Respite care services for families caring for a person with an intellectual disability: Decision making, experience and models of respite

Science Shop Research Project

Submitted as partial fulfilment of the requirements for the Masters in Social Work

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Executive Summary

Background to Study

This study aimed to evaluate how family based models of respite care locate themselves within the current climate of respite care provision with a view to informing the C.S.O. involved (Home Share Clare) on the future provision of their family based respite service. The research compared this model to the more traditional model of community based residential respite care through both a literature review and primary research carried out with participants that use both models of respite care. In doing so the research aimed to understand how carers came to the decision to use respite services, their feelings surrounding this and their experiences of using two particular models of respite care.

Objectives

Three main objectives shaped this piece of research namely;

- To identify the reasons why carers of persons with disabilities use respite services and gain further understanding of the feelings experienced regarding respite when it is used initially.
- To evaluate carers individual experiences of using community based residential respite care and family based respite care, outlining similarities and differences encountered with both models of respite.
- To highlight the factors that would attribute to a better service provision of respite care by Home Share Clare and overall by respite services in the area.

Methodology

The theoretical lens of this research is a qualitative interpretive one completed in the form of a comprehensive literature review and semi-structured interviews. A sample of ten full-time carers were purposively selected for interview. This included a cross section of carers of both adults and children providing experiences of both community based and family based respite. This sample included three participants who have a family member using both the family based and community based respite services; four participants who use only the family based service (Home Share Clare) and three participants who use only a community based residential model of respite.

Findings

This research found that while both community based and family based models of respite care are identified in the literature, current policy and funding in Ireland is largely tied up in delivering community based models and as a result this has remained the dominant model of respite care available to carers.

In looking at carer's experiences of accessing and using both models of respite a number of issues were highlighted. The need for a range of available respite services, including both family based and community based models of respite, was identified by participants in this study. All the participants identified that the quality of care and service both models of respite provide for them, once accessed, however the lack of adequate respite breaks in general was a voiced concern in this study. Participants identified the differing but complimentary roles that both family based and community based respite offers them in terms of meeting their short and long term need for quality respite breaks.

There was a consensus among all participants that there is a perceived lack of information regarding respite services available to them generally. Participants felt that information on available services was not freely available or provided to them, meaning this was something which they had to seek out themselves, and can lead to families accessing respite services long after they have begun to need them.

There was also an identified worry amongst participants about the future care of their dependant person. Participants regarded using community based respite as a means to gaining access to long-term care placements for when they can no longer provide full time care for their dependent person. Participants also felt that using this model of respite was important for their family member as it replicated and exposed them to a model of care arrangement they were likely to enter into in the future. This is in contrast to the purposes of respite care.

Participants also identified the lack of adequate government funding and support for respite services as an issue that requires addressing. All participants expressed awareness of the current economic climate and conveyed their concerns that respite services will become a targeted area for cutbacks. They feel that any cuts in respite services would impact on, and be detrimental to, the level, quality and maintenance of care that they can provide to their family member with disabilities within the home.

Recommendations

Recommendations arising from this study are made specific to Home Share Clare, respite service providers more generally and policy makers to assist in ascertaining a higher quality of respite provision for carers of persons with intellectual disabilities using the evaluated services in this study. The main recommendations of this study include:

- This study recommended that one way service providers could address the issue of a perceived lack of information about respite services would perhaps be to supply carers with the relevant information on available respite service as soon as they enter disability services. It is suggested that one way Home Share Clare may address this issue is to undertake steps to further market their service, and provide more information on its workings and benefits, making it more accessible to prospective families.
- The inequality of respite distribution highlighted by participants in this study as impacting on their ability to access respite breaks with community respite services may perhaps be addressed in terms of developing family based respite services in order to increase the availability of beneficial respite breaks for carers.
- The findings of this research show that participants identified many benefits that this model of respite holds for both themselves as carers and their family member using the service. This research recommends that Home Share Clare continues to roll out their family based service as it is found in this research to be a valuable and viable respite resource that could increase the availability and range of respite services available in this region of Ireland.
- It is a recommendation of this study that the Irish government invest in and provide resources to establish family based respite care as a viable source of

respite for families of persons with disabilities throughout Ireland. This research suggests that if funding was provided to further establish family based respite models, including Home Share Clare, carers may be more adequately supported in providing full-time care to their family member with an intellectual disability in their home having increased respite breaks available to them.

