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An Evaluation of St. Michael's House Contract Family Short Break Scheme

Mary Ryan

Science Shop Research Project



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Executive Summary

Background to the Study

Founded in 1955, SMH is a non-denominational voluntary body which provides facilities, services and supports to children and adults with an intellectual disability in Dublin City and County (SMH, 2011). This study evaluates the Contract Family Short Break Scheme (CFSBS), which is a new respite scheme set up by SMH to support children with a disability and reduce family stress, by providing access to a range of respite support options (SMH, 2011). The scheme involves independent host carers/ families in the community, who are recruited to provide short breaks in their homes for children with an ID. This evaluation was carried out from the perspective of the service user and their families.

Objectives

The overall objectives of this study were to evaluate the CFSBS from the perspective of service users, by investigating; the quality of care provided by the scheme; how accessible the service users found the scheme; whether the scheme is a support to families, and if it reduces family stress; and what service users and their families see as the strengths and weaknesses of the scheme.

Methodology

A constructivist ontology, an interpretivist epistemology, and a qualitative methodology was chosen for this study. This approach was chosen because it was considered most apt for the exploratory nature of the research into the evaluation of the CFSBS, and its effects on the family life of service users.

Results

The results of the interviews were analysed and the dominant themes that arose for the researcher were; motivating factors for using the scheme; acceptance of short breaks; desired carer qualities; overall differences to family life; and concerns around the scheme.

Recommendations

The study proposes that SMH need to build public awareness of the scheme so that more families can utilise this important family support. However, SMH also needs to be conscious of the likely demand for this service and possible need to expand the service to create extra capacity. The majority of participants of the study felt they would benefit from more short breaks again highlighting the possible need for SMH to expand the service and recruit more host families in order to facilitate these breaks. The study recommends that SMH need to ensure service users are happy during their short break experience with regards to activities and care provided. The findings of this study clearly illustrated that CFSBS helped in significantly reducing family stress and as a result improved family functioning. Overall this study found service users classified the quality of care provided by the host families of the CFSBS as excellent and were extremely happy with the running of the scheme.

Implications for practice, including social work

The results of this study indicate the need for practitioners to;

- Be aware of their role in providing the client with information around services that are available to them.
- Assess the individual requirements of the child while at the same time embracing a family centred perspective in order to find a service that is most suited to their needs.
- Provide support for the parents of service users around their acceptance of short breaks for their children.
- Possess good communication skills and ability to build a good rapport with clients.
- Recognise that parents and service users are experts in their own lives as evident based on the value participants placed on their relationships with their social worker

Author's conclusions

In conclusion, this study has fulfilled its aims and objectives and answered its core research questions. The principal findings of this study related to participants overall satisfaction with the CFSBS. However, participants would like more breaks to be made available and they identified the need for promotion of the scheme to make people aware of the service. In eliciting the answers to these questions the researcher recognised important and

consistent themes which arose around carers stress and their acceptance of breaks. The researcher also identified the requirements of good relationships and children's happiness as central to the success of the scheme, which have implications for social work practice.

Declaration

Research Title: An Evaluation of St. Michael's House Contract Family

Short Break Scheme.

Student: Mary Ryan

Student Number: 109220166

A dissertation submitted to University College Cork

in part fulfilment of Masters of Social Work (MSW)

and as part of a Science Shop project.

April 2011

Supervisor: Simone McCaughren

Science Shop Mentor: Feilim O'hAdhmaill

I hereby declare this thesis is my own work. I also declare that all names have been changed to protect the identity of all individuals involved in the research.

Signed: _____

Date: _____

Abstract

This dissertation examines the experience of St. Michael's House Contract Family Short Break Scheme for service users and their families. It uses two major research strategies to evaluate the scheme; (1) documentary research in the form of a literature review; and (2) qualitative research in the form of interviews with families of service users. The literature provides a platform for the study by exploring the care needs of children with an intellectual disability and how short breaks can support families in providing this care. The findings of this study show service users and their families are pleased with the scheme and satisfied with the quality of care provided. However, the study recommends promotion of the scheme to increase awareness of the service so that more families can utilise this important family support and expansion the service in order to create capacity for more breaks to be made available to current service users and their families.

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Abbreviations

*CFSBS = Contract Family Short Break Scheme

*ID = Intellectual Disability

*IPA = Interpretative Phenomenological Analysis

*MSW = Masters of Social Work

*SMH = St. Michael's House

*SS = Science Shop

*UCC = University College Cork

Welcome to Holland

By Emily Pearl Kingsley 1987

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this

When you're going to have a baby it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later the plane lands. The stewardess comes in and says, "Welcome to Holland!"

"Holland!?!?" you say. "What do you mean Holland? I signed up for Italy. I'm supposed to be in Italy! All my life I've dreamed of going to Italy." But there's been a change in flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible disgusting place full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you will learn a whole new language. And you will meet a whole new group of people you never would have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the loss of that will never go away, because the loss of that dream is a significant loss. But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

Chapter 1:

AN INTRODUCTION TO THE RESEARCH TOPIC

Unable to secure schooling for her son, Patricia Farrell, the mother of a young boy with Down Syndrome placed an ad in the Irish Times in 1955: *Association for Parents of Mentally Backward Children. Lady wishing to form above would like to contact anyone interested. Box Z 5061 Children.* From this grew St. Michael's House, an organisation which set out to develop new community services and bring about a change in how people with an intellectual disability were viewed

(St. Michael's House, 2011).

Introduction

1.1 Introduction to the Chapter

This chapter will introduce this research topic by providing background information on the organisation and the short break scheme and discuss the rationale behind carrying out the study. Following on from this, the chapter will outline the objectives, aims and research questions of the study. The chapter will conclude with a chapter outline briefly summarising each chapter to come.

1.2 Introduction to the Study

This study will examine the experience of a short break scheme for children with an intellectual disability (ID) and their families. The opening poem ‘Welcome to Holland’ provides an incredible insight into the emotions a parent can experience when faced with the situation of giving birth to a child with a disability. The researcher felt it was significant to include the poem in this study as it is a thought provoking piece which encourages the reader to think about how having a child with a disability can dramatically change or effect one’s life and the supports they might require.

A provider of such supports for those with an ID is St. Michael’s House (SMH). Founded in 1955, SMH is a non-denominational voluntary body which provides facilities, services and supports to children and adults with an ID in Dublin City and County (SMH, 2011). This study will evaluate Contract Family Short Break Scheme (CFSBS) which is a new respite scheme set up by SMH to support children with a disability and reduce family stress, by providing access to a range of respite support options (SMH, 2011). The scheme involves independent host carers/ families in the community, who are recruited to provide short breaks in their homes for children with an ID. This evaluation will be carried out from the perspective of the service user and their families. In order to elicit this perspective, this evaluation will involve interviews, conducted with the families of service users.

1.3 Rationale

This research was conducted as part of a Social Work Masters (MSW) degree under the auspices of a Science-Shop Project (SS). SSs are a service provided by research institutes for the Civil Society

Organisations (CSOs) in their region (UCC, 2011). Lürsen and Sclove (2001) explain that; “a SS provides independent, participatory research support in response to concerns experienced by civil society” (Lürsen and Sclove, 2001, p. 8). In this case, the SS Committee of University College Cork (UCC) sourced research projects required by various CSOs around Ireland, and offered these projects to the students of the MSW. The committee then allocated the projects based on interests of student applications. The researcher expressed interest in this project - the evaluation of SMH CFSBS. As part of this research process the findings and recommendations found by the researcher will be fed back to SMH in the form of a report. This report will identify the practical implications of these recommendations for the service provision of the CFSBS.

Consequently, a motivating factor for the researcher in choosing this research project was that it would involve a piece of live research. SMH require this research as the CFSBS is a pilot scheme that has been running for one year and now needs to be evaluated. Therefore, this evaluation serves two purposes: (i) it is required by the organisation to ascertain the strengths and weaknesses of the service, in order to ensure the quality of service they provide; and (ii) to investigate whether the scheme should continue as it is, or whether there is a need for it to be improved and possibly expanded.

Another motivating factor for choosing this project was the researcher’s ardent interest in the area of disability, and how social workers provide disability services. However, with no past experience of working in the area of ID, this research project offered the opportunity to gain knowledge of the area through direct interaction with the service providers and the families of service users.

As stated, this research was carried out as part of the academic requirements of the MSW. The researcher felt this study would be of relevance to social work practice as the CFSBS is a service to which social workers refer children with an ID, and their families as a form of family support. In carrying out this evaluation from the perspective of the service user, the research identifies the service user as the expert in his/her own care. This perspective will inform social work practice of what service users and families of children with an ID actually want and need from a short term care service. This client-centred study, will inform social work practice of the effect short-term care services can have for service users and their families.

1.4 Research Objectives

The overall objectives of this study were negotiated between the researcher and SMH. The objectives were to evaluate the CFSBS from the perspective of service users, by investigating;

- The quality of care provided by the scheme.
- How accessible the service users found the Scheme.
- Whether the scheme is a support to families, and if it reduces family stress.
- What service users and their families see as the strengths and weaknesses of the scheme.

1.5 Research Aims

From these objectives the researcher decided to investigate the views and opinions of the service from the perspective of service-users with the following aims in mind;

- Determine the quality of care provided by the host families.
- Investigate how accessible they found the scheme.
- Investigate the availability of respite options provided by SMH to service users and their families.
- Identify the needs of service users and their families regarding a respite service of this nature and if the scheme meets those needs.
- Investigate whether the scheme affected family stress.
- Ascertain the strengths and weaknesses of this scheme.
- Make recommendations for the service by identifying what service users would like to see changed or improved.

