



'My heart is always where he is'. Perspectives of mothers of young people with severe intellectual disabilities and challenging behaviour living at home

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Accessible summary

- The researcher visited twenty families over 2 years. In all of the families, there was a son or daughter (from 15 to 22 years old) who had severe or profound intellectual disabilities. This meant that the mothers had to do most things for them. They bathed and dressed them and helped them to eat. Many spent time in the night with them as well. Most of the young people could not speak at all. Many of them had epilepsy. They were very difficult to look after because they tried to hurt themselves or other people, or break up the furniture.
- The researcher wanted to find out how the mothers coped with all they had to do and how they felt about their son or daughter. In spite of all they had to do the mothers felt very close to them and were determined not to let them go into long-term care away. The mothers thought that if they lived somewhere else they would not be cared for and loved as they were now. They also thought that bad things might happen to them, and because they could not talk no one would know. The mothers felt that people who lived in long-stay homes were not at all like their children. Many of them hoped that they would live longer than their son or daughter, so that they could stay at home and be looked after by their mothers all their lives.
- Most of the families only saw their own sisters and brothers and other relatives now and again. They felt that other people did not really like having anything to do with them. This meant that they needed help and support from the social and health services, but they felt they had been let down by them as well.

Summary

Little research has focussed on the perspectives of families caring for someone with severe or profound intellectual disabilities and challenging behaviour. The main aim of this research was to gain understanding of the experiences and perspectives of families, especially mothers, of young people with these complex needs, including attitudes to long-term residential care. Ethnographic methods were used, consisting of intensive interviews over 2 years, mainly with mothers, and participant

observation. The analysis used grounded theory. The mothers' main focus was on their son or daughter with intellectual disabilities. Most were socially isolated, even from close kin. Their negative attitudes to institutions and fears for the safety and well-being of their sons and daughters led to determination not to put them into long-term care. Mothers struggled to care for the young people at home, in spite of difficulties, family tensions and social isolation. Lack of effective services, especially around transition to adulthood, increased parents' protectiveness.

Keywords Challenging behaviour, family carers, identity, mother-child relationships, severe intellectual disability

Introduction

This article is based on an ethnographic study carried out with twenty families who had, living at home, an adolescent or young adult with severe or profound intellectual disabilities and challenging behaviour.

The study was an attempt to gain an understanding of the worlds of these families, including the difficulties and dilemmas they faced in their attempts to access adequate and effective services, so that they could continue to keep their son or daughter at home. The study also documented the families' relationships, not only within the household but also with the wider kin group, and others in the outside world. The aim was to get to know the families well enough to be able to describe their lives as far as possible through their own eyes.

One of the original aims of the study was also to discover what factors influenced parents in their decision to place a young adult in permanent residential care away from home. In the event, only two families made this decision during the research period, with the result that this focus changed to the reasons why families decided not to let their adult children leave home.

Methods

The sample

The study was carried out in one county in southern England. The aim was to find a small sample of families in which there was a teenager or young adult (aged from 15 to 22) living at home, who had been classified, by the professionals working with them, as having severe or profound intellectual disabilities and severely challenging behaviour. A number of young people were initially identified by asking teachers in special schools, community nurses, social workers, psychiatrists, psychologists, residential care managers and other professionals to put forward the names of those they considered were within the

aforementioned categories. All of the names suggested were cross-checked with other professionals, and in a number of cases the professionals were not in agreement either about the degree of intellectual disability or the severity of challenging behaviour, or both. Individuals were only included in the sample when wide consensus was obtained. By this method, ten young men and ten young women (this was not by design) were identified. The young people in the sample had little or no speech and could do very little for themselves. All of them needed complete or considerable help with daily tasks such as dressing, washing, eating and toileting. The majority were incontinent, and three quarters were subject to epileptic seizures. Some were almost totally immobile, others highly mobile. Their challenging behaviour consisted of such things as attacking others, self-injury and/or destructiveness.