- In concurring with larger scale studies highlighted in the literature review (Merriman & Canavan, 2007; Hanrahan, 2010) the recommendation echoed in this study is that policy should explicitly support a range of respite options, including both community based and family based respite services, and that funding should be released to allow services to develop both these models in recognition of the valuable role both services play in the lives of participants in this study.

Authors Conclusions

A review of the literature revealed how supporting families in providing care to family members with intellectual disabilities has been a challenge for disability, and respite services, in particular ever since the move to community care in the 1960s. This was primarily due to the lack of funding supplied to this sector in the decades since (Woods, 2006). The model of community based residential respite remains the dominant form of provision in Ireland to date. This has meant that the majority of the funding available has been tied up in the maintenance of these service models. This has meant that little funding is left over to develop alternative viable forms of respite services such as family based schemes like Home Share Clare. Through meeting with participants using both models of respite care this research has highlighted how families value the availability of both models as viable resources for them in providing quality respite breaks for both themselves as carers and also for those they care for. The two models of respite examined were found to provide different, though complimenting benefits to service users and their families. Participants emphasised the impact that structural inequalities in the area of respite provision, namely inadequate funding and availability of respite service provision, has had on their ability to efficiently access respite services which in turn affects the well-being of their family unit.

Chapter One: Introduction

1.1 Title

'Respite care services for families caring for a person with an intellectual disability: decision making, experience and models of respite'.

1.2 Introduction to the Research

A new introduction to the Masters in Social Work programme this year was the option for students to undertake a Science Shop Project (here after SSP) as part of completing the mandatory research component of this professional qualification. The SSP allows students to undertake research on behalf of a Civil Society Organisation (here after CSO). The purpose of this option is to give students the opportunity to complete real life research which may impact positively on the lives of the participants. This is completed with a view to providing valuable research to the organisation on an identified topic specific to them. This research is part of this initiative on behalf of the CSO, Home Share Clare (here after HSC). In terms of background, HSC was initially developed in order to offer a family based respite option for families of persons living with disabilities. HSC commissioned this piece of research in order to evaluate their current respite service and two students were identified to undertake this project.

1.2.1 Background to the Research

The term disability is very complex and has been defined in several ways, for example the World Health Organisation (2001) states that:

> *Disabilities' is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations* (World Health Organization, 2001, p. 3).

It must be noted that although the term disability encompasses both physical and sensory disabilities as well as intellectual disabilities, this study will be specifically focused on the latter; it is however acknowledged that some of the participants in this study care for people who have multiple disabilities. The National Intellectual Disability Database (NIDD) published by the Health Research Board (2009) identified 26,066 persons registered with an intellectual disability in Ireland in 2009 with 16,742 of these living within the family home. It is acknowledged that this number includes both children and adults with varying levels of disabilities ranging from what professionals term as 'mild to profound' and some with a combination of physical as well as intellectual needs and challenging behaviours (Kelly *et al.*, 2009). Interestingly, the 2006 Census indicates that there is perhaps a mismatch between the NIDD figures and the self reported level of disabilities currently in Ireland. The 2006 Census of Ireland found that there is 50,400 people reported to be living with an intellectual disability. This indicates a disparity of figures and perhaps suggests the high level of perceived need in Ireland at present.

The NIDD shows that only 4,681 people received some form of respite care. McConkey *et al.* (2010) identified a growing demand for respite services stating that there are presently waiting lists of almost the same number of people awaiting respite placements. With the changing nature of disability care, internationally and in Ireland, the family is now perceived as the primary carers for persons with disabilities (Eyler, 2005). This coupled with the fact that people with intellectual disabilities are living longer may explain the increased demand for family support services including respite care (National Disability Authority, 2010).

1.3 Rationale

It is widely recognised that people with disabilities are best cared for within the home and "*the experience of family living is the single greatest influence on an individual's life"* (MacDonald *et al.*, 2006). Ireland has responded to this global stance in recent years with the reduction of large institutions to care for people with disabilities and more services emerging and developing in order to assist parents to care for their children within their own homes (Hanrahan, 2010).

