learning disabled adolescents in research (Stalker 1998; Stalker and Connors 2010) and in the applied literature available to social care professionals (for example Middleton, 1996;1999) so that their experiences can be better understood.

Psychotherapist Valerie Sinason (1992, p 7) who has worked extensively with learning disabled people observes that learning disability is ‘fluid state that people moved in and out of throughout the day’ and that emotional intelligence may be ‘left intact and rich’ despite cognitive impairment (Sinason 1992, p 6). Sinason’s view suggests that emotionality and relatedness are important communication resources which should be incorporated in learning disability research yet these perspectives appear to be largely absent. Part of the reason for disability research failing fully to engage with the emotions and relationality, it is suggested here, is due to conceptual debates on identity within disability studies which are dominated in the main by social constructionist ideas. This paper proposes that psychosocial perspectives which sensitively and ethically explore emotionality, drawing on non-verbal intersubjectivities (Hollway 2001) between young people, their families and the researcher, should be a clear aim within learning disability identity research to facilitate a more holistic understanding of severely learning disabled young people’s experiences.

Identity is an idea which has been described as ‘elusive and difficult to define’ (Wetherell and Mohandy 2010 p3); shifting and evolving as it is made use of in different contexts. In disability studies theoretical frameworks used to conceptualise identity have strongly influenced the direction of disabled children’s research. The idea of the social construction of disabled identities or ‘the social model of disability’ holds sway (Watson et al 2002;
Garland-Thomson and Bailey 2010). Some disability academics and activists have however challenged the prominence of social model thinking, suggesting that it leaves little space for personal, subjective and lived experience of impairment. The importance of ‘impairment effects’ (Thomas 1999) is highlighted as a criticism of the way in which social model thinking downplays and under-theorises ‘the body’ in disability studies (Hughes and Paterson, 1997). From this perspective, disability research should consider the intimate, subjective aspects of disabled people’s experience (’ontological’ views of identity), including painful emotional experiences of impairment and issues which might be raised by being dependent on others (Morris 1992; Beart 2005; Shakespeare 2006).

Attempts to write on personal aspects of disability have however been dismissed by some social model thinkers, who believe it reproduces oppression:

> Writers like Jenny Morris have elevated the importance of personal psychological experience in understanding disability. Such work encouraged a shift away from thinking about the real world. Finding insight in the experiences of discrimination is just a return to the old case file approach to oppression, wrapped up in social model jargon. (Finkelstein, 1996, p 6, cited in Walmsley 2001 p 199).

Thomas (1999) responds to Finkelstein’s criticism by proposing a social constructionist view of the emotions in which it is suggested that successful adjustment to impairment should not be down to individual personality factors. Psycho-emotional effects arise instead from ‘oppressive social relationships- which require their resolution not ‘adaptation’ of individual people with impairment to their ‘misfortune’, but changes in the social-cultural fabric’ (Thomas, 1999, p46).

While political dimensions of disabled identities are important, a theory impasse has resulted from this kind of debate which appears to have split-off learning disability research from making use of ‘depth’ psychodynamic perspectives which can help explore the important themes of emotionality and relatedness as aspects of identities. Other areas of research have been more open to inclusion of these themes (for example in childhood studies, Edwards et al 2006) but with the exception of Marks’ (1999) work in disability studies, who draws on psychoanalytic theory and practice in her writing, these perspectives remain unusual in the disability field. In a more general sense, division of this kind between
social and personal identity concepts, has ‘dogged identity studies’ for the last four or five decades in Wetherell and Mohandy’s view (2010).

The splitting-off of emotionality from learning disability research has reduced the potential for psychosocial theorising of learning disabled identities, including important reflections on the shifting nature of agency and subjectivity as it might apply to this group of young people. These ideas are potentially of great usefulness; able to inform the knowledge base for practice for those engaged in the complex task of assessing the needs (or ‘co-producing’ care plans with) those who through severe cognitive impairment, may find it difficult to speak for themselves.

2. The current state of play: ‘social’ identity research concerning disabled children, and psychoanalytic perspectives focusing on the emotions

Disabled children’s research, while it begins to include multidisciplinary approaches, (Watson et al 2000; Davis, 2000) tends to stick with views of identity as social in nature rather than including inner-world aspects which become available by including psychoanalytic theory. Useful findings (Watson et al, 2000) however include that disabled children describe experiences of social isolation, dependence on adults, but importantly also a sense that while young people may define themselves as ‘disabled’ other features of identity such as their gender, ethnicity and their personal tastes take precedence at different moments.