Research methods

Ethnographic methods were used, involving informal interviews and participant observation over time (Reeves *et al.* 2008; Savage 2000). Long, unstructured interviews were held over a period of 2 years, mainly with the mothers, because they were the main carers in all of the families. The interviews covered many aspects of their lives, not only those directly concerned with their disabled children. Where possible, interviews were also held with fathers or husbands and siblings. The time spent with individual families ranged from 8 to 33 h, with 8–10 h spent with the majority of families. In addition to interviews, the researcher carried out participant observation with the families whenever possible (Dewalt & Dewalt 2002). The material was analysed using a grounded theory approach (Pope *et al.* 2000; Strauss & Corbin 1998). Throughout the fieldwork phase, the interview notes were read and re-read, within the framework of the ideas and concepts that were developed before and during the fieldwork phase. Further concepts and thematic categories evolved during this familiarisation with the material. Thus, the analysis was firmly grounded in the data.

Findings

Life at home

One family

Eddie lived at home in one of these families. Eddie was tall, dark and handsome, and the apple of his mother's eye. Yet all through his life Eddie had been unwelcome everywhere except at home. His parents had battled constantly for his right to attend school, but even when he did go, they were rung almost every day and asked to come and take him home.

Eddie was frequently violent towards others. His mother talked frankly about these violent episodes, but she saw far more to Eddie than this. She saw him as a human being, with intellectual, emotional and social needs. She also realised that he was a large and energetic teenager who easily got bored if he had nothing to occupy him, like most seventeen-year-olds. At home, Eddie was included in their family life, and his mother spent much of the day listening to him, and trying to understand what he was struggling to tell her. By contrast, at school, and at the respite care centre in which he stayed for occasional weekends, his parents felt that the staff related to him only as someone who was potentially violent, and thus was perceived as 'dangerous', and that, as a result, his needs and abilities were not responded to. It seemed to them that teachers and carers tended to avoid him, and did not try to understand what he was attempting to convey to them. At the respite care unit Eddie was often heavily tranquillised, sometimes coming home 'looking like a zombie'.

This difference between the way Eddie's family saw him, and how other people appeared to see him, epitomises the problem that many of these young people with challenging behaviour had in their relations with the outside world.

Eddie's mother's focus on his needs was typical of all of the mothers in this study. Caring for someone who is very dependent, for whatever reason, is time-consuming and often exhausting. Apart from attending to their basic needs, parents also administered a range of medication (sometimes a long and difficult task) to control epilepsy, deal with challenging behaviour, help them sleep, ensure bowel movements, and sometimes others to counteract the side effects of the psychotropic drugs (Hubert 1992). Most of the young adults also required constant vigilance to keep them safe from the consequences of their own actions, from the dangers inherent in their surroundings and sometimes to protect others from their violence. They needed continuous care and attention, not only by day but also at night. In all of these households, this responsibility was taken by the

mothers, who seemed to 'listen' in their sleep and attended to seizures, wet beds and general wakefulness. Many mothers slept at least part of the night in the same room as their son or daughter, some every night.

Many years ago, these families had made the decision to keep their child with disabilities at home. They had held to this decision over the years, in spite of the difficulties, and the time and energy that this involved. The mothers were devoted to their children with disabilities and were involved in complex reciprocal relationships with them. Although they were often emotionally and physically exhausted, within the context of their relationship with their son or daughter they showed mainly enjoyment and pride. Grant and his colleagues have written extensively about the resilience of caregiving families (e.g. Grant *et al.* 1998, 2007), pointing out that:

Despite the persistence of research-based accounts that depict families with intellectually disabled children and adults in pathological terms, there is mounting evidence that caregiving can have positive attributions and rewards (Grant *et al.* 2007: 567).

They extend this to caregivers of people with profound disabilities, suggesting that these carers are able to retain their positive attitudes in spite of the apparent lack of response. They propose that the lack of reciprocity may be offset by the fact that parents accumulate 'a huge amount of biographical and highly personal knowledge about their offspring, and in so doing are in a [position]... to act on this in maintaining a buoyant relationship with them (Grant *et al.* 2007: 567). Grant *et al.* (2007) write of the 'lack of reciprocity' in the mother-child relationship, but it would be true to say that all of the young people in the current study were responsive, however minimally, although this was sometimes not apparent at first. This communication was perhaps one of the most unexpected aspects of these young people, who had been classified by professionals as having severe or profound intellectual disabilities (and see Morris 2001).

