Complexities in the Provision of Respite Care to Family Carers of Persons with Intellectual Disabilities

Hasheem Mannan[1*], Patricia O'Brien[1^], Ray McConkey[2], Frieda Finlay[1], Anne Lawlor[1], Gerry Harrington[1]
1. National Institute of Intellectual Disability and Centre for Global Health, Trinity College Dublin
2. Institute of Nursing Research, University of Ulster, N. Ireland
^Now at Centre for Developmental Disabilities, University of Sydney

ABSTRACT

Purpose: *Respite care is generally thought to benefit family carers of persons with intellectual disabilities and is regarded as an important component of family-centred services. However, the complexities associated with the provision of such services, from the carer's perspective, have been rarely investigated.*

Method: *This qualitative research study was carried out through a participatory action research process that involved collaboration among researchers and family members as co-researchers. Seven focus groups, involving seventy family carers (fifty mothers, fifteen fathers and five sisters), were held in seven locations across the Republic of Ireland.*

Results: *Three main themes dominated the discussions. The first theme related to the ambivalence of carers towards using respite services, as expressed in their reluctance to relinquish care-giving for even a short period; the feelings of guilt they experienced; and the greater needs of other carers. The second theme related to the benefits of respite breaks, but these were solely with respect to the carer and other family members, rather than to the person with an intellectual disability. The third theme regarding the quality of provision was dominated by concerns for the care the person received in using the services.*

Conclusions: *Respite care has the potential to make a difference, and these findings call for building much- needed alliances between all members of the family and professionals. This is in order to support one another through the difficulties associated with the redesign of existing respite provision, and the*

***Corresponding author:** Dr. Hasheem Mannan, Phoenix House, Trinity College Dublin, Dublin 2, Republic of Ireland. Tel: 00353 1 896 4178. Fax: 00353 1 677 9131. Email: mannanh@tcd.ie

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extension of these services to the growing number of carers who require respite breaks.

Key words: *Intellectual disability, respite, family members, Ireland*

INTRODUCTION

Respite care is a topic of deep concern among caregivers, advocates, and service providers (Chesson & Westwood, 2004; Mac Donald et al, 2006; McConkey et al, 2010; Power, 2008). It is widely acknowledged as an important component in the provision of family-centred services (Burns & Burchard, 2000; McNally et al, 1999; Mullins et al, 2002). Furthermore, international and European obligations continue to place great emphasis on respite care. The recently adopted United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2007) Article 28(2)(c) seeks State Parties "To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance, and respite care". In Ireland, respite care for persons with intellectual disabilities is financed by the Health Service Executive (HSE), mostly through state funded voluntary sector providers. Many of these were established by religious congregations and currently number over 70 (Health Service Executive, 2011). The different types of respite care currently available in Ireland include: (1) residential placement on either a crisis or planned basis; (2) respite with host family; (3) overnight respite in the family home; and (4) regular part-time or shared care arrangements (e.g., 2-3 days per week; every weekend; alternate weeks) (Barron et al, 2006).

In 2008, 4,549 persons with intellectual disabilities were recorded as being in receipt of planned respite services in Ireland (Kelly et al, 2009a) and 28.6% of family carers availed of respite breaks (McConkey et al, 2010). In recent years the demand for respite care has exceeded the supply, despite the expansion in the provision of respite care services and a marked increase in monies made available to intellectual disability services, from €363 to €731 million (Kelly et al, 2009b; Power, 2008; Department of Health, 2005). The provision tends to be more available for children than for adults (Beckford & Robinson, 1993), although this is not necessarily so in Ireland (McConkey et al, 2010).