Although a relatively underexplored area, research also suggests that learning disabled young people’s experiences may differ from those of disabled young people without intellectual impairments. Stalker and Connors (2010), in a small study, find that children with physical and sensory impairments experience discrimination, but as they get older they are empowered to a degree by recognising that this emanates from other people’s attitudes and from limiting physical environments. In contrast young learning disabled people (and adults, Beart 2005), seem less likely to develop a positive sense of identity in relation to their socially devalued impairment. It may be that through having an ‘invisible disability’
children are ‘passing’ as not having impairment, as Watson et al (2000) also found. Recent participatory research carried out by Russell and Flynn (2010) with learning disabled adolescents finds too that social isolation is a continuing, even growing problem into young adulthood. Finding out about the emotional experiences of young learning disabled people in the transitional phase of adolescence would seem then to be an important objective for practice-related research.

Researching the emotions, by drawing on psychoanalytic principles, has largely been left to psychotherapists in learning disability studies. Criticised at times for seeming to fit within individualistic, medical model modes of thinking (Davis 1997) psychoanalytic psychotherapists have been bold in their accounts of work carried out with learning disabled young people facing emotional difficulties. Themes include: ‘secondary handicap’ (Sinason, 1992); the impact of learning disability on young people’s ability to separate and individuate in adolescence and adulthood (Miller, 1998) and; parental defence mechanisms, such as projection, denial and idealisation, which are said to emerge when learning disability is experienced in the family, (Simpson 2005). These theories have however been informed by therapeutic work with young people and their families who are in emotional difficulties. The ‘ordinary’ experience of living with learning disability may be more nuanced, so research needs to be done outside clinical settings too.

The current state of play is therefore that learning disabled young people’s research, while it now includes understandings of different aspects of identity, has not grappled strongly with how to research experience at any emotional depth. Learning disabled respondents may even be excluded from taking part in research as their responses are not always deemed ‘rational’ (Lesseliers et al, 2009). As Stalker (1998, p 5) has shown, research with severely learning disabled people is even more restricted: ‘Very few studies, for example, beyond the observational, have succeeded in eliciting the perceptions of feelings of people with multiple or profound impairments’. Psychosocial identity theories are looked at now, with a focus on adolescent development, as they offer the potential to add depth to research in this area.

3. Psychosocial views of identity and adolescent development
Psychosocial views of identity suggest that studies based only on the social are ‘thin’ in nature, missing the ‘depth’ of a range of psychoanalytic views of the psyche and inner worlds (Frosh, 2010; Craib, 1998; Hollway, 2010). Hollway (2001) is frustrated with social constructionist accounts of identity which, she suggests, fail to provide an account of human agency. Recently she uses Winnicott’s ideas to help theorise identity, to consider how ‘social forces become embedded in the person’ (Hollway 2010, p217). Hall too, locates identity psychosocially: for ‘the rudimentary levels of psychic identity and the drives’ and the ‘social field’, ‘the term identity...arises precisely at the point of intersection between them’ (Hall, 1996, cited in du Gay et al 2000, p 20).

Frosh (2010) shows that psychoanalytic perspectives offer identity studies helpful ways of considering key issues:

‘including the tension between an understanding of identity as something fixed (repressed ideas producing stable ways of being that are resistant to change) and of identities as fluid and multiple (unconscious ideas are variable, contradictory and partial)’ (Frosh, 2010, p 29).

He relates this to the shaping of adolescent identity; Erikson’s (1963) psychosocial model of adolescence representing the former, more fixed approach, with adaption of the ego to the social environment seen as task of the ‘crisis’ of adolescence (Frosh 2010). This kind of thinking informs the social policy idea of ‘transition’ for disabled adolescence (DfES 2001; DH 2000); that once majority is achieved, policy and practice sees the young person as a fully fledged independent adult subject.

A second, more contemporary psychoanalytic model of adolescent identity development, ‘subjectivation’, (Cahn, 1998 ) gives greater emphasis to the mutability of postmodern perspectives, theorising adolescence as more fluid and often extended in form (Jones, 2006). This model, which draws on object relations theory, sees young people as oscillating between different states of mind (Klein, 1952), social and bodily conditions. In one position, they are ‘subject to’ their own internal emotions (‘objects’), bodily conditions and their external objects; constituted by parents, society and the outside world. That is, their personal agency is weak and they are ‘subject to’ events and feelings in their lives; feelings often associated with puberty and bodily changes as well as developing sense of self. At
other times, when they achieve a greater sense of agency they can be ‘subject of’ these experiences, a condition which is associated with developing adult subjectivity. The process of subjectivation gradually leads the young adult to become a more settled adult subject, though following Klein’s ideas, there remain times when this falters and adults may be ‘subject to’ events and experiences in their lives (see Briggs 2008 for a fuller discussion).