Mothers perceptions of their sons or daughters and maternal bonds

Although these mothers knew that their adult children could not look after themselves, they tended to see them, in some ways, as ordinary people with extraordinary needs and had to some extent ceased to perceive them as having intellectual disabilities, as one mother of a profoundly disabled son put it:

To tell you the truth I never really think of Tony as being a handicapped person until someone asks me to speak about it. He's just Tony, I don't know how else to put it.

Only in contexts outside the home were they reminded that other people found their son or daughter very strange, in looks and in behaviour. One mother, whose son's appearance attracted many open stares in the street, said that other people's negative attitudes had made her feel more protective than ever:

It's upsetting, and it hurts, I get hurt because of him, and I think, well, he doesn't look like a monster from outer space. I mean he's beautiful, he's got a lovely face on him... He's a good wee soul. He's hard work, but he's worth it, you know, I wouldn't part with him. I keep saying that I'll look after him till every breath in my body goes.

In the now classic article, 'The psychopathology of handicap', Bicknell (1983: 168) wrote that mourning the loss of the 'perfect child who has not arrived' was vital, and that parents' failure to work through the stages of bereavement would cause 'endless unhappiness' within the family (Bicknell 1983: 170). The statements by mothers that they no longer perceived their son or daughter as disabled could be interpreted as denial and part of a maladaptive bereavement response (e.g. Bicknell 1983; Simpson 2005), but in the context of these families this interpretation would perhaps be an oversimplification. The mothers were perfectly aware that their sons and daughters had severe (or profound) intellectual disabilities, and it was this aspect of them that took up most of their physical and emotional energy. However, most preferred to focus on the reciprocal and rewarding relationships they had with them.

There was more than just acceptance of what others conceived as differences. Between these mothers and their sons and daughters there was a fierce love that both displayed, and mothers often admitted to quite explicitly. This apparently unconditional love 'suggests that parents... will extend their labour and commitment to limits that others would not be prepared to endure' (Grant *et al.* 2007: 570).

However, as Grant suggests, this may also have the disadvantage of preventing people outside the family being seen as acceptable contributors to the care situation. This may also apply to some husbands, because less than half of them were actively involved in the care of their adult son or daughter.

Among these 20 families, there were 16 married couples. From interviews with the wives in these families (and in some cases based on the researcher's observations), seven of these relationships seemed to be mutually supportive, with the inevitable stresses acknowledged and usually contained. Relationships between the other nine husbands and wives appeared to range from those in which there were considerable tensions to those which were at breaking point.

The mothers' intense preoccupation with their disabled child had, in some cases, meant that the 'fragile balance

between overstretched physical limits and negotiated arrangements between husband and wife' (Hubert 1991: 78) had ceased to exist. In some families, the husbands had themselves opted out of the situation. The joy and sadness experienced by the mothers were part and parcel of the full acceptance of their child and his or her disability, but some of the fathers were unable to come to terms with the reality of their child's disability. Thus, they exposed themselves only to the sadness of the situation, missing out on the joy.

By the time the children had become teenagers, many husbands had become of secondary importance to their wives. Given a choice between giving up their husband or their child, some mothers said that they would have no hesitation in keeping their child:

I have never felt I didn't want Sheena, in fact in a strange way she has kept me going... If you took her out of my life now I'd have nothing left, my relationship with her is so strong that anything is worth keeping that relationship... My husband knows it as well. He used to say we ought to let her go – I said that I'd sooner let him go than Sheena.

And another:

Definitely Gary wouldn't go... there's no way Gary would be shoved off just to suit my husband.

Some were aware that their bond with their child had pushed their husbands to the edge of their affections and attention. One mother, whose son needed constant help to survive, said:

I'm terrible, I feel right possessive with Joe. Bob used to work away from home a lot and I was left with Joe, and I sort of wrapped my life round him – I used to forget when Bob came home, I was so obsessed with Joe... I couldn't care less if Bob went away as long as I'd got Joe.

