

Caring for a child with a learning disability born into the family unit: Women's recollections over time

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Abstract: Caring over time for a child/young adult with a learning disability requires that the family, and in particular the mother, negotiate their needs with services and professionals, and these negotiations are complicated further by significant behavioural issues in the children. This study reports on a series of interviews undertaken with mothers of children and young adults with learning disabilities and a history of challenging behaviours. The interviews were supplemented by documentary data from clinical and other notes in order to provide a more detailed view of the issues arising from caring over time. Detailed thematic analysis revealed five key themes demonstrating the cumulative effect of caring for someone with such complex needs, the centrality of that individual's needs to the lives of those interviewed and the ongoing negotiation between family and professionals required in order for the former to work out how to continue caring both effectively and on their own terms. All the names of mothers and children are pseudonyms.

Keywords: learning disability; family; negotiation; professional involvement; challenging behaviour

Introduction

The birth of a baby with a learning disability precipitates a biographical disruption, the anticipated life path of the parents and family no longer following the expected course (Bury 1982). The term 'disability' in this paper refers to both the individual impairments and the disabling barriers encountered in social life; it is the complexity of these barriers, which contribute to the family feeling that they too are a 'disabled' unit. Mourning for the planned perfect baby, combating feelings of grief, shame, inadequacy, and guilt are areas well-documented and experienced to varying degrees by all parents of children with a learning disability (Raphael Leff 1991; Leick and Davidson-Nielsen 1991; Garland 1999), though the impenetrable effects over time are perhaps less well understood (Bloom 2005). This is particularly so when there are additional difficulties making already complicated family circumstances even more complex, such as the presentation of persistent and disturbing behaviour.

The importance of strong family relationships might be regarded as the most significant factor in overcoming seemingly insurmountable problems particularly if mutually supportive and complemented by an equitable division of labour (Webster-Stratton 1990; Dyson 1991; Taanila, Kokkonen, and Jaervelin 1996). However, in a traditional sense it is the role of the mother to centralize care, which pivots on the primordial belief relating to attachment, bonding, and love.

Literature review

The handicapped family

The family's ability to cope over time in caring for a child with a learning disability is complicated by extraneous factors, primarily the degree of the disability, extent of challenging behaviour, and availability of support (Abidin 1990). The contention that 'a handicapped child makes a handicapped family' (McCormack 1978, 12) has been associated with a previous era, when parents were frequently regarded as responsible for their child's disability (Blacher and Baker 2002) and the legacy of the immediate post-war view of parents as disturbed or damaged (Schonell and Watts 1956) remained influential. Some now argue

that the negative effects of a child with a learning disability on other family members are quite minor and that behavioural difficulties are of much greater significance, particularly in terms of parental psychological wellbeing (Stores et al. 1998; Lordier, Blacher, and Swanson 2000; Rossiter and Sharpe 2001). Furthermore, there is a growing literature regarding the complex role of carers of learning disabled children in relation to gender (Traustadottir 2004; 2006), the tensions within advocacy (Mitchell et al. 2006) and the social consequences (Leiter et al. 2004). This clearly shows the diverse range of issues that embrace parents, and in particular, mothers and women of children with learning disabilities (Traustadottir 1991; Stokes-Gottlieb 1997; Kristiansen and Traustadottir 2004). Yet, the complexity of the burden on the mother, in terms of managing multi-factorial expectations - of mother, wife, daughter (in-law), friend, socialite, sexual partner, wage earner, and so on - have only received due research attention over the previous two decades.

Both positive and negative views

The impact of a child with a disability on family life, and in particular the mother, may be uncompromising (Baxter, Cummins, and Yiolotis 2000), particularly in creating feelings of self-blame, guilt, depression, helplessness, and hopelessness (Meyerson 1983) with the generally heightened levels of stress (Dyson and Fewell 1986) and the physical exhaustion and concern for the future (Withers and Bennett 2003). These effects, however, are counter-balanced by the recognition of the benefits gained from caring in adverse circumstances (Hong, Seltzer, and Krauss 2001), rising to the challenge (Larson 1998), coping effectively (Folkman 1997), and deriving satisfaction from successfully overcoming difficult and enduring family conditions (Helff and Glidden 1998). Abbott and Meredith (1986) argued that caring can result in reduced conflict and enhanced cohesiveness, whilst others point to life-enhancing possibilities (Scorgie and Sobsey 2000), long-term caring facilitating empowerment through the acquisition of expertise, skills, and confidence, the basis for developing more pertinent values and relationships to cope with unknown vicissitudes (Aldwin 1994). The contexts in which mothers operate are clearly determined by individual, family, and social network factors, which contribute to the established mothering framework in which she operationalizes her perspectives on the learning disabled child as being within the family.