Overview of Research on Respite Care

Primarily research has focused on family characteristics related to the use of respite care (Chan & Sigafoos, 2000; Chan et al, 2001; Hoare et al,1998; McConkey, 2005; Venet & Dery, 2004). In particular it has established that the level of parental stress is a predictor in the use of respite care (Grant & Ramcharan, 2001; McGrother et al,1996). Other studies have indicated that the severity of the person's disability is a predictor in the decision to use respite care (Chadwick et al, 2002; Treneman et al, 1997). Mac Donald et al, (2006), found that contrary to former research, the likelihood of Irish families using respite care was not significantly related to either their children's challenging behaviour or the level of support their children needed. They called for research questions to be positive, and for the use of qualitative research designs to investigate parental perceptions of respite care.

Certain studies indicate that respite care has made it possible for caregivers to work outside the home (Caldwell & Heller, 2003). Among other benefits attributed to respite breaks are the prevention of institutional placement (Heller & Caldwell, 2005) and improvements in the carers' social support and life satisfaction (Chou et al, 2008). Another study reported that using respite care gave the following benefits to parents: better mental health and peace of mind; improved family functioning; and concrete support (Canavan & Merriman, 2007). Earlier, Hartrey & Wells (2003) documented case studies which indicated that the use of respite care led to mothers feeling guilty, while also improving social activity. It has been indicated that respite care was "mostly geared towards those with limited impairment and no additional healthcare needs" (pg. 97, Power, 2008). Most importantly, it has been noted that "it is possible that residents are encouraged to visit their family homes at the weekend in order to free short-term respite places for adults on waiting lists" (pg. 305, Walsh et al, 2001).

However, parents who see their role as 'parent' as opposed to 'carer', may also contribute to parental reluctance to take up respite (Cuskelly, 2006). Moreover respite services that are more directly related to parental needs are generally perceived to be inadequate and inflexible (Llewellyn et al, 2004). Furthermore, research recommends promotion of positive adaptation to care giving rather than seeking to alleviate the burden (Nucleus Group, 2002). Despite the strong focus on the provision of respite care to families, there is a paucity of research on parental experiences of these services, especially with respect to the complex decision-making entailed in their use of them.

This paper focuses upon family members' perspectives on respite care, including their feelings about choosing to use respite care, its impact on family life, and their perspectives on the quality of respite care available to them. These arose within the context of a larger participatory action research study aimed at documenting what life was like for families across the life span of a family member with intellectual disabilities (Walmsley & Mannan, 2009).

METHOD

This research was carried out through a participatory action research process that involved collaboration among researchers and family members as co-researchers (Santelli et al, 1998; Turnbull et al, 1998). The use of parents as co-researchers increases the relevance and the rigour of the research; may reduce logistical problems, for example in recruiting participants; and may contribute to the uptake of the research results through enhancing parental empowerment (Turnbull et al, 1998). Parents were recruited to become co-researchers, working alongside the principal author, to facilitate focus groups of parents.

Recruitment of the co-researchers occurred as part of the recruitment of participants into the study. Invitations were distributed to 3,000 families across Ireland, through voluntary organisations including the 63 member organisations of the National Federation of Voluntary Bodies (NFOVB), the National Parent & Sibling Alliance, Special Needs Active Parents Ireland (SNAP), 22Q11, Inclusion Ireland, and Down Syndrome Ireland. These organisations forwarded the invitation letters to their members, with self-addressed stamped envelopes for families to reply indicating their willingness to participate in the study. The information sheet included information about the co-researcher opportunity. Families indicated whether they would like to be co-researchers, when registering their interest to take part in the study. The invitation letter also requested some background information from potential participants, about the age and residential circumstances of the family member with intellectual disability, and the age and the relationship of the family carer to the family member with intellectual disability. Respondents were informed that they need not have been involved in doing research earlier, as training would be provided.

Training the Co-researchers

The training workshop for co-researchers was held on the day of the focus groups. The training workshop followed the focus group, and offered a handson opportunity to lead a focus group as co-researchers. The training consisted of written guidance, a presentation and oral instruction on the method. This involved sharing information about setting up the room, the personnel required, setting a group culture, planning for and running the focus group, and dealing with potentially difficult situations that may arise during the focus group. The guidance was followed by role play, feedback and discussion on how the focus groups had fared.