One of the main services that supports families in their role of caring is that of respite services. According to *A strategy for equality: summary of the report of the Commission on the Status of People with Disabilities* (1996) respite should be flexible to suit individual family's needs and should also include a range of options. Within the Brothers of Charity Services in Clare a residential model of respite was the main option available to families of persons with disabilities until the establishment of Home Share Clare just over two years ago. Seeing the need for additional services in County Clare, HSC (a self funded initiative) developed a family based model of respite with the rationale of providing respite care through the recruitment of host families in order to support persons with disabilities and their families. Host families are recruited and matched with a person with intellectual disabilities whom they will provide respite for within their own home. The matching process considers similarity of interests, hobbies and activities as well as the host family being able to meet the care needs of the individual concerned. The host family are offered training and guidance specific to the individual needs of the person they are being matched with. They are paid a fixed stipend to provide the equivalent of five weekend respite breaks to their identified family per annum. This money is raised annually through fundraising carried out by HSC. It has been reported that in the past two years HSC has successfully provided respite for over thirty adults and children in the Clare region. However it can still be observed that the majority of these families (just under seventy percent) also avail of a residential respite service.

Previous research in the field of respite care has been completed in the past with much focus placed on the different models mentioned above (family based and community based residential respite). Chapter three will provide the reader with an overview of this research. In terms of developing a particular rationale for this piece of research the headline from much of the literature indicates that both models have their benefits and it is generally a case of family preference (Merriman and Canavan, 2007; Wilkie and Barr, 2008).

The family based model (currently in use by HSC) is a relatively new initiative in terms of respite care but has been successfully used both internationally and in other regions of Ireland (Hanrahan, 2010; Murphy, 2009). It has been found to be a very cost effective model of respite only running at a fraction of that needed to provide residential respite which according to Murphy (2009) costs approximately €125,000 per year to sustain a bed in a residential unit.

In the future, HSC have plans to further establish their respite service to families in the Clare area who are caring for persons with intellectual disabilities. However, they feel it would firstly be advantageous to ensure their current provision is meeting the needs of those using the service and to this end HSC have commissioned this piece of research. Woods (2006) identifies that a major frustration for people with disabilities and their families has been their lack of influence on the decisions affecting them. A core aspect of this research is to gain an insight of how families of persons with disabilities in Clare experience both residential and family based respite service. This will enable the researchers to provide HSC with valuable feedback as to what families that use respite look for from these services as a whole and how the different services meet their needs. It is hoped that this research will allow HSC to develop their service through investigating the views and opinions of those using the provision.

1.4 Aim of Research

This research aims to gain a greater understanding of why people use particular models of respite. The research will also explore carers' experiences of using both the Home Share Clare model and the residential respite model of respite and their perceptions of both. The aim of this study is to enable HSC to identify ways to further develop their service and better meet the needs of families of persons with disabilities in the Clare area.

1.5 Research Objectives

- Identify the reasons why carers of persons with disabilities use respite services and gain further understanding of the feelings experienced regarding respite when it is used initially.
- Evaluate Carers individual experience of using residential community based respite care and family based respite care, outlining similarities and differences encountered.
- Highlight the factors that would attribute to a better service provision of respite care by HSC and overall by respite services in the area.

1.6 Research Questions

1. Does the literature identify specific models of respite care services, and if so, what aspects of these models prove significant in delivering best practice in the provision of respite care?
2. How do carers come to the decision that they need to use respite care services?
3. How was the process of accessing respite services for this group?
4. How would carers evaluate their experiences with regards to using the respite services available to them?
5. How do these findings compare to current policy and trends in respite care provision in Ireland?

1.7 Conclusion

Over the past fifty years, disability services in Ireland have under gone significant changes with families now recognised as the predominant carers for persons with disabilities. With this, respite care has emerged as a valuable family support service that aims to sustain carers in their role. The figures in the introduction to this chapter outlined that almost two-thirds of people with Intellectual Disabilities are now being cared for within the home. This research aims to understand how families come to the decision to use respite service and their experiences whilst using respite service. Before undertaking this study the researcher must look to the literature in order to better understand the move to family based care, the models of respite available and the position of respite care within Irish social policy and legislation, all of which will be outlined in Chapter Three.

Chapter Two: Methodology

2.1 Introduction

Shaw & Gould (2001) states that social work research should "*Contribute to the development and evaluation of social work practice and services, enhancing its moral purpose and strengthen social work's disciplinary character and location*" (Shaw & Gould, 2001 p.3). The aim of this research is to evaluate the current respite care services for persons with disabilities in the Clare region of Ireland, taking in to account how carers came to the decision to use particular respite services and exploring their experiences of these. In doing so, the researchers aspire to provide factual research which may be used to provide an evaluation of respite to Home Share Clare and also with a view to developing social work practice and services in this area.