1.6 Research Questions

The research questions for this study were designed to help focus the study and were used for guidance throughout the research process. Again, these research questions were negotiated with SMH so as to ensure the questions and findings would be relevant to the organisation. From these negotiations the

researcher formulated research questions based on the view of service users of the scheme and their families, which were:

1. How did the service user find the accessibility and availability of this service?
2. What were the requirements of service users and their families for a respite scheme of this nature and were these requirements met by the scheme?
3. How did service user experience the quality of care provided by host families?
4. Did the service user and their families feel the scheme helped in reducing family stress?
5. What recommendations did service users and families have to improve the running of the scheme?

1.7 Chapter Outline

Chapter 1: Introduction to the Research

This chapter has briefly introduced the study and contains an outline of the content of the chapters to follow.

Chapter 2: The Use of Short Breaks in Caring for a Child with an Intellectual Disability

Chapter 2 will outline the theoretical framework for the study and examine the relevant literature and studies carried out in this area. The chapter will discuss a review of the literature and from this, formulate themes and questions to be further investigated by this study. The findings from this chapter will also inform and justify the particular methods of inquiry chosen for carrying out the research.

Chapter 3: Designing the Research

Chapter 3 will explain the methodology used in this research. It will answer the ontological, epistemological and methodological questions of this study, and explain the methods used for the data selection, data collection, and data analysis of the study. The limitations of this research will be examined and the researcher will outline ethical issues that arose in carrying out the study.

Chapter 4: The Contract Family Short Break Experience

Chapter 4 will bring together the findings of the research piece, all materials gathered will be collected and interpreted and the results will be given here. The limitations of the findings will also be discussed.

Chapter 5: Implications for Future Practice

Finally, in chapter 5 the researcher will conclude this piece of research. The chapter will; discuss the

research with regard to the core research questions; outline conclusions and implications for practice, based on the findings of the study; and reflect on how the researcher experienced the overall research process.

1.8 Conclusion

This chapter; introduced the research topic; explained the rationale by providing some background and context for the study; outlined aims, objectives and research questions; and illustrated a chapter outline. The next chapter will review the literature in more detail providing a basis for the rest of the study.

Chapter 2:

THE USE OF SHORT BREAKS IN CARING FOR A CHILD WITH AN INTELLECTUAL DISABILITY

I am always watching and taking care of him because in a way he is like a toddler but he has been like a toddler since he was born which is many years ago now.....as your kids get older you naturally expect their level of care go down, you know dress themselves, feed themselves etc. this has not happened with (child) due to his disability.

(Participant 1)

I felt like a pressure cooker about to explode with the stress and pressure that was building up. Now the breaks give us a chance to breathe and think.

(Participant 2)

The Use of Short Breaks in Caring for a Child with an Intellectual Disability

2.1 Introduction to the Chapter

This chapter provides a theoretical framework for the evaluation of SMH CFSBS, as well as a discussion of the literature relevant to this research. This chapter will start by describing the theoretical framework employed by this study and the reasons behind adopting this perspective. The second section will focus on the review of literature relevant to caring for a child with an ID and the use of respite. This section will outline; the historical background of respite; the development of short breaks; and discuss the features desired by service users and their families in the provision these breaks.

2.2 Part 1: The Theoretical Framework

The theoretical framework utilized for carrying out this study is that of Bronfenbrenner's (1979) ecological systems theory. This framework will serve as a lens through which a review of literature relevant to the research topic will be carried out and function as a framework to guide the researcher in evaluating the CFSBS.

Early literature on the effects of disability mainly studied the person with the disability, ignoring the family member as a legitimate focus (Scrutton, 2000). The focus of literature regarding this area has become broader since evolution of more systemic ways of thinking. These ways of thinking have been inspired by Bronfenbrenner's (1979) ecological perspective which incorporates wider environmental issues, which impinge on an individual's social action, such as contextual systems of relationships that form one's environmental structure. Bronfenbrenner's (1979) ecological system theory stresses the importance of understanding not only the relationship between the organism and various environmental systems, but the relations between such systems themselves (Bronfenbrenner, 1979 cited in Hetherington, Parke and Schmuckler, 2002) The development of this way of thinking expanded studies, such as those of children with intellectual disabilities, to look at whole families.

Recent literature highlights the importance of not viewing the individual with the disability in isolation and acknowledging the context of disability within the family (Dood, 2004; Burke, 2008). Seligman and Darling (1997) claim children are best understood as members of the social settings in which they live. For children with an ID, a systems view implies that the disability is experienced not only by the child with the condition, but by family and close friends also (Seligman and Darling, 1997 cited in

Roberts, 2001). Accordingly, this view has been taken by studies such as Cotterhill *et al.* (1997) who recommend that a holistic approach be taken when evaluating the success of models, which incorporates the different perspectives of family members.

The next section will review literature on this topic and analyse studies that have also use the lens of ecological systems theory and created an exemplary framework for this study.

2.3 Part 2: Literature Review

According to the most recent national ID database (Kelly *et al.*, 2009) there are 26,023 children and adults registered in Ireland as having an ID and of those aged under eighteen, 98% live at home (Kelly *et al.* 2009 cited in Hanrahan 2010). This illustrates families as the predominant providers of essential care and support for children and young adults who have intellectual disabilities (CSO, 2010). Irish government policy has recognised the benefits of living with family. Caring for a child at home is supported by the National Policy on Child Welfare (Dept. of Health and Children, 1999) and is outlined in the Childcare Act 1991 that it is in the best interests of a child to be brought up in its own family.

2.4 Caring for a Child with an Intellectual Disability

Although there are positive aspects associated with the role of caring for a child with an ID within the home, such as self-fulfilment (Lane *et al.*, 2000 cited in Hartrey, 2003), there are also well-documented negative aspects. Studies such as Hearne and Dunne (1992), Treneman *et al.* (1997), and Hoare *et al.* (1998) highlight these aspects noting the association between high levels of carer stress and caring full time for a child who has an ID.

Many children with an ID require full time care. The opening quotes to this chapter describe this care and the impact it can have on carers, these will be discussed further in chapter 4. Connaughton and O'Donovan (1999) describe how the care of a child with an ID can involve lifting, feeding, toileting, bathing and dressing (Connaughton and O'Donovan, 1999 cited in Hartrey, 2003). As a result of these increased care-giving demands, Plant and Sanders (2007) suggest it is reasonable to assume that parents of children with developmental disability are at increased risk for high levels of personal stress.

Studies such as Plant and Sanders (2007) suggest that many primary carers, at least at one time or another; feel overwhelmed, frustrated, unsupported and stressed as a result of their caring role. The origins of this stress can vary although Wallander and Pitt (1990) suggest it may be a combination of many factors such as the degree of daily physical care for the child, reduced social and leisure time, disruption to employment, financial strain, and feelings of guilt and isolation.

These identified stressors involved in caring for a child with a disability can affect the whole family by placing strain on family members and as a result cause significant disruption in family relationships (Gath, 1973).

However, access to appropriate support services such as respite can help carers and families cope with the stress of caring for a child with an ID's needs. MacDonald *et al.* (2006) claim respite care is a key strategy to support children with an ID and their caregivers.

2.5 What is Respite?

A commonly used definition of respite provided by Treneman *et al.* (1997) is “the shared-care of a person with learning disabilities and/or physical disabilities, either at home or in a short-term residential setting, in order to give the family a break from routine care-taking” (Treneman *et al.* 1997 cited in Wilkie and Barr 2008, p. 30). Respite usually takes place outside the family home. This type of care is seen as complementary to family care, rather than substitute, in order to support care givers in their role.

2.6 Why use Respite?

In 2008, 4,549 children and adults received planned respite breaks (Kelly *et al.*, 2009, p. 40), however, the demand for respite is steadily increasing. Access to regular, high-quality respite care can have a beneficial impact on a carer's ability to fulfil their caring role by supporting carers in a variety of ways. Lindsay *et al.* (1993) outlines: “1. It can give a child an opportunity for additional experiences outside the family home; 2. It can support the carers of the child; 3. It can prevent family breakdown and / or rejection of a child; and 4. It can avoid the possible admission of the child to long-term residential care or the necessity to find a substitute family placement” (Lindsay *et al.*, 1993 cited in Hoare *et al.*, 1998, p. 218). A review of respite literature for this research revealed the most common reasons for availing

of respite as; use as a coping strategy; need for a break; benefits for the child; and to enhance family functioning.

2.6.2 Coping strategy:

According to Lazarus and Folkman (1984) coping strategies include any attempt or effort to manage stress, regardless of how well it works. Judge (1998) explains this further by describing coping strategies as efforts to amend the cause of the stress and attempts to regulate emotional responses to the stressors. Respite care is an important strategy used by some carers of children with disabilities to help manage the emotional stress that can be associated with caring. Several studies have provided evidence regarding the beneficial effects of respite care particularly for mothers such as McGill (1996) and Botuck and Winsberg (1991) which found as a result of respite mothers were less stressed and were more involved in activities outside the home (McGill, 1996; Botuck and Winsberg, 1991 cited in Hoare, 1998).

2.6.3 Need for a break:

Hoare et al. (1998) identified the principal reasons for a carer's use of respite services are exhaustion – both physical and emotional. According to Ptacek *et al.* (1982), the provision of respite allows a 'revitalisation' to occur for carers. In this way respite enables parents to carry on caring for their child at home by offering temporary relief from the demands of caring. Thus, Wilkie and Barr (2008) argue benefits of respite care to families and informal carers should not be underestimated.