Professional support

The way in which parents perceive formal support appears to be significant in predicting the likelihood of the mother asking for further help (Greer, Grey, and McLean 2006). The extent to which the rhetoric of partnership, empowerment and collaborative working seriously addresses key issues in caring for a child or adult member with a learning disability remains uncertain. Some argue that parents, particularly mothers, are now partners in effectively meeting the social, psychological, emotional and educational needs of their children (Walker and Singer 1993). Furthermore, the mother, family and carers are increasingly considered potential participants in the research process (Turnbull et al. 1993). However, concerns have been raised around professionals being unable to make sense of the situation and therefore unable to offer the most appropriate support as they may misunderstand the complexity of the mothering role (Edelson 2000). One study, investigating the perceptions of parents of children attending residential schools, revealed considerable dissatisfaction with the support and services available prior to the residential option being sought (McGill, Tennyson, and Cooper 2006). These authors also reported high rates of exclusion from local services and elevated levels of concern about the future, indicating the fundamental uncertainty instigated by the child's additional behaviour problems. This tension often caused by a schism between

what professionals think/believe that the mother requires and what the mother herself wishes/requires from her inner perspective of understanding the family dynamic. Case (2000) suggests the primary problem to be that professionals insist on remaining in control of the relationship with the family, interpreting parental expertise as a barrier to shared decision-making; again, indicating a tension between professional and mothers' values/expectations. The search for control, however, along with the desire for meaning and identity, has been identified as fundamental in mothers and families becoming resilient to the adversity presented by a child or adult with a learning disability (Grant, Ramcharan, and Flynn 2007). Others claim that parents are often seen by services as a problem (Clegg et al. 2001), an issue taken up by Unwin et al. (2008), exploring parental views about the transition to adulthood. These authors report that parents consider that their efforts and knowledge are frequently disregarded, some professionals, significantly, regarding them as actual barriers to the child's future autonomy. The literature seems, therefore, to indicate an element of confusion, official policy welcoming parents as partners and enthusing over the expertise proffered in relation to the child or adult with a learning disability. Procedures and protocols have been developed to embrace the service user agenda and the need for collaborative working with parents and other carers. This must, however, be set against issues such as the diversity of caring experience, the degree to which the consumer agenda reflects the support parents require, and the specific additional issues surrounding ongoing complex behaviour, such as severe challenging behaviours. 'The experience of parent carers of people with learning disabilities is still not well understood' (Unwin et al. 2008, 28).

Research questions

This study was concerned with the ways in which mothers recollect their experiences of a child with a learning disability, with particularly complex needs, being born into the family unit and make sense of the event over time. Consequently three inter-related questions were identified and subsequently explored:

- What is the impact over time of having a child with a learning disability born into the family unit?
- What is the experience of the mothers of professional support to the family?
- How do the mothers make sense of their experience over time?

Methodology

A small number of case studies were conducted, wherein data from multiple sources were collected about the lives of a number of individuals with learning disabilities and additional issues around challenging behaviours. The focus of this study is on the negotiated lives of the mothers' of these individuals and the sources of evidence comprises a series of semi-structured interviews with the women, each of around 75 minutes duration, and documentary evidence from a range of written sources. Mothers were chosen primarily because of their traditional central position in the caring of the family and the social expectations that love and bonding transcend 'the imperfect baby', or at least ought to (Rossiter and Sharpe 2001). This relates to the social construction of motherhood/mothering in relation to the multi-factorial roles including wife and often wage earner (Porterfield 2002; Litt 2004). Table 1 provides some biographical detail and further information in relation to the sources of data.

Table 1. Profile of study participants (anonymised).