Participants

In response to the invitation, 630 families from all counties of the Irish Republic expressed interest in taking part in the participatory action research. Following maximum variation sampling based on information collected from the 630 family members, 120 were invited to participate in the focus groups and of these, 70 family members attended on the day, to take part in the ten focus groups (Walmsley & Mannan, 2009; Chadwick et al, 2010). Not many non-attending family members gave reasons for their absence, but the few who did, reported having other family commitments that prevented them from attending.

Various flexible sampling strategies were employed in the investigation, to access potential participants. These included purposive, maximum variation, and convenience sampling (Krueger & Casey, 2000; Lincoln & Guba, 1985). A purposive sampling technique was employed for the specific group which was the focus of the study (families of people with intellectual disabilities), and also to ensure that in addition to mothers, fathers and siblings also participated. Maximum variation sampling was used to ensure variation in: (i) the location of participants; (ii) the ages of the participant parents and siblings; (iii) the age, level of cognitive impairment and residential location of the family members with intellectual disabilities. Convenience sampling occurred via the self-selection of the family members who agreed to participate in the study and attended the focus groups. As co-researchers, five family members (one father and four mothers) co-facilitated the focus groups. With the consent of participants, the discussions in all focus groups were recorded and transcribed verbatim. Focus groups were used to understand and document the family members' perspectives presented in this paper. This created a responsive context for participants to voice their opinions about sensitive topics (Krueger & Casey, 2000). A 'grand tour' approach started with broad questions around what life was like for families, both positive and negative experiences (Walmsley & Mannan, 2009).

Data Analysis

To facilitate data analysis, all field notes and interviews were subjected to thematic analysis, with the aid of the qualitative software programme NVivo. In line with the Miles and Huberman (1994) suggestion, all information- rich codes that manifested perceptions of respite care were subject to fuller analysis. The first two authors reviewed all selected comment categories and coded segments that were relevant to respite care, and used the constant comparison method (Strauss & Corbin, 1998) to analyse codes and to interpret patterns and themes; and to ensure rigour (Lincoln, 1995; Lincoln & Guba, 1985). By this process, 135 coded segments were identified as relevant to this issue. Having two researchers (one of whom had not been involved with the focus groups) helped to ensure that the perspective of a single lead researcher did not predominate (Brotherson & Goldstein, 1992).

Establishing Trustworthiness – The Inquiry Audit Trail

In addition, a member of the research group who was not part of this phase of the research study, independently conducted an inquiry audit trail, following the process laid out by Halpern (1983, cited in Lincoln & Guba, 1985). The audit of the study materials established the credibility, confirmability and dependability of the investigation, by reviewing techniques employed in the study, including coding of the data, triangulation of data and member checking (Anfara et al, 2002; Lincoln, 1995; Lincoln & Guba, 1985). This independent member of the research team reviewed the respite coding analysis (i.e, reading a sample of the transcripts) to assess the credibility of the identified themes (Patton, 2002). The resulting analysis was presented, discussed, and confirmed in meetings with the co-researchers, as well as during member checks with families who took part in the focus group.

RESULTS

In the findings, the source of quotation is represented by Father (F), Mother (M), and Sibling (S) as appropriate. However, for ease of reference the term “family member” is used throughout. Three main themes were identified: (a) family members’ ambivalent feelings about using respite care; (b) the positive impact on families receiving respite care; and (c) the quality of respite provision.

Theme 1: Family Members' Ambivalent Feelings About Using Respite Care

A major theme was family members' ambivalent feelings with regard to using respite care. A few parents with young children were reluctant to use these services because they considered it their responsibility to look after their children themselves, and were unwilling to involve people outside the family in caring for their child. Some parents spoke of *"letting go of their child"* as a challenge to them, while others felt that respite care provided *"a practice at breakaway"* from their close involvement with their child. Some parents expressed these views so strongly, that using respite care verged on creating a moral dilemma for them. The following comments express these views: One mother said, *"I sort of still feel in the back of my mind I don't want to let her go yet, you know"* (M1). Another mother's words capture the strength of this perspective: *"I do have difficulty overcoming the guilty feeling because there are so many more, what I would term more difficult cases than mine, that I should leave more respite for them... Do you know, and because it's so scarce you're put into that kind of frame of mind"* (M2).