Subjectivation potentially provides a useful model for thinking about severely learning disabled adolescents’ development in that it does not presuppose anyone as a fully formed ‘subject’ and it therefore allows for the shifting experience and presentation of learning disability, as Sinason characterises it: ‘a fluid state that people moved in and out of throughout the day’ (Sinason 1992, p7). Adolescent development is seen as relational, emotional, bodily and social in nature; a model which is inclusive and can apply to all adolescents.

A research study considering young people’s adolescent experiences in relation to this theory is now briefly described, before an illustrative case study on ‘Billy’ is provided.

4. The research study

i. Outline of study and methods

Four severely learning disabled adolescents from diverse backgrounds, were observed for an hour a week over a period of six months in their individual family settings. An example of ‘practice near research’ (Froggett and Briggs, 2009), detailed observations are gathered and later presented as case studies in which the psychosocial wholeness of the research experience is maintained (similar to the concept of ‘thick description’; Geertz, 1973) using a methodology derived from psychoanalytic infant observation. Originally designed as a training tool for psychotherapists, psychoanalytic techniques are used in an infant observation to sensitise the researcher to the emotional and relational dynamics between the young person, the family and observer (Rustin 2006) making use of the idea of the unconscious intersubjectivity between observer and observed (Hollway 2001). A process of data analysis is undertaken with the observer’s notes, involving psychoanalytically-informed supervision and research seminars. From this, inferences are drawn from the observation material which leads to the construction of case studies. While the findings remain
subjective and exploratory, certainly not conclusive, they do however represent an attempt by the observer to make sense of the young person’s emotions and experiences at home directly from them, rather than filtered by parents, carers or professionals’ opinions.

In this study, purposive sampling was used, through a process of networking, to seek families who were thought to be managing life well; to learn about how they achieve this when they are caring for a young person has complex needs. As a social work researcher with a background of having worked with disabled children and their families, I negotiated an observation stance flexibly according to what the young person and family felt comfortable with, but in each case working to ensure a respectful approach where boundaries and expectations are kept clear (Stalker, 1998 gives a good account of this). I joined in with family talk if that was wanted, or helped out a little, for example listening to Billy’s sister read for her homework on one occasion. Parents’ consent was gained to conduct the research, as it is accepted that it can be difficult to gain informed consent directly from participants with severe learning disabilities (Stalker and Harris 1998, in Detheridge 2000). University ethics panel agreement was obtained. A fuller account of the qualitative methodology and data analysis is described in Author (2009).

ii. Introducing Billy

Billy is a white British young man of 14 years, who lives with his mother (Maggie) and a younger sibling Catherine (10). His father Tim, though separated from Maggie, spends a considerable amount of time each week helping out. Billy enjoys a warm relationship with family members and he attends a local school for pupils with severe learning disabilities. He has complex disabilities including cerebral palsy (spastic quadriplegia), severe learning disabilities, seizures, scoliosis, restricted physical mobility and feeding difficulties. He has no speech and he has a limited ability to communicate his wishes through some nodding and indicating his feelings with his eyes. Billy requires help to carry out all aspects of his daily routine and carers come twice daily to assist. 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 does not stay away from home, apart from an occasional summer break.
iii. Billy: a fragile and transient subject

The concept of subjectivation, as mentioned, proposes a relational, psychosocial view of adolescent development through highlighting four interrelated themes: firstly, considering the young person’s embodied, physical experience; secondly the inner world of the young person’s object relations and their emotions; thirdly how these interrelate with their external emotional objects (parents, siblings, carers and so on); fourthly, all of this is set within a broader social framework which includes policy and social attitudes. What follows is a brief account of observing Billy, which starts by focusing on his physical, embodied self; leading then to consider Billy in relationship with those around him and how this helps form a picture of him as a psychosocial subject.