The mothers' devotion and concern for these children was demonstrated by the fact that they were struggling to keep them at home in spite of what they perceived as inadequate support from health and social services. For almost all of the mothers, their children with severe intellectual disabilities had become the centre of their lives:

I tend to avoid cutting across traffic because I don't want to be involved in a car accident – Davey would have to be put away if anything happened to me. It has marked me in such a way that... everything I do has got Davey at the end of it or at the beginning of it.

And another mother:

My heart is always where he is... I feel closer to him than to anybody, it's an awful thing to say, really. I'm not worried... about what I'm missing out because

none of it, if I didn't have him, none of it is worth anything, anyway. That's just how I feel, that's why it's no big deal to look after him, I'm doing what I want really.

Transition to adulthood

For the families in this study, life had become set in a pattern which they may not have consciously chosen to follow, but which had become an accepted way of living. Although parents had been told, in the first months, that their child was going to be disabled, the extent of their disability had necessarily only become apparent over time. All babies are doubly incontinent, need constant vigilance, cannot walk or talk, and need to be fed, dressed and bathed. There was no distinct point at which these parents suddenly became aware that this situation was no longer a 'normal' one, as one mother said:

When these children are younger they are almost as other children, these [disabilities] don't manifest themselves until they are older, and they do this gradually; it creeps up on you bit by bit.

And another:

When you have children you have this baby to look after, but then it gets better, but when you've got someone like Den that getting better doesn't come, because you've still got that baby there, even more, to look after.

Thus, as their children grow up, parents are faced with 'a series of challenges to social and cultural norms' (Grant 2010: 171). As their children became adult, the problems for the families increased. Some of the difficulties arose from their increasing size and strength. Parents often found it hard to lift and carry them, as one mother described:

I've got arthritis in my back and I have to lift her quite a bit... I've got a hoist for the bath but I've still got to lift her from her wheelchair on to the changing area and then from there into the hoist, and then back again.

It also became more difficult to control violent behaviour. Incontinence became less easy to contain and, in some contexts, more embarrassing to deal with. The girls began to menstruate, and this, too, brought added complications – some disliked the feeling of wetness, or of pads, and tried to strip them off; some became more difficult at this time or had more seizures. Many parents, as their daughters and sons grew up, worried about the risks of sexual assaults when they were away from home, at school or in respite care, especially as they were unable to report the actions of others.

In some cases, overt sexual behaviour caused difficulties in public, and sometimes also between husband and wife, as

one father said with regard to his son's masturbation: 'I get very worked up over that, very worked up. I don't know why, but I do'.

Parents were often torn between the dictates of acceptable social behaviour and their own sympathetic understanding of their adolescent child, whose needs and emotions they felt they knew to be much the same, in many important respects, as for any other adolescent. Parents found that the attitudes of other people, including their own relatives, had become more hostile and fearful as their children grew older.

In spite of the added problems that their children's maturity brought with it, most of the mothers were proud of their sons and daughters and of the stage that they had reached – and were to some extent proud of themselves, that they had managed to get this far against all apparent odds. As one mother said:

We have a good thing going, me and Joe, in our own way... so many people see him as a burden, and I don't, it's a positive relationship. I am so proud of him, and I am so proud that he's got to 21, whereas most people say 'oh you've had that cross for 21 years', but for me, you see, it's what he's done already.

How they got this far was the result of determination and single-mindedness. As their children became adult, parents felt that the services had, with very few exceptions, become less reliable, poorer in quality and increasingly disorganised (Hubert 1991). Instead of more help and support at this time, when families needed it more than ever, there was generally less during the transition to adulthood (Department of Health 2001; Morris 1999).

Some mothers were given the impression by professionals that they considered them to be overprotective and over-anxious. The mothers themselves, however, felt that they had every right to be protective and anxious about their children, because in most of their dealings with the outside world their fears for them had proved to be justified. The report of the Joint Committee on Human Rights (2008) supports this:

Although comments are sometimes made about families holding back their relatives with learning disabilities or being 'over-protective', the evidence we received suggested that 'for most people, most of the time, their families are their greatest and most reliable allies.' (JCHR 2008: 37).