Name	Caring profile	Sources of data
Mrs. Anderson	20-year old daughter, Lesley. Always lived at home with parents. One older sister and one younger brother.	Interview with mother. Children support team notes, psychology and speech therapy reports, school reports.
Mrs. Clayton	25-year old son, Robert. Lived at home and residential schools. Now resides in specialist housing provided by the independent sector. Two older sisters.	Interview with mother. Family's personal files, letters of correspondence, professional reports, clinical notes, school reports, in-patient notes.
Mrs. Houghton	35-year old daughter, Sarah. Currently living with parents after several years of statutory and independent sector care. Only child.	Joint interview with mother and father. Community nursing notes, independent sector files, case conference reports, medical correspondence.
Mrs. Morris	26-year old son, Sam. Always lived at home with parents. One younger brother.	Interview with mother. Specialist clinical notes, community nursing notes, medical files.
Mrs. Wilson	32-year old daughter, Alison. Always lived at home with parents. Two older brothers and one older sister.	Interview with mother. Personal written statement from mother, specialist clinical notes.

The five cases represent a diverse group of mothers and families with differences in affluence, housing, earning capacity, and access to financial support. There are also differences in family structure, number of siblings, extended family support, and social networks with variations in educational attainment and activity in religious beliefs. The mothers also differed in their views on politics in relation to support for families and learning disabled children and in their personal views as to how to interact with professional services. Some adopted a passive approach whilst others were more assertive. The disparate nature of these mothers and families made the overall findings of this research particularly significant as the overarching themes emerged despite these contextual variations.

Ethical issues

Informed consent was provided by each of the research participants, who also contributed their own archive sources; access to documentary information was facilitated by Consultant

Psychiatrists responsible for the care of the individual with a learning disability. Relevant ethical committees were successfully negotiated prior to the study commencing.

Data analysis

Interview recordings were transcribed and anonymised and, together with the anonymised interview notes, entered into the computer software package MAXqda, which supports a thematic approach to analysis. The archive material (correspondence, clinical notes, professional reports) was added to the interview transcripts at pertinent points in the narrative, supporting or sometimes contrasting with the oral data. The framework for thematic analysis detailed by Braun and Clarke (2006) was utilized to structure the analytical approach. The data was coded and categorized according to its meaning and description, then retrieved sorted and categorized to elicit emergent themes, explanations, and connections. There was, throughout the research process, a dynamic interplay of data collection and analysis, constant comparison being made between developing themes and new data.

Findings

Five key themes emerged from the data, progressing from the shock evident in the child's birth toward the successful integration of learning disability and challenging behaviour into the life of the family. The five themes are termed (1) the dawning of disability, (2) the rise of disability, (3) the threat to the family, (4) the one-way and two way mirrors, and (5) figuring out a way of making it work. The dominant effect of the child, particularly in terms of the relationship with his or her mother, was marked, and the negotiation over time with professionals, culminating in the family working out how to best live their lives, is demonstrative of each of the stories described. The dawning of disability: a complicated birth: 'you didn't know whether she was going to live or die' The moment of birth remains significant throughout life, with parents, in particular, often able to recount the smallest of details around pregnancy itself, the trauma of delivery, and the exactness of the birth weight. The stories of the mothers in this study, however, are possessed of another dimension, that of the discovery of disability, the recognition that all is not well, the personal journey to make sense of the violence done to their baby. It is for this reason, the way in which the birth sets the scene for the coming years, none of the women interviewed overtly expressing regret, yet all revealing the almost incomprehensible impact of the realization of disability in the family. Four of the women present evidence of the immediacy of the baby's problems, only Mrs. Wilson indicating surprise at the delay in discovering there were complications. The stories of the other women surround birth trauma, delay, and larger issues of survival.

“. . . about two months premature . . . she got jaundice . . . and she stayed in an incubator for about two months.” (Mrs H)

“Emergency caesarean . . . about three months old when he came home . . . we just thought it was because he was small . . . because everybody kept saying that.” (Mrs M)

“Six weeks in an incubator . . . they had to tube feed her . . . you didn't know whether she was going to live or die.” (Mrs A)

This common theme involves the techno-language of experiences in special care baby units when mothers' (and possibly fathers') emotions are embroiled, or entangled, within the equipment that represents the outward sign of impending disability; the hospital, the machinery, the incubator, the tubes, the alarms, the lights, etc. This almost 'Carnavalesque Disneyland' (Baudrillard 1989) of flashing lights, colours, and noise specific to its own

relevancy for the individual mother, in which her emotions glide through the technological signposts of potential disability, indicate the point of embarkation on the disability journey (Foucault 1973). Sadly, this journey, for some, has no point of disembarkation.