2.6.4 Benefits for the child:

Good quality respite provision according to Flynn *et al.* (1995) can be constructive to the quality of life of service users by extending the available opportunities. Likewise, Cotterhill (1995) suggests "respite can provide positive opportunities for service users in terms of increased independence, a widened range of activities, improved quality of life and social integration" into the community (Cotterhill, 1995 cited in Cotterhill *et al.*, 1997, p. 777). These claims are confirmed by Truesdale-Kennedy *et al.* (2006) study on support services for children with an ID which reports that the children involved had become more independent and developed new skills notably in socialising and communicating.

2.6.5 Family functioning:

Respite can also facilitate the enhancement family functioning. According to Sines (1999) and Marc and MacDonald (1988) families commonly report that respite care enables them to make time for all

family members and do a wider range of activities as a family. The effects of this break and time spent with other family members can lead to a general decrease in family tension and improvements in family relationships and in turn family functioning when the child returns home.

2.7 Problems Associated with Respite

However, despite these benefits, some studies such as that of Hartley and Wells (2003) and Wilkie and Barr (2008) indicate that respite can also be a source of emotional stress for carers as they can experience ambiguous emotions. On the one hand many carers experience relief and gratitude when given a break from the duties of caring, while on the other, the experience can link these emotions to feelings of guilt and embarrassment. As a result, Hoare *et al.* (1998) note “the use of respite care has become an emotive issue for many carers as some believe that the use of this service indicates their inability to cope” (Hoare *et al.*, 1998 cited in MacDonald, 2007, p. 64).

2.8 History of Respite

As stated earlier, it is common for most children with an ID to live at home with informal support from family members. However this approach to care people with intellectual disabilities has only come about in the last few decades, as care has moved from long-stay hospitals to community-based options (Braddock *et al.*, 2001 cited in Wilkie and Barr, 2008). As a result of moving from institutional to community care, children with disabilities in Ireland are predominantly being cared for at home usually with formal support from services or agencies in the form of respite. The majority of respite facilities in Ireland are provided by a range of voluntary organizations and religious orders, which are partly financed by the State.

Respite care was stipulated as a requirement in every health board area in Ireland in 1996 (Report of the Irish Commission on the Status of People with Disabilities, 1996, p. 23). It was proposed that services should be expanded to including a range of respite options. Following this period (1996–2003) there was a 314% increase in the number of individuals availing of service-based respite services (Barron and Mulvany, 2004, cited in MacDonald, 2006, p. 63). However, despite an expansion of

services, the Department of Health and Children (2001) reported there were still unmet needs in the overall range of support services required by people with disabilities.

Respite is defined in the Chambers dictionary as “the temporary cessation of something that is tiring and painful, which implies that caring for a disabled child is a burden and that respite is the temporary removal of that burden” (Carlin, 2008, p. 3). Today the term ‘short breaks’ is used in preference to ‘respite care’, due to the negative implications which the term ‘respite’ carries. Carlin (2008) explains the above definition of respite places an emphasis on the needs of the parent, rather than on the needs of both the disabled child and their family. The term ‘short break’ is therefore used, in recognition of the fact that short breaks are seen as a positive method of support, from which children should benefit as well as their parents (Tarleton and MaCaulay, 2002).

2.9 Definition of Short Breaks

The Shared Care Network uses the following definition of short breaks:

Short breaks provide opportunities for disabled and other vulnerable children and young people to spend time away from their primary carers. These include day, evening, overnight and weekend activities and can take place in the child’s own home, the home of an approved carer, a residential or community setting

(Carlin *et al.*, 2004, p. 3).

A range of short-term breaks or respite services have become available in recent years to families who have a child with an ID. McConkey *et al.* (1999) outline the options as; short stays in residential homes or hospital settings; the child staying with a host family; as part of a residential holiday; or a care worker staying in the child’s home.

2.10 Family Based Short Breaks

According to Stalker (1990) the host family or family based respite model was pioneered in Canada, America and Britain in the early 1970s, as an alternative to traditional residential ‘respite’. The family-based short breaks consist of the recruitment of individuals, couples and families from local

communities as carers and matching them with people with disabilities. Carlin *et al.*, (2004) describe the aim of the breaks to give people with disabilities, and their relatives, a break from their everyday routine and to provide positive opportunities for real and sustainable social contact. The amount of care provided can vary from a few hours a week to several days each month

Carlin (2008) notes that prior to the introduction of family based short breaks, many of the children would have either remained on waiting lists for long periods of time or would have been referred to residential short break services for overnight short breaks. Hanrahan (2010) asserts that there is no doubt that family based short breaks are the way forward and are fit to support families to nurture their children at home.

2.11 Why choose Family Based Short Breaks

The form of respite service most valued by carers of children with an ID is that which is family and home based, rather than hospital and residential based (Cotterill *et al.*, 1997; Sines 1999 cited in Hartrey, 2003). Families often express a preference for using family-based respite services. Cotterhill *et al.* (1997) suggests that families value the flexibility of family based services due to its availability in emergencies (Cotterhill *et al.*, 1997 cited in McConkey and Adams, 2000). Some carers believe that family based service means their child will be cared for in a ‘more ordinary’ environment or it provides greater consistency because fewer people are caring for their child (Carlin, 2008, p. 10). While McConkey *et al.* (2004) found parents felt family based short breaks gave their children the opportunity to build trusted relationships with the host parents and their family and open up their social world.

However, while the benefits of family based short breaks are clear, this ideal has been hard to realize due to availability of such breaks. The demand for short breaks is often likely to exceed supply as they are a much-valued service by families. McConkey *et al.* (2004) study found that this demand for family based short breaks can mean a reduced choice of dates for parents. Furthermore, in certain geographical areas, a range of short break options may not yet be established (Robinson and Stalker, 1993 cited in McConkey and Adams, 2000). Hence, families can often end up accepting whatever form of service is available rather than the one which best suits their requirements and those of their child.

2.12 Desired factors of Short Break Schemes

McConkey *et al.* (2004) study identified significant features of short break services for children with an ID which carers valued in services. They were; “small, homely services in pleasant surroundings with a child orientated approach, and high care standards” (McConkey *et al.*, 2004, p. 71). This review of respite literature recognises the features of Short Break Schemes desired by carers as; a family centred approach; quality of care; well matched needs; access; support of professionals; and their child to have a good experience of the breaks.

2.12.1 Family centred approach:

Family-centred approaches have been recognised internationally as the most ecologically appropriate way of working with families (Dale, 1996) and are seen as a “best practice approach” to meeting the needs of children with disabilities and their parents (King *et al.*, 2003 cited in Truesdale-Kennedy *et al.* 2006, p. 378). A family centred approach to short break services has been found to be highly regarded by parents of service users as it stresses the family’s role in decision-making about their child, and recognises parents as the experts on their child’s status and needs (Rosenbaum *et al.*, 1998 cited in Law, 2003).

2.12.2 Quality of care:

Quality of care is an important aspect of short break services as the knowledge that good quality care is being provided for children has been found to give parents peace of mind. Hubert (1991) points out respite services have sometimes been slated regarding the quality of care they provide, and their lack of understanding of the emotional needs of the parents and siblings (Hubert, 1991 cited in Hoare *et al.*, 1998). Good relationships between host families, service users and parents are critical to this understanding as noted by Cotterhill *et al.* (1997).

2.12.3 Well matched needs:

McConkey and Adams (2000) stressed the importance of support services being matched to the needs and preferences of families. Consistent with this Swift *et al.* (1991) claims good quality respite is one that listens to what “users are saying and is one that is needed, reliable, flexible, responsive, and personalised” (Swift *et al.*, 1991 cited in Cotterhill *et al.*, 1997, p. 780).

2.12.4 Access:

It has been shown that short breaks are most effective to families when they are thoughtfully planned and easily accessed. Sholl *et al.* (1991) report that one of the most important factors affecting the choice of respite service is that it was available locally.

2.12.5 Support from professionals:

As mentioned earlier, experiencing the benefits of a respite service can often allay feelings of guilt and anxiety for many carers of children with an ID. Therefore, professionals such as social workers need to be aware of the distress respite separation can cause to carers and provide appropriate support and preparation prior to the child entering respite care “so that family carers can feel that respite is an integral and legitimate part of being a caring carer” (Hartrey *et al.*, 2003, p. 341).

2.12.7 Child’s happiness:

Good quality short break provision can contribute positively to the quality of life of service users by providing them with experiences and social activity they would not otherwise be exposed to. Consistent with this view, Cotterhill *et al.* (1997) claim that short breaks should provide service users with opportunities for increased independence, a widened range of activities, improved quality of life and social integration into the community (Cotterhill *et al.*, 1997 cited in McConkey *et al.*, 2004).

2.13 Conclusion

This chapter has discussed the theoretical framework employed by this study and explained why an ecological systems theory approach is an appropriate framework in carrying out this research. Following this, the chapter illustrated literature and other previous studies that have been carried out using this approach and that have created an exemplary framework for this study.

The literature review section of this chapter, has discussed some of the requirements of caring for a child with an ID and the effects of this care on the caregiver. It has shown that as a result of these effects there is a need for short-break services.