This chapter will outline the theoretical framework and methodology employed in this study. The interpretivist framework that underpins this research will be explored and discussed in terms of how this guided the analysis of the research. The methods utilised in this research – namely a literature review and qualitative semi-structured interviews – as well as how these were analysed will also be discussed. Consideration will be given towards ethical issues regarding the sample, consent and confidentiality as well as the limitations of this research.

2.2 Methodology

The purpose of a research design is to answer the research question or test the research hypothesis (Bailey, 1994). May (2001) informs us that the research design consists of the following components including the research assumptions, the process of inquiry, the type of data collected and the meaning of the findings. The researcher's intention is to evaluate the current respite services for persons with disabilities within a specific area of Ireland through the experiences of the carers of these persons. In selecting a research approach, for this study, both quantitative and qualitative methodologies were evaluated for appropriateness.

2.2.1 Quantitative Research

Quantitative research simply attempts to display and present findings in terms of frequency and amounts. Quantitative research is dependent on numbers for its conclusions and usually employs statistical techniques (Punch, 1998). The purpose of this type of research is to generate new knowledge pertinent to the general population, formulating generalisations from the results (Flick, 2009). The quantitative approach is based on objectivity and impartiality and involves systematic strategies that describe, test and examine cause and effect relationships (Sarantakos, 1998).

2.2.2 Qualitative Research

Qualitative research approaches are naturalistic inquiries which attempt to study real life situations as a means to understand perceptions and actions of participants (Shaw & Gould, 2001). Ritchie & Lewis (2003) argue that qualitative research aims to provide an in-depth and interpreted understanding of the social world, or research participants, by learning about their social circumstances, their experiences, perspectives and histories. Qualitative methods are used to address research questions that require explanation or understanding of social phenomena and their contexts (ibid, 2003). Qualitative research has a smaller sample, where rich, thorough analysis of data such as perceptions and opinions can be examined (Sarantakos, 1998). The rationale for this type of study is that the researcher can contextualise people's behaviour and perceptions of the world in which they live from within their own environment and in their own words (Punch, 1998). Due to the nature of our study we employed a qualitative research methodology to explore experiences regarding respite within these families.

2.2.3 Why use Qualitative Research for this Study

MacDonald *et al.* (2006) suggested the need more qualitative research to be completed to investigate further the reasons why carers use respite services. They highlight the need to recognise the importance of these services in forming part of a coping mechanism for families of people with Intellectual Disabilities (ibid, 2007).

McConkey *et al.* (2004) highlighted the necessity to understand family's needs in order to provide a quality service, and meet parent satisfaction. Endeavouring in this research to represent the perceptions of this group of carers towards the respite services they use enabled the researchers to feed back to Home Share Clare the views' of some of the families that use their services and to draw up recommendations with a view to reinforcing, or enhancing, their own service provision.

2.3 Theoretical Framework- Interpretivism

This study follows an interpretivist perspective. In contrast to the scientific positivist approach to measuring the social world this view holds that how we understand and write about human knowledge must be through interpreting the social world by how individuals themselves experience it (Ritchie & Lewis, 2003). Interpretivism attempts to understand the social world which has been created through lived experiences which continue to be reproduced through daily activities (Blaikie, 2003).

Interpretivism puts the individual and their social world central to everything else and for this reason takes on an anti-positivist approach. This study seeks to examine the meaning and importance respite has for this group of carers and how this has shaped how they access and use respite services. Using this interpretivist framework allowed the researchers to explore this link between how participants experience respite and in turn how this affects how they use these services. This was important as this study aimed to understand more fully how participants experience particular models of respite care with a view to providing feedback to Home Share Clare as to what families would like from their service in the future.

2.3.1 Interpretivism and Qualitative Research

Using a theoretical framework of interpretivism enhances qualitative research. This framework allows the research and its findings to be more perceptive, subjective and insightful. The interpretive perspective views reality to '*be what people see it to be*' (Sarantakos, 1998, p. 36), therefore researchers must attempt to understand not only the experience but the thought process behind the experience (Ritchie and Lewis, 2003).

This can be achieved through interactions in the form of interviews, focus groups or observations all of which are identifiable qualitative methods (Punch, 1998). For the purpose of this study, the researchers used semi-structured interviews with a sample of carers of both children and adults that use two models of respite service in the Clare area of Ireland.

2.4 Research Approach

As explained in Chapter One, this research was undertaken as part of a science shop project which is a new initiative within the Masters of Social Work. As a result of the project type and the proposed size of the project, it was felt that this would be best met if two students completed this research. The research was completed in the form of a comprehensive literature review and semi-structured interviews.