“... the worst of the three ... it took some time before they realized he was stuck ... his head jammed ... eleven hours labour.” (Mrs C)

“I was two weeks overdue, they induced me ... we didn't know there was anything wrong till she failed her hearing test at nine months.” (Mrs W)

This temporal dimension, often heard in stories of having a baby with a learning disability, represents the ‘dawning’ experience of coming to ‘know’ that as a parent one is also transcending the boundary from ‘normal’ to ‘abnormal’. That is, in one sense, one is a reluctant passenger on this ‘journey’ and a passenger, probably with little choice. All the women demonstrate distress in their early dealings with experts, though Mrs. Anderson shows the occasional brutality in her interpretation of professional words, given perhaps with honesty or directness, almost certainly without the intention to mislead, but nevertheless with devastating effect.

“... they said that Lesley was blind, she was deaf, she'd never walk, she'd never talk, she was severely brain damaged and she'd be no use to society whatsoever ... they didn't expect her to live anyway ... it was kinder to just let her go.” (Mrs A)

Again, this cataloguing of disability markers as a form of list for others to check off, and judge, as a pre-establishment of degree, or severity, of disability, is a common theme. It appears to function as a psychological justification for an assessment of the child's quality of life and a contribution towards a rationale for ‘let[ting] her go’. Mrs. Houghton, though aware of there being something wrong, reveals that medical evidence could have been acted upon much earlier, the shock expressed in the second statement perhaps avoided by the information contained within the first.

“I'd had German measles in the first three months ... (and) (the consultant) said it wouldn't affect the baby in any way.” (Mrs H)

“... when she was fourteen months I took her to (the consultant) ... he said that she'd got hearing difficulties ... cataracts and that she was mentally handicapped and not to expect her to walk at all ever ... it was a real bolt from the blue, it was devastating.”
(Mrs H)

It is important, of course, to remember the context of the 1980s in comprehending the medical reaction to disability and the thoughts around societal contribution, though of equal importance are the factual inaccuracies, Lesley being neither deaf nor being unable to learn to walk, Sarah also becoming mobile but the likely effects of Rubella during pregnancy being well known. Medical prognoses are extremely impressive when they are correct, however, they can be even more profound when they are not (Illich 1977).

The rise of disability

Mrs Wilson, reflecting the views of all the mothers interviewed, talks of the restrictions placed on family life by her daughter's presence; activities would need to be organized with military precision, issues of spending too long in the car, encountering crowds of people,

negotiating public spaces, all required extra thought. The subtle differences between social inclusion and community presence transpire during the reality of engaging in the seemingly simple pleasures of organizing a family trip.

“The only thing that I do regret is that, even though I love my children, they didn’t get the love they should have had, because of Alison . . . not being able to take them where we wanted, take them to the seaside. We used to have to wait till Alison had gone away somewhere (respite) before we could go out, and it’s the same now.” (Mrs W)

The temporal dimension is consequently expanded and compressed according to the availability of time; the dilemma of how to achieve a balance, which might mean other family members having less time than desirable or family activity arranged to avoid busy or crowded events. Mrs Anderson considers how to organize her allocation of respite care, a serious consideration in family life, calling into conflict the desire for inclusion and the needs of other siblings. The first quote reveals the decision made and the ultimate rationale, whilst the second provides the organizational detail, the amplification of regular maternal concerns; in short, the ‘rise of disability’, issues of inclusion and integration paradoxically balanced around the centrality of having a normal family life.

“I tend to have it (respite) at weekends because that’s when it benefits the family.” (Mrs A)

“...you’ve got to take a bag, you’ve got to take her clothes to change, you’ve got to take personal care stuff. You know, you’ve got to arrange to be somewhere to eat, you know, you’ve got lots of things. You’ve got to make sure it’s not overcrowded, where you can get spaces and so on.” (Mrs A)

Threat to the family: preventing family fracture

The women interviewed perceived the relationship with their child with a learning disability to be central to the life of that individual; it was both something of which they were acutely aware and the source of tension regarding their overall family role. The toll, however, was considerable, extracted both mentally and physically. Mrs Wilson talks of the onset of her anxiety, its exacerbation by long-term caring, the mixed comforts of medication and the sometime despair that has to be negotiated.

“ . . . I didn’t go unconscious because I knew . . . they said that’s definitely panic attacks . . . especially with you having problems with having [Alison] . . . you’ve worked yourself up for some reason. So, I’ve been on nerve tablets now for nearly two years, and I can’t get off ’em . . . it builds up, doesn’t it, you know, a breaking point . . . life’s worth living more now than it was then . . . there’s a price to pay, yeah.” (Mrs W)

Mrs Anderson addresses her own psychological distress a little differently, the complex mixture of the mental manifested as physical, the refuge sought in role playing, the accumulation of trauma, and contemplation of seeking a permanent solution. She herself becomes ‘dis-abled’.