The mothers felt that their protectiveness of their sons and daughters was accepted when they were children but was deemed less acceptable as they became adult. But it was at this point, as their adolescent children grew into manhood or womanhood, that the compassion the mothers felt towards them sometimes became even more intense:

I don't like this awful feeling that I get now, that he's so vulnerable... its just that he is a man now, I know that in my mind, he's not a child, and I suppose that's why I feel more sorry. I don't think I had even realised he was a teenager, he was just Will, a little boy, and suddenly he became a man.

Other relationships

All of the families in this study had struggled to function over the years as normally as possible, a feat that had imposed considerable stresses and strains on relationships both within the family household and with kin and friends outside.

These individual families tended to operate in their own, almost closed, world. For many of the mothers, their commitment to their son or daughter with disabilities had been at the expense of diverse social relationships or close ties with their relatives. Many felt very isolated, not only because they were tied to the house, or because people preferred not to visit them, but also because, as their children grew up, they found that they had less and less in common with friends and relatives who had children of the same age. The successes and failures in the lives of these parents often had no counterpart in the daily lives of others, whose sons and daughters lived their own lives.

Few of these families were part of an active kin network which provided even moral support. It appears that in these circumstances, kinship rights and obligations are liable to collapse under the strain of asymmetrical and necessarily unfulfilled relationships. Some grandparents effectively disowned their grandchild with disabilities, and for parents who loved this child as much as, or sometimes more, than their able children, this was difficult to bear, as one mother said sadly: 'I do feel anger, and also bitterness'.

One father said of his mother:

She disowned him for a number of years to start with, as though he'd never been born... she said 'Oh, I never talk to people as though I'm a grandmother yet'.

Some grandparents seemed to think that the families would be better off without the child at home:

They... think he ought to be in care... that we've given up our life to him, but I don't see it that way, because I'm doing what I want to do... [My father-in-law] said 'don't you think you've done enough, long enough?'

Some even implied that it would be better if the child died:

She's always implying that when he's not alive any more I'll be able to carry on with my life... they've always got him on the slab... [as though] if anything happened to him we would suddenly say 'oh, we're free! Now we can carry on'.

It was hard for these mothers, whose lives revolved round their sons and daughters with disabilities, to understand these attitudes, especially in their own parents. It was particularly ironic that grandparents could believe that life would be so much better for the parents if their son or daughter died, because these parents had spent much of the last twenty years or so desperately trying to keep them alive, sometimes against all apparent odds.

Many parents felt that their own extended families, and people who had been their friends, instead of helping to integrate them into the community, or into their own social worlds, tended to treat them as though they were separate islands, adrift from the known wider world.

Conflicting emotions

The parents of these young people were aware of the attitudes and feelings of others and sometimes may even have had similar feelings themselves – but not in the context of their own children. A few said that they would advise any parent whose baby had as severe physical and intellectual disabilities as their children not to have anything to do with it. Yet they loved their own children and fought to keep them alive, and at home. As one father said:

It's not all sadness and woe, I mean, she's a lovely little kid... you get used to her over the years, you know, what would be an annoyance to other people. It's like the sun comes up tomorrow, you know, its just part of life, isn't it? It becomes part of your life.

Another father felt that the life of his family had been 'destroyed' by his son and resented the extent to which he monopolised his wife's time and emotional energy. Yet there had been many times when he could have let his son's fragile life slip away by not reacting instantly when he choked and stopped breathing:

Several times I've thought 'you're a fool, Greg, you could let this go and no one would ever know' – and if they did know I don't think anything would ever have been said. But there's absolutely no way I could let him go, I've saved his life numerous times.

The complex emotions many of them had about the question of the right to life are very evident in this context. None of the mothers in the study would have preferred that their own child with severe intellectual disabilities did not exist or that they had died, but at the same time some felt that if their own daughter gave birth to a child that was likely to be profoundly intellectually and physically disabled, then the child should not be kept alive. One mother, who had battled over the years to keep her son alive, and with her at home, nevertheless was able to express the fundamental conflict felt by a number of these parents. At

the thought of one of her other children giving birth to a similar child she said: 'I hope that I'll have the courage to put a pillow on its face'.