2.4.1 Literature Review

The literature review allowed the researchers to analyse data applicable to this study from previous research, highlighting what is already known about this area of study and allowing the researchers to identify gaps in the literature. This assisted in the formulation of the interview questions where the data could be tested and was then reformulated in the analysis to compare with the findings from the interviews. Various literature searches were completed to retrieve materials related to the topic, see Appendix D for further details.

2.4.2 Semi-Structured Interviews

To get a full understanding of how respite care services are perceived by those that use them it was decided that semi-structured interviews, with full-time carers of adults or children with intellectual disabilities, would be undertaken. Initially focus groups were considered as a method in carrying out this study as it would have allowed for the inclusion of a large number of participants in the research over a short space of time.

However, after reflecting further on this it was decided that it may have been too unreliable a method as the researchers would not have been able to ensure that a sufficient number of participants would turn up in order to carry out a valid focus group. Bryman (2008) reflects on this as one of the main limitations of focus groups. The researchers were also mindful that the potential participants were all full-time carers who may be more inclined to engage in research that allowed them to meet at a time and place that best suited their individual schedules. For these reasons, it was decided that carrying out semi-structured interviews with participants would best illicit the information the research was looking to analyse.

Semi-structured interviews enable the researcher to have a sense of themes or topics which they wish to explore (Ritchie & Lewis, 2003) while providing flexibility to further explore participants' responses (Whittaker, 2009). Semi-structured interviews also enable the interviewer to modify the question order as appropriate to the context of the interview and also in terms of arising themes for later interviews (Robson, 2002). The use of semi-structured interviews allowed the researchers to review, and amend, our interview schedule (see Appendix A) in order to glean all relevant information needed for our research. They also enabled both interviewers to produce a set of interview transcripts that were both structured enough that they covered similar ground and were therefore easier to compare and analyse. Within these transcripts and the writing up of this research, the researchers aimed to ensure the anonymity of all the participants. Ten semi-structured interviews were completed with families that all had a family member attending either the Home Share Clare service or a community based respite service.

2.5 Sample Selection

As this research was completed on behalf of the identified CSO on their services, the sample comprised of willing participants who were full time carers to a person with a disability that availed of one of the respite services. A database was provided from the CSO to the researchers outlining contact details of all full-time carers who had a family member that used the respite services.

The CSO had previously contacted these individuals to advise them that the research would be taking place. To ensure the anonymity of the participants from the CSO each individual carer was then contacted by the researchers, through letters, informing them on the research project and requesting them to contact us if they were willing to participate (see Appendix B). Fifteen carers gave positive responses and from these a sample of ten full-time carers were purposively selected for interview. This included a cross section of carers of both adults and children providing experiences of both community based and family based respite. The sample included a total of three male and seven female carers; no couples attended the interviews although this option was provided. This sample of ten included three participants who have a family member using both the family based and community based respite services; four participants who use only the family based service (Home Share Clare and three participants who use only the community based model of respite. Whittaker (2009) writes that interviews are most successful when participants have significant experience in the research topic and are likely to want to discuss it. This technique ensured that the researchers yielded an optimum body of research data, in that only families, that use two particular models of respite, and who were willing to take part in the research were interviewed.

2.6 Ethical Considerations

As this research was completed under the Science Shop Project scheme permission was granted from the CSO to complete this research prior to the research commencing. Bryman (2004) outlines four main areas which should be considered when completing research; *"whether there is harm to the participants, whether there is a lack of informed consent, whether there is an invasion of privacy, and whether deception is involved"* (ibid, p. 509). To respect all of the above issues the researcher compiled a participatory consent form (see Appendix C) which was provided to each participant prior to the commencement of each interview. The form outlined that the researchers were independent bodies to the CSO and therefore would strive to obtain anonymity of all participants from the CSO. It also highlighted that the interviews would be recorded on dictaphones and later transcribed but assured these would both be destroyed on the completion of the research.

Their voluntary participation was outlined ensuring them that they could opt out of the research at any time without prejudice (McQueen & Knussen, 2002). A copy of the final research project was also offered to participants. As this research required participants to share their experiences, some of which may be emotive, it was a priority of the researchers to ensure respect for and value the participant's opinions throughout the research (Ritchie and Lewis, 2003).