Some parents passionately and eloquently expressed the belief that they would benefit from support in considering the use of respite care. A mother said, *"Parents could do with some support in coming around to the idea because it was hard for me to leave my son for respite. He was crying when I left him. But he had a great time. You know you worry about them too much too sometimes"* (M3).

Another parent indicated that, *"I think the sooner he adapts to that (respite care), the easier it would be for him and for me. You know, so it can be a gradual thing and he can get used to it"* (M4).

Parents who used respite care indicated a sense of both guilt and relief. Parents indicated that as time went by, the feeling of guilt dissipated as the family gained from the breaks. One mother stated, *"We were kind of saying he's so far away, it took a year of this huge guilt, but at the same time we were able to start functioning as a family"* (M5). While another mother described using respite care as *"great"*, she added, *"You could book a weekend away with the other children and not feel guilty about it"* (M5). Another mother indicated that, *"It would have been nice for a family maybe to just have E cared for so that you could do something together (as a family)"* (M6).

Family members' ambivalence to using respite was compounded if they were dissatisfied with the services that were available to them. They could be torn between wanting and needing a break for themselves, and concern about the quality of respite care that their child would receive. Echoing this sentiment, a mother stated, *"When you get respite care, you're nearly saying how can you be giving out about anybody (i.e. complaining), (How) could you say (that there was) anything wrong"* (M10).

Another dimension of ambivalence arose when parents spoke of the challenges which were faced if their family members did not want to avail of respite care. This sentiment was summed up in the following way: *"They said to me I should send M into respite and get a break but sure I asked him and no he didn't want to go"* (M 11). Another parent stated: *"She has been given respite in C Services but refuses to go, so that's another problem"* (M 12). A sibling stated: *"If she hadn't wanted to go I wouldn't have been able to get her to go"* (S1).

To sum up, the use of respite care by family members involves complex decision-making on the part of family carers, having to balance their own needs and emotions, as well as those of other family members, with considerations as to how it will affect their son or daughter. In the focus groups, participants gave a strong impression that respite providers and professionals did not appreciate the dilemmas they faced. They thought that they were being given little support in resolving these issues which, in turn, impacted on the value of breaks to them.

Theme 2: The Positive Impact on Families Receiving Respite Care

All parents viewed respite care in a positive light although their perspectives varied, ranging from viewing it as enhancing family functioning, to being essential for their survival. Parents mentioned that they needed respite care to go on holiday and to spend time with their spouse and other children. Enhancement of family life is illustrated in the following way, where a family had not been on holiday *"until we were 31 years married"* and as a *"result of respite now we're having a break every year and I get a couple of breaks during the year"* (M4). On the other hand, the desperation of the need to survive was represented in the following way: *"We needed it (respite care) as a family. My dad was still alive then and he was 80. She (sibling with intellectual disability) was giving him a terribly hard time. He wasn't able to handle her at all. But respite was just for the weekend and it was just heaven"* (S2).

Similarly, for another family where the 77 year old husband had suffered a stroke, his wife (M13) indicated that she received eight weeks of respite a year and that *"keeps me sane"*. Another mother indicated that the need to survive superseded the quality of the respite care that was provided for her son, and stated that she would not care (M14).

One father said that availing of respite care for his son, played an important part in creating a *"totally different environment"* at home for his daughter while his son was away. He added, *"It's absolutely brilliant and it does take huge pressure off the family life because the people that are suffering (siblings) they need more time as well"* (F1).