This literature review has illustrated the literature available about respite services tends to focus on the perspective of carers rather than that of the primary users of short break or respite services. The researcher found it difficult to find studies which adopt the perspective of the primary service user,

however, an exception to this is a review of respite services in Liverpool conducted by Margaret Flynn in partnership with people with learning disabilities (Flynn *et al.*, 1994). Consequently, the researcher has chosen to evaluate the scheme from this perspective as this research agrees with Cotterhill *et al.* (1997) that “the experience of service users is the crucial ingredient in the enterprise of evaluating the quality of a service, and the nature of the benefits it brings to service users and carers” (Cotterhill *et al.*, 1997, p. 780). The researcher believes that an insight into the service user perspective enables providers to “address the needs and wishes of service users for positive experiences and integrative opportunities; and, at the same time, provide carers with a break which they are ‘happy with’” (Cotterhill *et al.*, 1997, p. 783). An evaluation, therefore, from this perspective will be beneficial to both SMH and its service users as it will provide a chance for service users and carers to express their views and opinions and at the same time provide the organisation with this valuable information in order to incorporate it into their service and match the needs of service users.

The findings from this literature review will inform and justify the design of this study which will be discussed in detail in the next chapter. It will also inform the interview questions and methods of analysis chosen by the researcher, which will be discussed in later chapters.

Chapter 3:

DESIGNING THE RESEARCH

And then, there are times when I think my whole life has been shattered into pieces -- all our plans and our ideas of how the second half of our life was going to be.....A mother of a child with Down Syndrome said that the one piece of advice she would give us was to remember always that Mary is our baby, one half of each of us, and not a member of some tribe of Down's people, a membership that sets her apart from us. That was a very helpful insight. And Mary reminds us all the time that she is one of us

(Brendan O'Connor, 2010)

Designing the Research

3.1 Introduction to the Chapter

The researcher found this opening quote by O'Connor (2010) clearly portrays the range of emotions a parents can experience when faced with the situation of giving birth to a child with an intellectual disability. This insight made the researcher aware of the need to design this study in way that would be sensitive to participant's experiences.

In order to evaluate the CFSBS the researcher will conduct an empirical piece of evaluative research. Matthews and Ross (2010) explain that empirical knowledge is knowledge based on available research evidence. The available research evidence will involve documentary research on secondary sources. According to Greene (1994) evaluation research is concerned with the evaluation of occurrences such as social and organisational programmes or interventions, and investigating to see if the programme has achieved its anticipated goals. Evaluative research is, therefore, suited to this study as the purpose of this study is to investigate if the CFSBS has achieved its goals of supporting families of a child with an ID, and reducing family stress. The findings of this study will be used by SMH to inform decisions on the running of the CFSBS. This chapter will look at how the researcher set about evaluating the service and made decisions on how to carry out the research based on theoretical approaches and research methods appropriate in evaluative research. The researcher made these decisions, bearing in mind McConkey's (1996) argument for the need for more human and socially valued approach to evaluation, which requires involvement of the client as a receiver and evaluator of his/her services.

3.2 Inquiry Paradigm

This chapter will now demonstrate how a particular research approach was chosen and implemented in the carrying out of this study. According to Patton (2002), a well-considered research strategy provides a framework for decision making and action, by providing overall direction. The research strategy for this study is largely informed by the work of Guba and Lincoln (1994), who refer to these frameworks for research as inquiry paradigms which define for the researcher the legitimate limits of inquiry. They suggest that "a paradigm may be viewed as a set of basic beliefs (or assumptions) that deals with ultimates or first principles" (Guba and Lincoln, 1994, p. 107). The researcher's basic beliefs and

assumptions determine the inquiry paradigm and are derived from the answers to three metaphysical questions; the ontological; epistemological; and methodological questions.

3.3 The Ontological Question

According to Della Porta and Keating (2008) the ontological question asks what ‘reality’ is and what is known about ‘reality’. Guba and Lincoln (1994) discuss possible answers to this question under four different paradigms, each with their own assumptions: positivism, post positivism, critical theory, and constructivism. The ontological position taken by the researcher for this study is constructivism. Guba and Lincoln (1994) explain ‘reality’ is a construction of the human mind shaped by experiences of the world, it is dependent on the individual and changes with new information, this is known as constructivism.

Popper (1979) explains that constructivist ontology is in direct contrast to realist ontology. The latter is associated with positivism and its belief that it is possible to obtain objective knowledge. The objectivist approach which is found in the paradigms of positivism and post positivism would not facilitate the study of the feelings and attitudes of the participants of this scheme as ‘objectivism asserts that reality exists independent of social actors’ (Bryman, 2004, p. 16). A constructivist position suggests that social properties are outcomes of the interactions between individuals. Therefore a constructivist ontological position is appropriate for this study as it looks at the experiences and interactions of participants, and how they view the world and in this case the CFSBS.

3.4 The Epistemological Question

According to Della Porta and Keating (2008) epistemology is about how we know things. In other words, it requires the researcher to ask themselves how they will interact and interpret the phenomenon of which they are interested in studying. Matthews and Ross (2010) outline the three different epistemological positions – positivism, interpretivism and realism.

Under the ontology of constructivism the epistemology of this research is interpretivist as the research deals with people’s experiences. An interpretivist epistemological position was taken for this research as an ‘interpretivist epistemological position prioritises peoples subjective interpretations and understandings of social phenomena and own actions’ (Bryman, 2004). Neither positivist nor realist

epistemologies would be applicable in this study as they adopt an objective approach and ‘assert that knowledge of social phenomena is based on what can be observed or recorded’ (Bryman, 2004), rather than subjective interpretation.

Using an interpretative approach allowed the researcher to focus on the participant’s views of the CFSBS and the meaning of these views. The researcher was interested in learning how families understand their realities of living with a family member with an ID and how they experienced the CFSBS. An interpretative approach made this objective possible. The rationale for this study is based in the premise that people’s perspectives should be respected and understood and the interpretative approach ensures this by enabling the researcher to include the participants’ voice in the study. This approach also stems from the idea that events and experiences may have different meanings for different people (D’Cruz and Jones, 2004, p. 46) and so this study acknowledges that everyone’s experience of disability is unique.

3.5 The Methodological Question

Della Porta and Keating (2008) refer to the methodological question as the instruments and techniques we use to acquire knowledge. Guba and Lincoln (1994) explain this question asking how the researcher will go about the research. The constructivist ontology and interpretivist epistemology outlined above requires interaction between the researcher and the subject of the research to form an agreed and informed construction through dialectical exchange. This form of interaction is best suited, therefore, to take place through a qualitative research design.

Qualitative research designs contrast with controlled quantitative “experimental designs where ideally the investigator controls conditions by manipulating or changing external influences where a very limited set of outcome variables is measured” (Patton, 2002, p. 39). In this study, the researcher has set out to understand and record the reality of participant’s experience of the CFSBS, making no attempt to control or eliminate situated variables or programme developments but accepting the complexity of a changing programme reality (Patton, 2002). Hence, a qualitative research methodology was seen as most suitable for this study as it centred on understanding families perception of the CFSBS.

3.6 Methods

Patton (2002) explains qualitative research methods “are often used in evaluations because they tell the programme’s story by capturing and communicating” the participant’s “stories, the purpose of which is to gather information and generate findings” that illuminate the “processes and outcomes of the programme for those who must make decisions about the programme” (Patton, 2002, p. 10). These methods combined with a constructivist ontological position allowed the researcher to gain a greater understanding of the experiences of the participants of the CFSBS. According to Guba and Lincoln (1994) interpretative research requires the researcher to watch, listen, ask, record and examine. This interpretive approach then dictated what methods could be used in this study.

Methods can be defined as research techniques which are employed to gather information and analyse data. Two main methods were used in this study; document analysis; and fieldwork. Patton (2002) claims field work is central to the activity of qualitative inquiry as it entails having direct and personal interaction with people under study in their own environments. The fieldwork methods used in this study took the form of interviews with the families of service users.

3.6.1 Document analysis:

In order to ensure the document analysis undertaken was credible the researcher was mindful that documents accessed were from authentic and credible sources (Flick, 2006). The researcher used online and hardcopy literature search protocols (Hart, 1998, p. 34) to design a search strategy. The main literature identified were academic publications, commissioned reports to government and non-government organisations, legislative acts of government and official publications (Meriman and Canavan, 2007). The researcher used the UCC portal for access to library catalogues, electronic journals and databases. A number of search engines were used to examine a wide range of these databases such as EBSCO, SAGE, J-STOR AND INGENTA using key search words associated with short breaks and respite such as ‘short breaks’, ‘respite’, ‘ID’, ‘children’, ‘and ‘social work’. This source of information was also supplemented by electronic and manual bibliographic searches.

This documentary analysis formed the foundation of this research project. It allowed the researcher to construct a detailed literature review on the respite services available for children with intellectual disabilities. It also proved useful to gather such secondary research, as it highlighted the key issues that families of a child with an ID can experience, and their requirements for a respite service. These issues were then utilised to construct an interview schedule.

3.6.2 Sample selection:

In order to select a sample for the study, SMH initially sent a letter to all participants of the scheme notifying them that a researcher would be getting in touch with them to evaluate the CFSBS and that they were under no obligation to take part. The researcher then sent a letter to all families of service users involved in the scheme, explaining; the purpose of the research; the fact the evaluation would be conducted by an outside body; what would be expected of participants of the research; and anonymity and confidentiality aspects of the research. This letter asked that families wishing to participate in the research should; fill out the enclosed consent form and reply to researcher using the enclosed addressed envelope. A sample was then picked for the research from the first six replies received.