Attitudes to long-term care

Professionals sometimes suggested to parents that this close bond with their adult son or daughter was unhealthy and that they should leave home and become 'independent' as other young people did (Hubert 1991). Indeed, at this stage it might have been expected that parents would have been making plans for the future, looking ahead to the time that they became too old or frail to look after an adult with challenging behaviour. But the mothers disagreed with the professionals about the potential independence of their sons and daughters and felt that they would, necessarily, remain dependent on other people for the rest of their lives and in fact would become even more dependent, because it was only at home that their complex ways of communicating, and thus their wishes, feelings, dislikes and preferences, were likely to be understood. They also believed that it was only at home that they would continue to receive the love that they were used to, and the physical care that they needed.

Parents felt sure that, away from home, their sons and daughters would probably never have another close relationship with anyone, and were afraid that they would be treated as unthinking and noncommunicative beings, which they obviously were not. It was clear that although they had little or no speech, they were able to communicate with those who were prepared to take the time to 'listen'.

Faced with the classification of their sons and daughters as having severe or profound intellectual disabilities, and aware of the attitudes towards people who are categorised in this way (see JCHR 2008: 45), mothers were reluctant to hand them over to others for their care. However, they could not see any viable alternative, and, as a result, most of them felt unable to contemplate the future and had become 'paralysed about making the right decisions' (Grant *et al.* 2007: 568). Some of the anxieties about the care of their son or daughter in long-term care varied, depending on their characteristics and needs. For the ones who were immobile and vulnerable, there was the added fear was that they would be forgotten and neglected and subjected to abuse. Their experiences of short-term care showed that this fear had some basis (Hubert 1991):

I worry that he [would not be] well cared for, that's what bothers me, who would care for him? If he could speak it would be better – because he can't tell you what happens... I'd rather he died first and then I could think, well, I cared for him all the time. It's wicked, isn't it? But a lot of my friends feel the same.

The parents of those who were mobile and violent had different but equally valid fears. Many of these young people tended to be tranquillised – sometimes even before they exhibited any threatening behaviour (Hubert 1992). Eddie's parents, for example, were adamant that he would never go into long-term care. His mother said repeatedly that if the day came that she could no longer look after Eddie at home, she would make sure that he had no future at all, rather than let him face a future in permanent care. She believed that he would be tranquillised 'into oblivion' because of his aggressive behaviour:

No, I think I'd rather kill him, quite honestly, I'd rather give him an overdose, than see him go in there... he'd be better off dead. What sort of life would he have? ... They're suffering there because they can't say any different... You've got to think about the content of life, haven't you, when you're talking about living.

Once their children had gone into long-term care, parents were afraid that they would have no control over what happened, as one mother said of her daughter, who often showed very aggressive behaviour towards other people:

She'd probably be heavily drugged, she'd probably go incontinent and, well, I don't know what would happen to her. If ever I thought she would have to live somewhere like that... if I had an illness or something, and I wasn't going to get over it, I'd give her an overdose.

And another, with regard to a local long-term institution (now closed):

To the parents, it is a bit like Dachau... I'd top me and him rather than him go there.

These reactions may appear extreme. However, two recent investigations into services for people with intellectual disabilities provide some support for these views (CHAI 2007; CHAI and CSCI 2006).

Parents' perceptions of people who lived in institutions

It was not only the institutions themselves that these parents feared to this considerable extent. They also perceived people who were living, or had lived, in long-stay hospitals as quite different from their own sons and daughters. In some areas, people from the long-term institutions were resettled in residential homes that were also used for respite care. One mother said that it grieved her greatly to think of her son among people who 'scream and do odd things'. Another said that her son's behaviour had deteriorated because men and women from the institution had moved into the respite care unit.

He's never thrown a plateful of food across the floor until he mixed with those... They're awful, some of them, I mean they are so different... all our kids [who live at home] are different.