This same sentiment was echoed by another father (F2), *"I would think respite as an overall quality of life, and also to be able to give, I suppose, to give some time to your other children."* In general, parents talked about the impact that respite care had on them, as families, and less about its impact on the person with an intellectual disability. This may be because they had little direct contact with the service.

Another parent described the feeling of freedom in terms of *"my time is mine"* and went on to add that, *"When C is in respite the doors don't need to be locked, the windows don't need to be locked. It was like being on holiday in your own home"* (M7). Yet another mother summed up this perspective most unequivocally as follows, *"You know he does go for respite and you do get the day break and it's like Jesus now I am alive"* (M8). The challenge regarding availability of respite care is highlighted however in the following quote, *"He'd (Son) be gone in the morning if we could get him respite care"* (M9).

Theme 3: The Quality of Respite Provision

A third theme reflected the quality of respite provision, how it impacted on their decision to use it and the extent to which they benefited from it. Various participants expressed dissatisfaction with the inappropriateness of the settings in which respite care was provided, and they thought it was a key reason to advocate for better quality of service. In these cases, they described their frustration leading them to *"come out to fight"*, resulting in *"a lot of heartache"* and eventually receiving respite *"as a result of constant harassment"*. They called for respite settings that were *"as good for the clients as it is for parents".*

Parents commented on both positive and negative perspectives in relation to settings they had experienced. They indicated that they were satisfied when respite care settings were *"home from home"* where their family members were *"safe and secure"*. They emphasised that respite care settings should be *"appropriate"*, and knowing that their children were *"happy"* when attending, encouraged them to seek continued use of such an option. Most important were those positive experiences where staff were *"taking care of"* and *"looking after their relative well"*. Resonating with this sentiment one mother (M15) stated that, *"Staff understood* *her daughter, knew her likes and dislikes and what she liked to eat and everything"*. For another mother this was expressed as satisfaction about the *"beautiful lovely little house"* her daughter used for respite. There was appreciation also that respite breaks were taking place in dedicated houses, rather than people being slotted into vacant rooms in residential homes, when residents were away for the weekend.

Parents also talked about the benefits of having been offered respite care when their children were young. Commenting on receiving respite care early in life, one mother indicated that it would be a good strategy. She said, *"I would think the younger you are offered it, the better. She's been doing it for years and years and years. It's always been a fun experience"* (M16).

Parents in this study had also experienced what they believed were inappropriate settings for respite care. The occurrence of sending children into adult settings was identified as inappropriate. *"Well, there should be appropriate respite (settings) for children (not) mixing children with adults together…it was inappropriate"* (M 17).

Parents who resisted such settings, indicated that they would be, *"Reluctant to allow their children to go into a situation like that. Because they feel that respite is not appropriate"* (M 18). Another father (F3) lamented that, *"It was in an institution and it was just horrific. We were so upset because she didn't like it and she hated it so we didn't bother"*.

Nevertheless, coupled with the feeling of inappropriateness, there was a sense of resignation in accepting the setting, rather than expressing dissatisfaction with it. Participants thought it *"unsuitable"* when males were placed in an 'all women's' residential setting.

Various participants bemoaned the lack of respite provision. One mother indicated that, *"They have emergency respite. They would have if somebody died. If I died we might get respite"* (M 19). A father expressed his dissatisfaction and frustration with both the service system and the appropriateness of the settings: *"It's extremely difficult to get both the respite care when you need it, the type of respite care you want. It seems too as if the services have their own agenda. Well, the agenda I think is to suit themselves, what the staff want, or need within the place of respite, rather than what the person needs when they go in"* (F2).

In addition, parents pointed out that they believed the system *"with the best of intentions"* focuses on safety from harm, rather than self-determination. A mother (M20) specifically illustrated how staff in respite care settings are inclined to leave persons with intellectual disabilities *"sitting on chairs and they make a meal for them but the people are (my son) capable of doing that themselves".* Calling for more appropriate respite care settings, one father indicated that *"Respite care should be a priority because people who are keeping their children at home are making a huge contribution to the state and they're saving the state a lot of money and they should be offered the facility of appropriate respite"* (F2).