3.6.3 Data collection:

Due to the qualitative, interpretivist approach employed for this study, the research data was collected via interviews in the homes of the families of service users, using open ended questions. As Patton (2002) explains, a qualitative approach means people are interviewed with open ended questions in places and under circumstances which are comfortable and familiar to them. The researcher decided on the interview questions based on the findings of the literature review and based on discussions with SMH. This process involved refining the interview questions to suit both the interests of the researcher and the organisation. As a result the researcher decided to use semi- structured interviews as they enabled the researcher to appreciate the interviewees 'perspective'. This reflects the constructivist ontological position of this study and at the same time answers the questions required by SMH. According to Smith and Osborn (2003) a semi-structured approach facilitates rapport with the participant, allows flexibility of coverage, and allows the interviewer to explore unique participant responses. The researcher audio taped each interview so as to facilitate for accurate transcription and to help the interview run smoothly.

3.6.4 Data analysis:

Data analysis, which was conducted during and after data collection, involved "the identification of dominant themes and the clustering of themes into categories" (Merriam, 1988 cited in Agostinho, 2005, p. 4). The audio-taped interviews were transcribed and analysed through Interpretative Phenomenological Analysis (IPA) which is a form of thematic coding. According to Smith and Osborn (2003) IPA aims to explore how participants make sense of and understand their personal and social

world, in particular, the meaning they attribute to experiences, events, and states of mind. This method will be discussed further in Chapter 4.

3.7 Ethical Considerations

As “social research is conducted by, for, and about people, there is always the potential to harm others” (Estenberg, 2002, p. 44), this is why it is necessary to consider ethical issues when carrying out a social research study. The evaluation of the CFSBS raised a number of ethical considerations for the researcher. In order to ensure the researcher protected the interests of the families interviewed the following ethical issues were identified, considered and adhered to throughout the field work.

3.7.1 Ethical approval:

The researcher sought approval for this research by submitting a research proposal (*see Appendix A) and interview schedule (*see Appendix D) to the Ethics Committee in SMH prior to contacting service users and families. The committee recommended some alterations which the researcher included before making contact with service users.

The Ethics Committee and the researcher decided that the research would be carried out from the perspective of service users however the parent/guardian of the service users were to be interviewed rather than the children themselves in order to illicit this perspective. This was considered to be most ethically appropriate technique as the service users are children with an ID, therefore, there would have been issues regarding informed consent and the children’s capacity to articulate the service user’s perspective.

3.7.2 Informed consent:

The initial letter sent out to families of service users involved in the scheme outlined the confidentiality aspects of participating in the research and explained that withdrawal from the study was possible at any time. It outlined the timeframe for the target families to consider whether they wanted to participate or not, and they were provided with contact details so that they could get in touch with the researcher if they felt they needed more information upon which to base a decision. All participants of the research signed the consent forms (*see Appendix C) prior to interviews and were archived. The researcher obtained each participant’s consent on record for the interviews to be audio taped at the beginning of each interview.

3.7.3 Confidentiality:

All aspects of confidentiality were outlined to research participants in both the initial letter and at the beginning of each interview. Any information regarding the research sample was kept confidential and the organisation was not informed. The interviews were transcribed by a member of the administrative staff of SMH. However, a confidentiality agreement (*see Appendix E) was drawn up and signed so as to ensure no other staff of SMH were privy to the information transcribed. Once interviews were transcribed the researcher replaced all the participant names with pseudonyms and ensured any identifying information was omitted from the final report presented to SMH. Darlington and Scott (2002) recommend using theme based headings to present findings in a disaggregated way to “reduce the risk of recognition” and this was employed when distilling the findings (Darlington and Scott, 2002, p. 29). The audio tapes were also destroyed after the findings had been written up.

3.8 Limitations

A limitation to this study was the low number of participants in the research sample. Six replies were received for the sample however, only five could be used as one of the replies had been sent to SMH, therefore, breaking the criteria of the confidentiality of that participant.

3.9 Conclusion

This chapter discussed and justified the research approach which was selected for the purpose of this study. It was decided that a constructivist ontology, an interpretivist epistemology, and a qualitative methodology was appropriate for the research aims, objectives and questions. This approach was chosen because it was considered most apt for the exploratory nature of the research into the evaluation of the CFSBS, and its effects on the family life of service users. The chapter then discussed research design issues which needed to be addressed prior to going to the field. Documentary research of the literature was a crucial resource in making these methodological decisions, concerning: sample selection; data collection; and data analysis. Following on from this, the chapter reflected on the ethical considerations undertaken throughout the entire research process namely; ethical approval; informed consent; and confidentiality. Lastly, the chapter looked at limitations of the research design. The next

chapter will give a detailed analysis of the findings of the study and explore further limitations encountered.

Chapter 4:

THE CONTRACT FAMILY SHORT BREAK EXPERIENCE

She is like part of their family now, the carer is like her second Mam

(Participant 4)

The Contract Family Short Break Experience

4.1 Introduction to the Chapter

This chapter contains two sections; first it will discuss the method of analysis used in this study and secondly illustrate the findings of this analysis. The latter will explore and analyse the meanings of these findings in relation to available literature and research.

4.2 Part 1: Method of Analysis

For the purpose of this study the parents of five service users of the CFSBS were interviewed. The interviews were recorded and individually reviewed and transcribed. The transcripts were then analysed using Interpretative Phenomenological Analysis (IPA) as according to Smith and Osborn (2003), IPA is a suitable approach when one is trying to find out how individuals are perceiving the particular situations they are facing. This analysis involved the identification of emerging patterns, common themes and key points which were then used to distil findings.

4.3 Part 2: Findings and Analysis

This section will discuss the themes identified under the interview question topics and examine the meanings of these themes in relation to this area of research.

4.4 Topic 1: Accessibility and Availability

When asked how participants became involved with the CFSBS, the researcher found all participants were previously involved with SMH through use of other services provided by the organisation. The majority of participants revealed the scheme had been recommended to them by their social worker as a form of support as they were not in receipt of any respite care. The remainder revealed that although they were in receipt of residential respite they felt it was not meeting their needs, and as a result their social worker offered this scheme.

4.4.1 Motivating factors:

A dominant theme throughout every interview was that of stress. Each participant expressed feelings of stress and need for a break as motivating factors for becoming involved with the scheme. Participants depicted this stress by using phrases such as: *'I was pulling my hair out'* (Participant 4). This theme corresponds to the studies of Chan and Sigafos (2000) and Robinson *et al.* (2001) which found carers of children with an ID are more likely to experience stress and need intensive support. Participant 2 recounted her feelings of stress and need for outside support: *'we were worn out, I felt like a pressure cooker about to explode with the stress and pressure that was building up'* (Participant 2).

4.4.2 Why family based short breaks?

The researcher found participants commonly held the view that there were respite options available to them within SMH; generally residential respite or the CFSBS. However, they largely believed the residential respite to be unsuitable. One participant did not have an alternative respite option within SMH but she believed this was due to the young age of her child and saw this scheme as *'the first step on the respite ladder'* (Participant 1). This finding contradicts the recommendations of Hanrahan (1997) and Carlin *et al.* (2004) which propose family-based respite should be offered as part of a wide range of service options (Hanrahan, 1997 and Carlin *et al.*, 2004 cited in Hanrahan 2005).

A consistent perspective was found among participants regarding reasons for choosing family based respite. Participants outlined the family setting of the CFSBS as an appealing factor in respite choice as they believed it to be a more 'normal' setting for their child. Participant 2 described the *'idea of a family setting is comforting'*. Participant 4 informed the researcher that she viewed this type of break as *'more personal'* and saw the chance of getting to know the carer as important in her choice of respite. This view concurs with those found by Stalker and Robinson (1994) which found "parents appear to be more satisfied with breaks provided through family link schemes than they are with residential homes or health authority provision" (Stalker and Robinson, 1994 cited in McConkey *et al.*, 2004).

Many of the participants highlighted their understanding that the CFSBS would facilitate a gradual progress into respite care as they were not involved with respite schemes previous. Participant 1 gave details of her need for this gradual process:

Initially the idea of respite did not sit well with me....to give one of my children away...the gradual process gave me time to become comfortable with letting go and realise this is not the case.

This need for a gradual process was reiterated by other participants also. They saw the CFSBS as flexible in this regard, that they could go and meet the carers and their home and build up the short breaks in a way that both they and their children were comfortable with.

Verifying the results of Truesdale et al (1998), the researcher found the participants perceived the family short breaks as beneficial to their children. All participants mentioned the one to one attention of the CFSBS as a factor which they regarded as important in meeting their child's needs. Participant 3 stated '*we identified the family break as much more in our favour as oppose to the residential because (child) gets complete one to one attention*'. Additionally, participants felt the scheme would be beneficial to their children as it is an opportunity to open up their social world and meet new people. This is comparable to McConkey et al. (2004) study which found parents had concerns, that their child should also gain from the short break experience and saw the breaks as "an opportunity for their child to interact with others and to experience different activities" (McConkey et al. 2004, p. 71).

4.5 Topic 2: Requirements and Expectations

The researcher found participants expectations and requirements of the scheme varied. However, a common response was that they did not know what to expect but just hoped it would suit their child's needs. Participants explained '*we did not know what to expect, it was more a matter of meeting the carers and seeing how they coped with (child) more than anything*' (Participant 3). Participants gave accounts of how they had anticipated their children would be happy and comfortable in their place of respite and be well cared for; '*I expected or hoped (child) would have a great time*' (Participant 1). Participant 2 spoke of her trust in SMH regarding the carers and how she expected '*their carers would be well trained, garda vetted etc. ...we were not let down*'. Participants commonly applauded the scheme describing how it had exceeded all their expectations.

4.5.1 Acceptance:

Participant 1 raised an interesting point and described how she had hoped the scheme would help her to accept respite breaks for her child:

....that I could get to a point where I would not always be on high alert.....I am always on high alert with (child) and you never quite relax. I

think managing to kind of get yourself off that high alert for a few hours and realise that it is not a bad feeling not to be looking out for (child) all the time is important. There is no question about it, my expectations have been met.