These parents regarded the challenging behaviour of the men and women from the institution as quite unlike the behaviour of their sons and daughters. To some extent, they may have been right (Hubert & Hollins 2006). The nature of the challenging behaviour exhibited by the people who had spent their lives in a long-stay institution would have reflected the lack of individual care and the resulting lack of opportunities to form close individual bonds. The mothers saw their own children as total individuals, with a wide range of distinctive characteristics, and with their own ways of communicating. They were unable to see these in their brief encounters with the residents who had moved from the big institutions.

These perceptions of people who had lived in institutions are reflected in the material from a research project with men and women living in locked wards of an old institution (Hubert & Hollins 2006; Owen *et al.* 2008), which revealed that they were not perceived or treated as full human beings, and had been deprived of their individual, social and gender identities. They had also lost their familial identities – they were not thought of as sons or daughters, brothers or sisters. They were simply seen as they were at this moment, without any acknowledgement of their pasts. In contrast, the people who had stayed at home did have pasts, presents and futures and enjoyed reciprocal relationships. They were, albeit sometimes only to a small extent, part of the community in which they lived and were by no means invisible. They had retained their individual and social identities to a great extent and were nephews and nieces, uncles and aunts and grandchildren, even if some of their wider kin group tried to exclude them from these kinship relationships. Above all, within the immediate family, they were sons and daughters, beloved by their mothers, and in many cases also by their fathers. They were also accepted – and often much loved – brothers and sisters, and often also became acknowledged aunts and uncles. Within the immediate family, at least, they were part of – and belonged within – the complex web of family relationships

Discussion and Conclusions

This material has shown that caring for a son or daughter with severe intellectual disabilities and challenging behaviour is a full-time and demanding task. For these mothers, this did not decrease over time but became even more time-consuming and often increasingly problematic, as their children became adults. Their devotion to the care of their son or daughter often resulted in mothers struggling against

unremitting physical and emotional exhaustion. In a number of cases, it also put marital relationships at risk and contributed to the breakdown of relationships with family and friends. Thus, a number of mothers became socially isolated. At the same time, they found that support from the services declined when their children moved into adult services.

However, it is abundantly clear from the material that all of these mothers retained a highly resilient and positive approach to their sons and daughters and to their lives as carers. Any discontent, and in a few families even desperation, only arose from the inadequacy of the help and support from others, and not from the nature of the caring relationship with their son or daughter. The mothers were involved in complex, reciprocal relationships with their young adult children, and in many cases this child appeared to be the most important person in their lives. Within the context of their relationship with their son or daughter, and in their determination to continue to care for them at home, the perspective of the mothers was primarily one of strength and enjoyment.

Given the nature of their relationships with their sons and daughters, it is perhaps unsurprising that these mothers were unwilling to consider a future for their children in an environment where they would have to live without the close relationships and loving care that were part of their life in the family home.

Their refusal to contemplate the possibility of long-term care led 15 of the 20 mothers to express the hope that their son or daughter would die before they did. In some cases, this appeared to be put forward as a statement of intent. This is clear evidence of powerful emotions, whether any of the parents would actually harm their son or daughter if the situation arose.

Implications

- It is vital that this strength of feeling is taken into account in discussions and planning for the futures of young people who have severe or profound intellectual disabilities and challenging behaviour.
- Most parents rely on their considerable experience to deal with the multitude of problems that arise at different stages throughout the life of their son or daughter. However, they need more than this to deal with new and unfamiliar circumstances that evolve. Access to advice, practical help and counselling throughout the life of their son or daughter is essential, including access to someone who will visit regularly, listen to them and provide material and emotional support.
- If parents choose to continue to care for their son or daughter for as long as they can, it is vital that the existence of alternative care situations, acceptable to

them, should be made known to them at an early stage. These may involve residential care away from home but may also include arrangements whereby someone comes into the home – the same person each time and on a regular basis, so that the young adult, and his or her mother, can become used to a different situation and a new relationship.

The implications of the material reported here cannot be simply summed up in terms of the need for more effective services. The needs of individuals such as those portrayed in this paper, and their families, go deeper than this and will continue for as long as the prevailing attitudes towards people who have severe intellectual disabilities and challenging behaviour – and hence their families – continue to be negative, unsupportive and socially excluding.

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