“ . . . at that time I wasn’t myself anyway, cos I was strange, I mean, I went away in the October . . . I had my lapse where I couldn’t see properly, I was still very weak then.” (Mrs. A)

“I used to put on this act . . . but inside it was killing me . . . so much pain inside you . . .

I felt suicidal.” (Mrs A)

A third view, from Mrs Clayton, combines psychological exhaustion with the need to withdraw, albeit only transiently, and the extreme violence that, ultimately, has to be both forgiven and understood.

“I’m beginning to doubt my own sanity at the moment . . . there have been occasions when I’ve said ‘look, I’m not coming to the next couple of meetings, I want a period of time where I’m not involved’. But that can only last for a very short period of time.”

(Mrs C)

“...he’s dislocated my jaw before now. When he does get going, he’s too much for me . . . but he’s totally out of it when he’s doing it, desperately apologetic and usually in tears afterwards.” (Mrs C)

This form of domestic violence is itself ‘fractured’ as the usual analytical frameworks do not ‘fit’ the disabled family. The perception of learning disabled family members as automatically being violent, or at least challenging, is not uncommon, and it appears almost as a bonus when the fractured family can reveal that ‘at least s/he is not violent’.

One-way and two-way mirrors: experience of professional involvement

A sequence of statements by professionals taking place over a three-year period, when Mrs Morris’s son is in his early teens, provides some insight into the relationship between family withdrawal and professional perceptions of the family, ways in which psychological motivations are sometimes constructed on the most uncertain of evidence. The final statement provides a condemnation of the relief experienced by restrictive apparatus coupled with a similar view about Mrs Morris’s parenting skills, with the eventual punch line being an expressed threat about withdrawal of expertise.

“ . . . perhaps I can persuade the family to come to a meeting and discuss their problem that they have with Sam.” (community nursing notes)

“...father’s tendency to feel very hopeless about Sam and to deny his problems and mother’s problems managing Sam and also coping with his normal brother, who tends to be a valued child and onto whom mother tends to displace her frustrations.” (correspondence between child and adolescent psychiatrist and community nurse)

“Mrs. Morris does not ever seem to have come to grips with controlling Sam’s unacceptable behaviour at home and now that the arm restraints he has actually stop him from self mutilating then (she) is quite happy . . . considering closing the case.” (community nursing notes)

Similar experiences appears to affect Mrs. Anderson, the two quotes below separated by a five year period, yet both casting aspersions on her mental state with the frustration over her acceptance or otherwise of suggested interventions revealing, perhaps, more than might initially appear. As with Mrs Morris, there is an element of certainty that professional knowledge concerning treatment appropriateness outweighs the parental understanding of the situation; yet the limits of professional expertise are becoming increasingly evident during this period of dawning.

“Mrs. Anderson used a great deal of her own ‘personal language’ and I felt to some extent that she had placed her own interpretation on the doctor’s statements.” (community nursing notes).

“...[the community nurse] found Mrs Anderson to be quite a complex person to work with -? psychological needs of her own and she is quite assertive about what implementations she will and will not accept. (child support team referral to psychology)

This is the one-way mirror in which professional consensus views the family as itself disabled; the family begin to formulate an alternative analysis, assembling ‘expertise’ based on their understanding of the situation combined with experience of professional involvement. The impact of challenging behaviours on the family constitutes one issue, yet professional understanding of it might provide a problem equally as complex, even behavioural amelioration suggesting contrasting explanations. The following extract from a letter by Mrs Clayton, the exhaustion evident in the face of success, sits uneasily with the pompously expressed acceptance of the communication difficulties revealed in the second letter.

“I really do not think I can cope emotionally with another meeting where everyone is in a self-congratulatory mood about their own role in Robert’s improved behaviour.” (Mrs C correspondence with consultant psychiatrist)

“...confusion due to communication problems between [health services], social services and Mrs Clayton prevailed. Such were the cause of great turmoil and further meaningless meetings and letters from Mrs Clayton to all concerned and replies thereto. The procession of letters and poor understanding only served to exacerbate all parties concerned.” (Social Services report)

Now the two-way mirror is exposed, as the family grow disillusioned with professional expertise and disappointed at its limited value in supporting the daily life of the disabled family.