The researcher found this view of the need for participants to accept breaks arose in many of the interviews. Wilkie and Barr (2008) documented similar findings and suggested these negative emotions around accepting respite can often stem from a mother questioning her parenting and coping abilities and / or the notion of ‘sending my child away’. Participants informed the researcher how knowing their child was being well looked after while on the short break and that they were being occupied with activities they enjoyed, were important factors in accepting the breaks and relieving stress and worry around using the CFSBS. This is consistent with the recognition of Nolan and Grant (1992) and Levin *et al.* (1994) that “the experience of respite should be positive for the person actually using the service as well as for the carer” (Nolan and Grant, 1992 and Levin *et al.*, 1994 cited in Cotterhill *et al.*, 1997, p. 777). Participant 1 explained ‘*knowing that I could not have him in a better place reduces the stress of letting (child) go*’. Participant 4 also noted ‘*the comfort if letting (child) go, you know, I don’t have to worry about (child) because (child) is well looked after*’.

Participants identified the social workers role in assisting their acceptance of the short breaks as crucial. Social workers aided participants in this regard by preparing the participant and child for the short break and acting as a support throughout the process. Participant 4 described:

The social worker helped a lot because you know, I’d say right, I don’t know whether I am ready yet to let her go on her own, but the social worker helped me with that.

This view is supported by Hartery *et al.* (2003) which emphasise the role of social worker regarding the provision of support for parents around accessing respite. Participant 4 also highlighted another interesting point regarding the payment of carers and how this helped her in acceptance of the short breaks:

One thing I feel as well is that I am not under any obligation, they are being paid, which in a way is a good thing, do you know what I mean, I don’t know if you understand that, but I don’t feel they are doing it for nothing...now they are doing an excellent job and I would not take that

away from them but I think them being paid makes me feel better. The social worker helped me realise this also.

4.5.2 Use of short break time:

Participants of this study consistently reported using the short break time to do things with their other children; *'we do things with our other child and give (child) the chance for some one-to-one attention that (child) would not otherwise get'* (Participant 2). Likewise, McConkey et al. (2004) found the primary value of respite valued by parents is the chance to have a break and the chance to spend time with other family members. Participants reported making a point of going out for the day and using the time to do things they could not do if their child with an ID was at home such as going out for meals, shopping, or walks, things that *'normal families take for granted'* (Participant 1). These experiences are supported by Seltzer and Heller (1997) as they consider it is generally accepted that caring for a child who has an ID can involve frequent disruption to family routines and activities.

Two participants relayed accounts of just taking the time to relax and how just having the option to do nothing is a great feeling. Participants described an overall feeling of calmness during these periods; *'the house is real calm...I have to say everyone is calmer'* (Participant 4). Participants supported Mullins et al. (2002) by revealing their use of this time to distress:

Like the type that (child) is, like you are always on tender hooks until (child) is in bed asleep and then you can distress yourself, so it's kind of when (child) is not here you are distressing and you are relaxed

(Participant 4).

4.6 Topic 3: Quality of Care

Participants unanimously described the quality of care provided by the carers as excellent and believed the knowledge and skills of the carers around caring for their children could not be faulted; *'they are absolutely brilliant, I am delighted with them'* (Participant 1); *'they are really good I can't praise them enough'* (Participant 2). The researcher found the overall standard of care provided by the carers was regarded by the participants as exceptional.

4.6.1 Carer qualities:

Participants consistently praised carers around; their concern for their children and their safety; their communication skills; their reliability and consistency in providing breaks; and their understanding of their child's disability. Participant 1: *'they are so caring and conscientious'*. Another stated:

They are so tuned into (child) safety, it makes it much easier knowing (child) is in safe hands.....also the carer will ring me before planning activities for the weekend, great communication

(Participant 2).

These views correlate with those found by McConkey et al. (2004) which outlined carer qualities as significant.

4.6.2 Relationship with carer:

Participants of this study expressed the value they place in their relationships with carers. Similarly, Cotterhill et al. (1997) claims good relationships form the basis of good quality service provision by facilitating people to develop a trust and confidence in those services. At various points in the interviews participants noted the importance of having a good relationship with carers and how this relationship has helped them in a number of ways especially around acceptance of breaks and in reducing their worries about their child while on the breaks. Participant 4 depicted her relationship with the carer and explained how she feels this relationship is helped by the fact the carer really understands her child:

What I find sometimes is that like, it's hard to kind of describe certain things with (child) and you know I'd see them but would be hard to put across...but like the carer, she is seeing what I see and really understands. We would sit and have a chat and you know like I am happy for her then to say well I have noticed this or that because you know even after all this time (the disability) is hard to accept. So it's a good thing, someone else being able to sit there and you know they understand.

4.6.3 Respite needs:

Participants generally stated they were happy that the CFSBS is meeting the respite needs of their family. However most participants said they would like more breaks and the others said they would like more breaks as their children got older. All participants reported that the time and dates of the breaks are given to them in advance so they work around these break. Each participant felt the locations of the short breaks were extremely convenient and accessible as the carer either collected or dropped back the child or both. This finding concurs with the recommendation of Mansell and Wilson (2009) study which asked how existing respite services could be developed and found locally based provision was suggested as a significant feature.

4.7 Topic 4: Strengths and Weaknesses

4.7.1 Difference to family life:

A dominant theme found throughout the interviews was that of the effect of CFSBS had on family life. Participants informed the researcher of the significant impact the scheme had on family life by reducing family stress and pressure. The sample therefore, mirrored the findings by Joyce *et al.* (1998) which found the provision of respite to be linked to improvements in family functioning. Participant 2 outlined:

It has improved all family relationships in ways we had never thought possible, just by lifting some of the stress and giving us some time to ourselves.

Likewise other participants commented how they felt their families as a whole were benefitting as a result of their involvement in the scheme. Participant 3 described the scheme as ‘*like a lifeline to our family, it is the pin that holds us together*’.

4.7.2 Parental stress:

The researcher learned the most significant difference the CFSBS has made to participants is that of reducing stress. Participants commonly explained how they feel the pressure of caring is off during that time and how it gives them a chance to breathe and think. Participant 1 described how the scheme helped her ‘*with respect to just taking a deep breath and being able to relax and actually learn to*

relax'. These experiences are echoed in studies such as Cowen and Reed (2002), Mullins *et al.* (2002) and Hoare *et al.* (1998), which found relaxation and stress reduction to be the main effects of respite care on carers. Participant 3 also reported feeling her mental health had improved due the breaks. This claim is supported by Hirst (2004) who describes how caring for someone with an ID often impacts on the carer's physical and psychological health however, "access to regular, high-quality respite care is known to have a beneficial impact on a carer's ability to continue in their caring role" (Hirst, 2004 cited in Mansell and Wilson, 2009, p. 256).

4.7.3 Thought of the breaks:

An interesting point which was regularly raised by participants was how even the thought of the breaks can bring a sense of relief. The knowledge that the breaks are consistent every month was viewed as critical by participants as they feel it gives them a date to work towards and allow them to better manage the stress and pressures of caring for a child with an ID. Participants relayed these experiences through these descriptions; *'when you know it's coming you just have to get to that time of the month to get a break'* (Participant 3);

It has made things easier, you have three months of dates so you know right things are a bit hectic this week, but next week she is going, so it has made a difference, you know what I mean. You kind of deal with everything and know then that (child) is going on a little break

(Participant 4).

This acknowledgement differs slightly with that of Wilkie and Barr (2008) who found participants yearned for more consistency in respite services as this study found participants were happy with the consistency of breaks in the CFSBS.

4.7.4 Problems:

Participants did not report experiencing any problems with the scheme. When asked who they would talk to should a problem arise the majority said their social worker and one said the carer, the reason for their choices being they had good relationships with the social worker or carer and felt they could easily talk to them. Comparably, Swift *et al.* (1991) highlight the centrality of relationships for the success of respite services. However, one participant who was not involved in the scheme as long as

the others felt a little unsure about making a complaint as she would be afraid to lose the short breaks. This concern around losing the scheme was also raised by two other participants:

The only fear is that oh what if this just end suddenly, you know you are kind of hanging in the air, (child) had built up a relationship with these people and oh god what if they just dropped out. I know they have a long term commitment so that's good but you still sometimes worry

(Participant 4).

Likewise, participants commented on the value they place on the support and how they were unsure of how they could cope without it:

SMH been outstanding to us...I don't know how we would have survived without all this support. I think from a support point of view, if we lost it, I think we would be at a loss ourselves

(Participant 3).

4.8 Topic 5: Recommendations

When asked whether the participants had any recommendations for the running of the CFSBS participants common response was they were happy with how the service is provided at the moment. Some participants however, did raise the point that there could be more promotion of the service to *'have more information available to people about the service and to let them know it is there'* (Participant 4). This recommendation concurs with that of Sholl *et al.* (1991) and Cotterhill *et al.* (1997) which acknowledged a lack of awareness that a respite scheme exists is a problem for some types of provision in particular.

4.9 Topic 6: Childs View

When questioned about their child's experience of the CFSBS, participants unanimously reported their child thoroughly enjoy the short breaks. The researcher found participants consistently identified the development of relationships between carers and children as crucial to their enjoyment of the breaks,

Participant 3 even described '*the carer like her second Mam*'. Participants regarded the activities and attention the children receive as an important factor in their child's happiness with the scheme;

(child) loves it, (child) gets to do so many activities and gets so much attention.... I think (child) has a better time there than at home because I just don't have the time and energy to those things with (child)

(Participant2).