DISCUSSION

Respite care was an emotive issue for these family carers and they expressed their views forcefully. It emerged unprompted, as a core topic in a wider-ranging discussion about what life is like for carers in modern Ireland. Ongoing debates about the lack of respite provision have overshadowed a closer analysis of the complexity of delivering appropriate respite provision, which addresses both the needs of the family and of the person who receives the respite care. The three inter-related themes on respite care identified in this study, help define the core issues to which service providers and commissioners of services need to give closer attention.

Parents who participated in this study considered it their moral obligation to look after their children, and thought that the needs of others might be greater than their own. Yet they perceived it as essential, both for them to be able to let go and to overcome any feeling of guilt they may experience in seeking a break from caring. These findings are consistent with Hartrey and Wells (2003) who indicated that use of respite care provided "an opportunity for (their) psychological calm" (p. 340), while sending their children into respite care "led to a sense of guilt" (p. 340).

Parents felt that support from others would help them with 'letting go' and with their feelings of guilt, but often this support was not forthcoming, especially when availability of provision was constrained. Others spoke of having 'to fight' to get the services. The benefits to the carer and the wider family were also well-attested to in these findings, as in previous studies. However, parents were also balancing the potential benefits to themselves and other family members through using respite care, with the wishes of their relatives who did not want to go away from home, due to the poor quality of respite care they were likely to receive. This finding not only substantiates the requirement for a formal and comprehensive assessment of carers' needs (Disability Federation of Ireland, 2008), but also calls attention to areas of "conflicts of interest" identified between people with intellectual disabilities and their family carers in having a break from caring (Williams & Robinson, 2001). The issue of quality, or lack thereof, and "service often works for the service, not for the users" has been documented previously (p, 96, Power, 2008).

Resolving differences between service providers and users has to be part of the process of family-centred service planning. In particular, the stress for mothers needs to be proactively addressed with a range of inter-connected strategies, of which planned respite breaks is one dimension (Edmond & Eaton, 2004; Horsburgh et al, 2002). However, respite breaks are often offered as a 'stand alone' service that is unconnected to other support services provided to families. The availability of a co-ordinator for a range of family services, is one proposal for overcoming this fragmentation.

The family members affirmed that a foremost concern is the setting in which respite care is provided. They preferred more homely services, serving small number of compatible persons in a facility that was specifically for short breaks, rather than people going into residential provision using other people's bedrooms. Their preferences echo those reported in previous studies, notably person-oriented services where a high standard of care was provided and there were stimulating and fun activities (McConkey et al, 2004). Walmsley and Mannan (2009) indicate that involving parents as co-researchers is an initiative with wider potential benefits, in the development of more appropriate services and mechanisms that need to be developed to sustain their participation.

Implications for Practice and Research

The findings of this study have significant implications which are especially important for practitioners who want to become reliable allies in facilitating the uptake of respite care services. Based on themes presented in this study, social workers and allied health professionals may ask the question, *"Given parents' views on respite care and our role to enable respite services designed in consultation with families, what can we do to enhance the process and outcomes of respite care?"* The findings of this study suggest that building respite care around the needs of families is required. A much-needed alliance between all members of the family and professionals is required, in order to support one another through the difficulties associated with the uptake of respite care. A shared understanding of the trauma for families in letting their sons or daughters go, particularly where the respite options are not of high quality, should surely act as a catalyst for change. Respite care has the potential to make a difference but creative solutions are needed. This is to ensure that it provides opportunities that people would wish to use and choose naturally to be part of, as opposed to being slotted into another form of service setting.

Future research could focus on the development of integrated models of respite care for individuals with intellectual disabilities, and on documenting outcomes for individuals and their families in using appropriate respite facilities. This current study could be complemented by a National survey examining the extent to which respite care services has grown, both in quantity and in terms of standards of quality care.

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