Figuring out a way of making it work

Mrs Morris reflects on the inexorable nature of her son’s relationship with challenging behaviour (in this instance self-injury), the occasional relapses more evidence of the physical toll of his behaviour than the success of professionally-orientated interventions. The compromise lies between the extent to which she is determined to accommodate the suggestions made and the likely consequences for family life, the growing certainty that this is how things are, coupled with the knowledge that she’d always known it. The temporal dimension is now better perceived as a form of ‘time warp’.

“... I knew years ago . . . even when he was about ten . . . you go along with it, but really you know . . . still going to be the same pattern. Kept banging his head... He’d have ulcers on his head, they’d open, he’d bang his head . . . then he’d have a good couple of months . . . and then it would come back . . . you know what’s best for yourself and him.” (Mrs M)

The relentlessness of the behaviour is also graphically portrayed by Mrs Wilson, the lack of respite from challenging behaviour and its exhaustive consequences; though she is ultimately more concerned with the impact on her other children, a regret expressed earlier in this paper, the love stolen from the others by the overwhelming nature of the relationship she needed to have with Alison.

“... because every day was the same, you’d wake up in the morning and you’d know what was coming, and you couldn’t think what day it was . . . I had four children . . . except that I had to go for her all the time.” (Mrs W)

A more directly cynical view is forwarded by Mrs Houghton, the realization that a more tacit approach yields few rewards, the sad recognition that such silence is interpreted as coping, and a degree of bitterness that the reality of ongoing experience means little to apparently erudite professionals. The subsequent quote by Mrs Anderson seems to confirm these suspicions of the rewards of making one’s needs known loudly, though, as we have seen there are different consequences to such vociferousness.

“So long as you’re coping, they don’t care how you’re coping . . . the louder you shout the better you are . . . they think it’s inherited from the mother, that you must be thick.” (Mrs H)

“... I’ve had to fight and fight really hard . . . I’m fortunate in the fact that I don’t keep my mouth shut . . . when I ask for things I tend to get ’em, because they know I won’t keep quiet till I do get ’em. I didn’t want the wheelchair they had, so they said, ‘we’ll give you a voucher, you can find one’. So I found my own wheelchair, its £750 but they paid for it.” (Mrs A)

Discussion

The impact on family life, so central to the lives of the women participating in the study reported here, of a child or young adult with a learning disability and a propensity for challenging behaviour has both positive and negative dimensions. The complex process of successfully negotiating one’s experience over time varies according to the degree to which these negative and positive aspects act as counterweights to each other. All the parents participating in this study accepted the ongoing burden of caring over many years, integrating disability into family life, negotiating and re-negotiating professional contributions, accepting the consequences of the emergent doctrine and policy of community care. This last point is particularly evident in overcoming those occasions when the burden is intolerable, family fracture seemingly inevitable, professional involvement both desultory and of little practical value, and merely coping, getting by, the predominant preoccupation for long periods; choice has been effectively removed. The five themes identified in this study answered all three of the research questions and, interestingly, appear to us as reinforcing the adage ‘you do not have a handicapped child, you become a handicapped family’. The first major theme was the dawning that the child may be disabled and this is a complex dynamic in which time begins to stretch and there are a number of signposts that indicate that something may be wrong or something is not right. These signposts may be explicit in terms of hospitals, incubators, monitors, and so on, but may also be less visible in relation to slow development, not meeting milestones, not keeping up with other children and seeing indicators of this in charts, graphs, parameters and scales. Professional comments relating to rolling, sitting, standing, and the plethora of childhood events that the disabled child may not reach at all or may not reach as quickly as other children. In this study the dawning of the disability began to stretch through time.

The second theme to emerge was the rise of disability as it took over the entire family unit, again altering the temporal dimension. The family had to adjust to the disabled child and take extra time but with time running short. There was less time for the parents to be with each

other as there was less time to devote to the other children. Thus, the family was under threat, which emerged as the third theme. Perceptions of the family being under threat led to tensions within the unit but also appeared to bind them together in a unified battle against any impending fracture to their family unit. The relationships with professionals could become tense as the family adjusted to needs of their child, the bewildering complexity of persistent challenging behaviour, re-structuring their lives and the life of the family accordingly. They began to challenge or discuss professional orthodoxy and were subsequently viewed as themselves being 'dis-abled' with tacit, sometimes expressed, threats to withdraw involvement. This we termed 'the one-way mirror' as the professionals viewed the family from this one-way perspective, the family itself being fractured. However, the family came to view the professionals as not really understanding and not really knowing what is best for them. Thus, a form of 'two-way mirror' was formed. This we termed the 'one-way, two-way mirror' theme. Despite family fracturing being completed they appeared to either positively attempt to work towards the future or inevitably felt that they simply had no choice to do so. In any event they each attempted to 'figure a way forward', which was the final theme. This thematic structure can now be illustrated (see Figure 1).