The researcher observed the widespread view held by participants; that their child's happiness with the short breaks is fundamental to their involvement in the scheme. Participant 4 provided an explanation of this view; '*(Child) often asks when (child) is going to the carers...so I know (child) is happy, I would not be sending (child) otherwise*'. This finding compared with that of Cotterill et al. (1997) that the services users' enjoyment and happiness with the respite provision is imperative.

4.10 Limitations

In presenting the findings of this study the researcher was very aware of the need to protect the confidentiality and anonymity of the participants. This proved problematic for the researcher at times, as often the researcher found that within verbatim passages which revealed interesting findings it was easy to identify the individual involved. Therefore, as suggested by Richie and Lewis (2003) it was necessary to alter the descriptions participants gave or change insignificant points of detail, in order to incorporate the findings into the study without compromising the anonymity of the participants. In this way the researcher carefully chose the findings presented and delivered the confidentiality promised to participants.

This evaluation was limited to some extent due to the small scale of the study and time limitation. As a result only two research methods were used to gather data and only a limited number of interviews were undertaken. Therefore, further research is required in order to fully evaluate the CFSBS, which would involve using the view of contract carers in order give the study increased depth and increase the validity of findings.

This topic would benefit from more extensive research to ensure a greater realisation of the issues that arise for parents and families caring for a child with an ID in relation to respite services in Ireland and the experiences of these families which could be used to inform social work practice in this area. The

perception of ‘normality’ and ‘a normal family’ were discovered by the researcher as underlying themes in carrying out this study. A similar underlying theme was that of participant’s feelings of ‘guilt’ around seeking support for their caring role. The researcher interpreted this theme of guilt throughout the interviews, as participants often felt the need to express how they loved their children before elaborating on the negative effects of caring for their children with an ID. Another interesting theme identified by the researcher was that of how participants consistently commented how they knew ‘how lucky’ they were to have the breaks and how glad they were to be getting any form of support. The researcher feels these themes are particularly significant in understanding the effects of caring for a child with an ID however, the researcher chose not to discuss these issues in greater detail as the focus of this study is on the evaluation of the CFSBS.

4.11 Conclusion

This chapter discussed the main issues that arose from the interviews by looking at the topics of; access and availability; requirements and expectations; quality of care; strengths and weaknesses; recommendations; and the child view. Within these topics the chapter looked at the dominant themes that arose for the researcher which were; motivating factors for using the scheme; acceptance of short breaks; desired carer qualities; overall differences to family life; and concerns around the scheme. The chapter analysed these themes in relation to the literature and previous research. The chapter also considered the limitations of the study and put forward ideas for further research in this topic. The following chapter will outline the conclusion and recommendations of the study and the implications for social work practice.

Chapter 5:

IMPLICATIONS FOR FUTURE PRACTICE

*I have a disability, yes that's true, but all that really means is I
may have to take a slightly different path than you*

(Hensel, n.d)

Implications for Future Practice

5.1 Introduction to Chapter

This chapter will begin with a discussion answering the core research questions of this study, and proposal of recommendations for the CFSBS. Following on from there, the conclusion will highlight the principal findings of the study and the most noteworthy conclusions to be drawn from it. Finally, the chapter will propose implications of the study outcomes for social work practice.

5.2 Part 1: Discussion

The primary aim of this study was to evaluate the CFSBS from the perspective of the service user with respect to five research questions. The most prominent points raised in relation to these questions will now be discussed and based on these, the researcher will propose recommendations for the scheme.

5.2.1 How did the service user find the accessibility and availability of this service?

The study found service user's accessibility to the scheme depended on social workers provision of information regarding the scheme. This implies the visibility of the service among the wider population is poor. As a result the researcher proposes that SMH need to build public awareness of the scheme so that more families can utilise this important family support. However, SMH also needs to be conscious of the likely demand for this service and possible need to expand the service to create extra capacity.

Once involved in the scheme the study found breaks were made available to service users in a regular and consistent fashion, which was much appreciated by participants. Nonetheless, the majority of participants felt they would benefit from more short breaks again highlighting the possible need for SMH to expand the service and recruit more host families in order to facilitate these breaks.

5.2.2 What were the requirements of service users and their families for a respite scheme of this nature and were these requirements met by the scheme?

The main requirements identified by the participants of this study for the CFSBS included the need for their children to be happy in the scheme and for parents to accept the breaks. Consequently the researcher recommends that SMH need to ensure service users are happy during their short break experience with regards to activities and care provided. The researcher also proposes that SMH social

workers need to continue their support for parents utilising the scheme and be aware of how beneficial their work can be in helping parents to accept the short break scheme.

5.2.3 How did service user experience the quality of care provided by host families?

Overall this study found service users classified the quality of care provided by the host families of the CFSBS as excellent. Carer qualities such as; good communication, reliability, their knowledge of caring for children with an ID and their concern for the service users were highly regarded by participants. SMH needs to consider these qualities when training contract carers in order to ensure the provision of this high standard of care is maintained.

5.2.4 Did the service user and their families feel the scheme helped in reducing family stress?

The findings of this study clearly illustrated that CFSBS helped in significantly reducing family stress and as a result improved family functioning. This finding implies the CFSBS is fulfilling its aim and that SMH should continue to provide this service using a family centred approach.

5.2.5. What recommendations did service users and families have to improve the running of the scheme?

Overall the study found participants were extremely happy with the running of the scheme and had few recommendations to improve it. The main recommendation outlined by participants confirms the recommendation outlined under the first research question regarding SMH need to promote and raise awareness about the service.

5.3 Part 2: Implications for Practice

The findings of this study from both the literature and qualitative research highlight the important role of social workers in working with children with an ID. The literature review outlined the use of the ecological systems theory as a theoretical framework for this study and the findings supported the use of the theory for social work practice in the area of disability. The use of this theory in social work practice will facilitate social workers to work more effectively with clients by developing, maintaining or strengthening supportive interventions and reducing or replacing, or challenging stressful systems.

The results of this study indicate the need for social workers to;

- Be aware of their role in providing the client with information around services that are available to them. This study shows the positive influence the provision of short breaks can have on family life. As a result it is imperative that social workers raise awareness about these services so as to ensure families are given the chance to utilise them.
- Assess the individual requirements of the child while at the same time embracing a family centred perspective in order to find a service that is most suited to their needs.
- To provide support for the parents of service users around their acceptance of short breaks for their children. They also need to be aware of the possible emotions and issues that may arise for parents around their use of short breaks and prepare them for dealing with these emotions.
- Possess good communication skills and ability to build a good rapport with clients as this study implies the development of a good relationship between participants and the social worker was needed in order for the participant to portray any negative views without a threat of loss of service
- Recognise that parents and service users are experts in their own lives as evident based on the value participants placed on their relationships with their social worker

5.4 Part 3: Conclusion

In conclusion, this study has fulfilled its aims and objectives and answered its core research questions. This study employed an ontologically constructivist, epistemologically interpretivist and methodologically qualitative approach. This approach enabled the researcher to clearly interpret the participant's experience of the CFSBS in order to answer particular research questions and at the same time represented the voice of participants in the study.

The literature review carried out for this study provided the researcher with background knowledge into caring for a child with an ID and a brief history on respite care and the development of short breaks. The findings of the literature review informed the researcher of some of the issues faced by parents and families caring for a child with an ID and contributed to the formulation of overall research questions and interview questions.

The analysis of interview transcripts allowed the researcher to identify dominant themes which arose across all interviews and construct findings. The principal findings of this study related to participants

overall satisfaction with the CFSBS. However, participants would like more breaks to be made available and they identified the need for promotion of the scheme to make people aware of the service. In eliciting the answers to these questions the researcher recognised important and consistent themes which arose around carers stress and their acceptance of breaks. The researcher also identified the requirements of good relationships and children's happiness as central to the success of the scheme, which have implications for social work practice. However, as outlined in the findings limitations, the researcher recommends that in order to fully evaluate the CFSBS further research needs to be carried out.

The introductory quote to this chapter; "I have a disability, yes that's true, but all that really means is I may have to take a slightly different path to you" (Hensel, n.d) sums up the researcher's learning from this study and represents for the researcher how as social workers we must view those with a disability and support them on their different paths.

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APPENDIX

APPENDIX A

RESEARCH PROPOSAL FOR SMH



St. Michael's House

DATE RECEIVED

RESEARCH PROPOSAL FORM

TITLE OF RESEARCH: Evaluation of St. Michaels House, Contract Family Short Break Scheme.

NAME & TITLE OF PRINCIPAL RESEARCHER: Mary Ryan, MSW2 UCC.

RESEARCHER'S CURRENT ADDRESS:

OFFICE TEL. NO:

MOBILE No:

E-MAIL ADDRESS:

STAFF: No

Relief / Permanent: N/A

UNIT:

N/A

ORGANISATION/INSTITUTION TO WHICH AFFILIATED: University College Cork.

NAMES & TITLES OF OTHER RESEARCHERS INVOLVED: N/A

Date Submitted to Research Department: _____

Signature of Applicant: _____

NOTE:

Research Proposals must be with the St. Michael's House Research Ethics Committee 5 working days in advance of the next sitting -
(Contact Elaine Burns at 8840208 for date of next sitting)

INFORMATION REQUIRED BY THE RESEARCH ETHICS COMMITTEE

In order for the Committee to respond to your research proposal, we will require the following details:

1. What is the aim or purpose of your research? What are you trying to find out / establish / evaluate?

To evaluate the Contact Short Break Family Scheme from the perspective of service users, by trying to establish:

- The quality of care provided by the scheme.
 - Whether service users found the scheme accessible.
 - If the scheme reduces family stress.
 - What service users and families see as the strengths and weaknesses of the scheme.
 - What recommendations service users and families have for running of the service.
-

2. Who will benefit from this study, and how will they benefit?

St. Michaels House: will benefit from the research as they will receive an evaluation of the contract family short break scheme from the perspective of the service user, highlighting what they see as the strengths and weaknesses of the service. This information can then inform the organisation of the elements of the scheme that are doing well and the possible areas that may need some changes to be made.