During my first visit, Billy’s mother welcomed me and we spoke for some time about what life was like and how busy she was in meeting Billy and his sister’s needs. As I sat with Billy firstly and over time, I tried to find space to focus on observing him on a ‘surface’ level as well as trying to take notice of ‘deeper’ levels of emotional communication (or counter-transference; Hinshelwood, 1991). What did he look like and how did he appear to experience himself in a physical, embodied sense? From this, it was possible to see that he was a physically developed adolescent of fourteen years, who closely resembled the other family members:

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... 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 (1:10)

Billy’s parents dressed him in fashionable teenage clothes indicating their respect for his age and development and he seemed to be developing expected physical features of adolescence, for example his voice was heard to have deepened and he was growing in height. As an observer in a busy family environment, I tried not to initiate talk, but often responded to the parents wish to discuss their thoughts and feelings if this felt right. One thing I noticed after observing for a number of weeks was that despite Maggie’s willingness to discuss her daughter’s development on entering puberty, while she was not around, I
found that the parents were not very forthcoming in mentioning Billy’s developing physicality and sexuality; as though they put this out of their minds. By the ninth visit I found myself overstepping my observer role (perhaps the social worker in me emerging) by unconsciously encouraging the parents to view Billy as a maturing young man:

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)

Over the weeks of observing, it seemed to be the case that it was 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. Billy’s impairments seemed to take centre stage at times, as his mum often emphasised in great detail aspects of the physical care regime she had to carry out for him and the anxiety associated with the fragility of his health:

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

Inevitably, due to the need to monitor and respond to changes in Billy’s health status, he needed to be watched closely by his parents. They also interacted with him frequently and caringly through my visits, to try to work out what he was thinking or feeling at any given time. This was a difficult business as Billy’s ability to notice and to respond seemed contingent on how tired he was and how engaged he was able to be:

Maggie said ‘are you uncomfortable Billy? What is it?’ He looked at her and stopped vocalising. Maggie said ‘you’ve been on your electric wheelchair today Billy, haven’t you? Is that right? Yes?’ she said quite firmly, wanting Billy to nod to show he understood and confirmed the detail she knew of his day. She was sitting a few feet
away from Billy and Maggie looked over at his mum and didn’t respond much. When she asked again, he nodded and it was unclear whether he was responding to her question, or nodding more to please her by giving a response to her speaking to him. (9:2)

At such times, Billy seemed disconnected and it was hard to interpret his feelings, as though in terms of the notion of subjectivation he was ‘subject to’ the cares and wishes of others, his external objects. At other moments, Billy was however able to assert his physical and emotional presence on others to a greater degree, indicating an emerging sense of personhood and identity; ‘subject of’ rather than ‘subject to’ external and internally related emotional experience:

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).

These physical, embodied expressions of Billy’s showed that he was able to have transient, but powerful moments of subjectivity; states of mind which are in keeping with any non-disabled adolescent, though perhaps more fragile and illusive. 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. At school, as I was told by his 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 gauge Billy’s communicational ability. It would have been helpful to also observe Billy at school, but as the research was aimed at observing young people’s experience in their own home I decided to focus on this setting alone in terms of what emerged.

While Billy’s parents seemed to ascribe meaning to his communications and demeanour at times, I found that this seemed to be contingent upon the circumstances at a given moment. For example, Maggie would describe Billy’s attitude towards his sister Catherine as that of a ‘typical big brother’; sometimes irritated with her if she was being difficult and demanding, and at other times more as a protective older brother. On occasion however, Billy’s status as a subjective, feeling individual was down-played. One account concerned Billy’s protest at having a hospital procedure carried out to test his kidney function (visit 13):
‘He’s got to go to hospital next Monday, for a kidney check up.’ 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 cannula attached to his hand. Maggie said ‘they offer aesthetic 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)

From this distressing account, it is apparent that adults, carers and professionals might at times discount the possibility of Billy’s status as a conscious subject. It suggests that while time and care are devoted to trying to understand Billy’s feelings and wishes, limits were placed on this.

I conjectured that if Billy’s subjectivity was transient and fragile in nature, his parents were left with space into which their thoughts and fantasies about him might be placed and that this might be an emotionally complex and uncertain place for them and for Billy to be. Theories of adolescent development suggest that experimentation with peer relationships have the role of broadening the field of emotional experience for young people. In terms of psychosexual development, as Anna Freud suggests, the young person is thought unconsciously to shift their ‘love interest’, to invest libido in other people or ‘objects’ outside the family:

‘The adolescent too is engaged in an emotional struggle, and moreover in one of extreme urgency and immediacy. His libido is on the point of detaching itself from the parents and of cathecting new objects’ (Freud, A, 1958, p260)

This can be a wrenching, unsettling process which can result in parents feeling rejected, with some of the typical struggles of adolescence being experienced as the young person comes in and out of relationship with their parents; oscillating, as subjectivation suggests, between being more or less situated in a new found ‘adult’ identity, or subjectivity, which is gradually more acceptable both to them and those they are close to.