This figure represents time passing within the knowledge dawning that a mother has a child with learning disabilities and within the 'dawning' era there is a fracture of normality represented by the smaller arrow traversing the temporal stretching experienced by the mothers (the thick line). As the notion of disability rises, time, for the mothers, becomes difficult to manage or 'tight' (thick line) as they referred to it. This leads to a perceived 'threat' to family normality and time becomes 'warped' as they are locked into the temporality of the caring for the learning disabled child. Penultimately, in this study, the relationships with professionals, again, produced a temporal distortion between 'normal' life (thin line) and the 'disabled' life (thick line). Finally, there was an effort from the mother to establish a 'way forward' within a temporal realism that the future may look bleak/rosy/different, despite it looking a long time into the future. Although we depict the stages as discrete in the illustration in reality the phases would undoubtedly overlap and extend forwards and backwards dependent on the individuals concerned and the situational vagaries.

Impact on policy formulation

There are a number of issues that emerge from this study in relation to policy development in terms of attempting to ameliorate the negative impact that having a learning disabled child can have. This is not to dismiss, or belittle, the severity of this event but to suggest ways in which we, as healthcare professionals, may make adjustments to assist those in this situation. First, there appears to be a case for professionals to engage with mothers of learning disabled children to a greater extent and to be more aware of their assessed needs of the situation. This may offer a platform of planning and operationalizing services more in tune with the overall family unit as relayed by the mother. Second, policy formulation should take cognizance of the fact that the mothers in this situation may be under intense stress over a lengthy period of time and there should be intermittent and pre-programmed assessments undertaken in relation to service provision and the mother's perspectives on the situation. When a person feels 'trapped' into a situation it is often the psychological impact rather than the physical environment that pushes the person beyond the tipping point. This needs to be addressed by including mothers on policy boards and committees dealing with service provision. Finally, respite care is of central importance in alleviating the ongoing stresses of daily life of a mother who is caring for a learning disabled child and there needs to be swift and thorough interventions to assist all those within the situation.

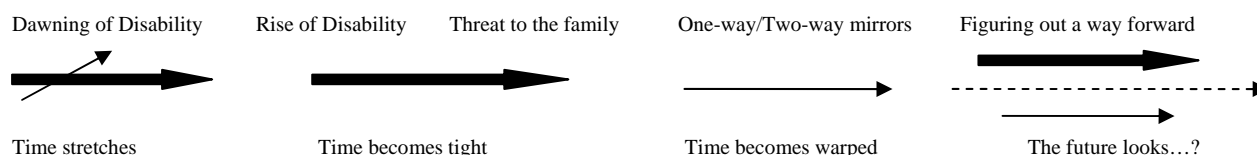


Figure 1. The temporal dimension.

Limitations to the study

Clearly there are a number of limitations to the study. First, despite the in-depth interviews and the extensive supportive documentary evidence there is always a criticism of small numbers involved in this type of qualitative research. Second, it is difficult to draw generalizations regarding the nature of this type of research, and indeed we are reluctant to do so. However, again, we feel that this criticism may be somewhat assuaged by supportive experiential accounts.

Conclusion

The intense nature of caring over time for an individual with a learning disability and additional issues in relation to challenging behaviour is clearly in evidence in the women's stories presented in this article. Second, or even third, generation community care has proven that many people with learning disabilities live rich and fulfilling lives: approaches like person-centred planning and measures such as direct payments help to make family life even more fruitful and important. People with learning disabilities are not, nor ever were, however, a homogeneous group, and there is a need to avoid the burden implicit within Mrs Houghton's observation that services care little about the detail of people's lives, 'so long as you're coping'. This will ring true for many carers whose lives have not been fully explored and whose voice has not been heard. The complexity of accepting professional support has to be balanced against the life-long negotiation of family life, the rhetoric of inclusion set against the reality of caring.

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