The Service user: will benefit from this research as it will give the service user and their families a chance to give their views and opinions on the service which will then be fed back to St. Michael's house to inform decisions made on how the scheme is run, with the view to provide the best quality of care possible.

3. Is this study part of a recognised qualification or course? (give details)

Masters of Social Work (MSW), is a two year full-time programme that combines academic study with fieldwork placements. Successful completion of the programme leads to the award of the NQSW - the national qualification in social work. This research will be submitted in the form of a thesis for this course as part of the practice research side to the course.

4. What research methodology are you using:

Methodological approach I feel most suitable for this research is a mixed method approach of qualitative and quantitative methods.

▪ **What data are you collecting?**

(include copies of any questionnaires / instruments)

Quantitative data in the form of the survey and qualitative data in the form of semi-structured interviews, all of which are to be conducted in person.

▪ **How will you collect your data?**

(from interviews, files, postal questionnaires, etc.)

Survey will be posted with initial letter and will include a self-addressed envelope for participants to send survey back to me. Data from interviews will be collected through audio recording and note taking, providing the participant consents.

▪ **From whom will you collect data (include details of your sampling method and sample size) and how long will data collection take in each case?**

I will collect my data from the families of service users of the Short Break Scheme. I will carry out six in depth interviews and this will be a mix of single and joint interviews depending on how many parents are present in the home. The sample will be chosen by firstly sending out a letter and short survey asking families that are interested in participating in the research to fill out survey and send it back to me. From this response I will then choose six families to interview based on their geographical location and the length of time they have been availing of the service. I will carry out the interviews in person by calling to the participants home once this has been agreed to. I will carry out one interview with each family and it is hoped this will take about one hour to collect the data.

▪ **What is your timescale?**

(for literature review, data collection, analysis, written report)

20th December to 10th January (Christmas holidays): carry out reading for literature review.

Mid- January: Once proposal has been approved, send out letter and survey to families.

Mid-January to mid-February: wait for participant response; carry out pilot interview

with a contract carer; and finalise the interview structure and questions.

Mid- February to mid-March: carry out interviews with families over 2/3 weekends.

Mid-march to end of march: transcribe and analyse findings.

End of March to mid-April: write up Thesis and report.

19th April: Thesis due to be submitted to UCC.

End of April: written report to be submitted to St. Michaels house after it has been corrected and approved by UCC.

-
- **If your research is part of a further degree / qualification, who is your supervisor and what is their area of expertise?**

College Tutor: Simone McCaughren, lecturer of Applied Social Studies.

Science shop Mentor: Feilim O'hAdhmaill, lecturer of Applied Social Studies.

5. How will you acquire full, free and informed consent from your respondents?

- Please see enclosed cover letter to service users.

-
- **How will you inform them of the purpose of your research and what information you are seeking from them?**

Initially I will send out a letter to the service users of the contract family short break scheme, introducing myself and the research. I will outline the purpose and aims of the research and the types of information I will be seeking from them through an interview. I will advise that if they would be willing to participate to fill in the enclosed survey and post it back to me using the enclosed self-addressed envelope.

-
- **How will you ensure they understand this information? (If the person can't understand, who will speak for them?)**

This research will be carried out from the perspective of service users but it will be the parent/guardian of the service users I will be interviewing to elicit this perspective, so they will speak on the service users behalf.

The social workers from the social work team in St. Michaels House will help any

participants who need help to fill out survey during their home visits should there be any literacy issues.

- **How will you support them to decide freely? (e.g. giving time to consider, friend/family member to discuss it with)**

The initial letter will outline that should they want to participate in the research to send back the survey by a set date, giving them time to consider their participation and make contact with me should they want to find out any more information about the research and also allowing them the decision whether they would like to participate or not.

- **How will you ensure they are under no pressure to agree to participate?**

The letter will outline that they are under no obligation to write back to me should they not wish to do so and that is completely their decision.

- **How will you let them know they are free to withdraw at any stage?**

I will outline this in my initial letter and in subsequent contact with them.

6. **Are there any risks associated with this research, for the respondents or for St. Michael's House?**

There are no risks as any identifying information will be confidential.

7. **How will you protect the confidentiality of the individual respondents?**

Once interviews are transcribed I will replace all the participant names with pseudonyms and I will ensure that any identifying information is omitted from the final report to ensure participant confidentiality.

8. **How will you share your findings with respondents?**

By sending them a copy of the final report once it has been submitted to St. Michael's House.

9. Is there a deadline by which your report must be finished?

End of May 2011.

10. Do you intend to publish your findings? Will St. Michael's House be identified?

No.

11. At what stage will the data gathered be destroyed?

Directly after submission of report to St. Michaels House.

APPENDIX B

Initial Letter

Dear Parent / Guardian,

Re.: (Child's name)

My name is Mary Ryan and I am a social work research student from University College Cork and I have been asked by St. Michael's house to evaluate the Contact Family short Break Scheme. The aim of this evaluation is to ascertain the strengths and weaknesses of this service and to assess the quality of care provided by the service. I have been asked to carry out this research as I am not employed by St. Michael's house or affiliated with the organisation, so as to ensure objectivity in carrying out this evaluation. As a result it is hoped that families and carers will not feel uneasy about giving me their opinions about the scheme.

I will conduct this research by carrying an interview with the parent(s) / guardian(s) of the service user. This interview will take place in the service user's home and should take approx. one hour. I will carry out the interviews in early March. Should you wish to participate in this research please fill out the enclosed survey and post to me before 18th February 2011.

Your responses and any information discussed will be kept completely confidential. Based on the response I receive from this letter, I will choose a sample of six families to participate in the interviews. I will use the comments given in the interview to write a report of family's assessment of the quality of care provided by the Contract Family Short Break Scheme, however omitting any identifying information. This report will then be fed back to St. Michael's house to inform the running and future development of the scheme.

You are under no obligation to partake in this research and should you decide that you do not wish to proceed with the research at any stage, you can opt out. However this research will be of benefit to service users and families, as it is a chance to give your views and opinions on the service and inform St. Michael's House of the quality of care the scheme provides and whether any changes need to be made. Should you wish to partake in this research please fill out the form attached and post to me using the enclosed envelope. Thank you in anticipation of your help in this matter.

Yours sincerely

Mary Ryan

Social Work Student

University College Cork

APPENDIX C

Participant Consent Form

Name of the service user: _____

Name of parent /guardian: _____

Address: _____

Do you consent to participate in this evaluation of the Contract Family Short Break Scheme?

Yes / No

If you are agreeing to this research, please advise how long your child has been availing of this support service:

Signature of parent / guardian: _____

Date: _____

APPENDIX D

Interview Outline

Topic 1. Accessibility and Availability:

Q.1 How did you become involved with the Contract Family Short Break Scheme?

- How did you find out about the scheme?

Q.2 Did you feel there were a range of respite options available to you within St. Michaels House?

- If so why did you choose this particular scheme?

Topic 2. Requirements and Expectations:

Q.3 What expectations or requirement's had you in mind for this scheme?

- Do you think they have been met?

Q.4 One of the aims of this service is to provide support for the families involved and in doing so help reduce family stress. Was this an expectation you had of the service?

- If so was it met?

Q.5 Can you describe what you and your family do whilst your child is on family based respite with contract carer?

Topic 3. Quality of Care:

Q.6 How do you feel about the quality of care provided by the carers of the scheme?

- Do you feel they have adequate skills and knowledge to care for your child?

Q.7 Do you feel this scheme meets any of the respite needs of your family

- Do you feel you receive enough breaks?
- Are the breaks at a time and date that suits you?
- Is the location of the carer's home convenient and accessible for you?

Q.8 Overall, how would you describe the standard of care provided?

Topic 4. Strengths and Weaknesses:

- Q.9 Overall what difference has the scheme made to your and your family's life?
- Q.10 Have you ever experienced any problems with the scheme?
- If so have you ever aired these concerns?
 - If not would you know how or feel able to make a complaint should a problem arise?
 - To whom would you express your dissatisfaction?

Topic 5. Recommendations:

- Q.11 Is there anything you would like to change about this service or that you would recommend St. Michaels House could do in order to improve this service?
- If yes have you informed the contract carer or a social worker of the organisation about this previously?

Topic 6. Childs View:

- Q. 12 In your opinion how happy is your child with the breaks he/she receives through the service?
- Can you explain or give a description of this?

Closing Question:

Are there any aspects of the scheme that you feel I have left out or overlooked that you would like to add?

APPENDIX E

Confidentiality Agreement for Transcription

I, Mary Ryan, a student of UCC, am carrying out research on St. Michael's House Contract Family Short Break Scheme. This research will involve interviews with the families of service users in order to evaluate the scheme. I will require the assistance of administrative staff _____ with transcribing the interviews involved in this research.

In order to maintain the families and participants confidentiality in partaking in this research it is critical that staff of St. Michael's house cannot be privy to the content of these interviews.

I _____, a member of the administrative staff of St. Michaels House, understand the above and agree to be bound by it and shall not disclose any confidential information that I may come in contact with while transcribing these interviews.

Signed: _____

Date: _____