Relating this to Billy’s experiences in his family, as I observed them, I wondered whether perhaps Billy was sick and tired of his life at home and would like nothing more than to be
away from his parents, some of the time. It did not seem possible for his parents to know
this however and certainly it did not appear to be the case as Billy was mostly relaxed and
comfortable at home, in his parents’ presence. Denied the opportunities to be meaningfully
separate and apart from Billy with him taking the lead, except in the fragile, partial ways he
was able to express his subjectivity however, the parents are prevented from experiencing
their son’s moves away from them; to be able to anticipate and rehearse what it would be
like to have an ‘empty nest’ and to have to get used to Billy having a new and more separate
identity. The intricate and intimate elements of caring for Billy both physically and
emotionally throw the kinds of value judgements often heard from professionals about
parents being ‘over-involved’ and ‘unable to let go’ of their learning disabled son or
daughter into a new light. Adolescent separating and differentiating from their parent is a
relational process which shapes parents’ personalities almost as much as the young person’s
himself; there is no experience or advice readily available to draw on, about how to ‘do
adolescence’, for parents or young people in these circumstances.

This is where the fourth aspect of subjectivation, the social domain, is so important; social
policy and social care agencies holding a template for how young people with learning
disabilities might transition into an adult identity, in the context of a society with its
ambivalent attitudes and prejudices towards those with impairments. During my time
observing Billy, his parents did not seem confident that things would work out as they
hoped when they talked about his transition review held at school:

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 his sister 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).

This ‘all or nothing’ model of social care is not in keeping with contemporary social policy
with its emphasis on personalisation (Putting People First, 2011) and in reality, Billy and his
family might well be offered wider and better choices. Their perception however, at that
moment, was that rather like Billy; they too are ‘subject to’ the whims of outside powers, rather than being able to take a lead in planning for his future.

Conclusion:

In this paper, a case is made to augment social constructionist views of disabled identity with a psychosocial perspective which includes psychoanalytic ‘depth’ approaches to considering emotion. Existing research on the experiences of severely learning disabled adolescents is extremely limited and psychosocial concepts of identity have the potential to add richness to this field as the young people concerned feel and experience emotions in their lives just as any non-disabled person does. Subjectivation provides a useful theoretical framework as it does not conceive of adolescence as a simple progression from a state of dependence to one of independent adult subjectivity. Instead, it sees all adolescents as moving between different states of mind and bodily conditions as they grow and develop, but always in relationship with significant others in their lives and the broader social field.

In Billy’s case, it was found to be useful to use the framework of subjectivation to anchor observations in bodily, physical experience. Spending time noticing how Billy’s body was experienced by himself and his parents led to reflections on how difficult it is for parents to put aside disability and impairment. At times they and other adults around him downplay Billy’s feelings making him ‘subject to’ the acts they felt they needed to carry out to ensure his physical well being. Billy was described as being able to protest at this. On many occasions however, I experienced him as having a fragile, delicate and transient subjectivity, his parents seeming to struggle to understand his feelings and needs. This led to considering how adolescence is a relational process affecting parents’ development as well as their offspring’s. The parents had to deal with Billy not being able to challenge their authority strongly, missing the gradual separating and differentiating adolescent processes that are the usual pattern for ‘doing adolescence’ and which prepare young people, but also their parents, for their progression towards adult identity.

The role of professionals, social care agencies and peer support for parents and young people, to assist them in managing transition to adulthood is highlighted by this work. Recent developments in shaping the idea of person-centred planning and individually held budgets are all important. Central to these must be however, the ability to work with
relationships; for professionals, advocates and agencies to acknowledge the feelings of the adults involved in providing care in complex situations such as Billy’s, but more importantly to be able to recognise and to work with the emotions of the young people themselves (Ruch et al 2010).

One image remains with me of Billy and his family, which seems to show the family in the midst of the matrix of their relationships; a tableau which shows that relationships ebb and flow and that all have a part to play:

Apart from dad, the rest of them were united in front of me; Catherine in next to her mum, Billy next to Catherine. I noticed that Catherine had her 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)

References


Watson, N. (2002) Well I know this is going to sound very strange to you, but I don’t see myself as a disabled person: identity and disability. *Disability and Society*, 17(5), 509-527.