2.7 Confidentiality

As this is a science shop project a report of the research is returned to the CSO on the completion of the project. All participants were been guaranteed that their identity would not be revealed to the CSO and that all of the research would be anonymised to ensure this. However, within our findings some aspects or circumstances detailed in the information may enable the CSO to recognise the participant. This was explained to the participant with an assurance that the researchers would avoid unnecessary infringement of privacy where possible.

2.8 Limitations

There are limitations incurred in all social research and inevitably this research will include some aspects of these. One of the main limits of this study is that persons with intellectual disability were not interviewed themselves during the research process. The limited scope of this study would not allow for this. However, in interviewing the carers of persons with intellectual disabilities it was hoped that the views of this group may be represented. A central principle outlined in The Commission on the Status of People with Disabilities (1996) is one of advocacy where the importance of facilitating people with disabilities to have their views heard and acted upon is outlined. The Commission suggests that one form this advocacy can take is through consulting family members (ibid, 1996). It was hoped that by interviewing the family members of persons with intellectual disabilities in this study that this limit may be somewhat addressed.

As this is a small scale study, using a qualitative approach, it is recognised by the researchers that the findings are only applicable to the sample of participants involved in the research and do not qualify to be extended to the wider population of service users. Also, as this study focuses on one respite care provider it is understood by the researcher that the findings in this way can only be applied to this organisation and findings may differ in respect of other respite services. As identified previously there may be ways in which the CSO could recognise some of the participants however exhausted efforts have been made to avoid this.

Although the researchers aimed to remain objective throughout the process, May (2001) argues that it is '*difficult to create the right environment to gain qualitative data, while also being detached and objective'* (ibid, p. 127). By applying the framework of interpretivism and using semi-structured interviews, the researchers immediately impose some methodological limitations on the study.

2.9 Conclusion

This chapter has identified the methods, approach and theoretical framework which were applied to the research process, outlining the reasons for this and the appropriateness for the study. The ethical considerations, confidentiality and limitations of the study were also explored as were the actions taken to inform participants of these. The completion of semi-structured interviews provided the researchers with vast amounts of data which represented the perceptions of the participants in this study. These, along with a review of the relevant literature will be outlined and analysed in the remaining chapters.

Chapter Three: Literature Review

3.1 Introduction

The aim of this chapter is to critically review existing literature in the area of respite care services for people with intellectual disabilities in Ireland. It will give a brief overview of the development of respite services in Ireland and the legal and policy framework behind this. It will focus in particular on the two models of respite provision that are the focus of this study namely; community based residential models of respite provision and family based respite care models while examining the role of these in current service provision.

3.2 The Move to Community Care

Since the 1960s there has been both a social and political move away from providing institutional care for people with intellectual disabilities towards the provision of such services in the community. Originally, this move to community care was seen as providing something human and personalised that embraced a philosophy of normalisation (Wolfensburger, 1972) without the profusion of rules and regulations indicative of institutional care (Woods, 2006).

Indeed in 1965, the Commission of Enquiry on Mental Handicap accepted that care in the community was usually superior to and ‘more therapeutic’ than institutional care (Department of Health, 1965) and community based care has been the ideology of Irish policy in this area since then (Report of the Review Group on Mental Handicap Services, 1990; Report on the Commission on the Status of People with Disabilities, 1996). Mansell & Ericsson (1996) argue that the abandonment of institutional care arrangements and its replacement with smaller community based dwellings has been the most significant policy development in intellectual disability internationally in the post-war era.

This community care ideology values keeping people with intellectual disabilities in their family homes so they can live a full, inclusive life nurtured by those around them (Quin & Redmond, 1999). However, this move has also received much criticism. Both the international and Irish literature point out that deinstitutionalisation was seen by states as a less expensive option as the ‘community’ which in most circumstances effectively translated as family care in essence meant unpaid carers in the home (O’Connor, 1987; Finch, 1990; Woods, 2006).

Over 30 years after this movement began in Ireland, Quin & Redmond (1999) remark that “*while the policy of community care, which has now been in existence for almost half a century has had many positives, its downside has been its tardiness in having sufficient alternatives to family based care and its failure to provide adequate support services to families providing care”* (ibid, 1999: 161). Much of the literature both in Ireland and internationally highlights the strain that a legacy of inadequate community care support services has had on families and carers as well as on the person with the intellectual disability themselves (Beresford, 1995; Woods, 1997; Bain, 1998; Sloper, 1999; Quin & Redmond, 1999).

Cotteril et al (1997) in a review of the literature on respite services concludes that the success of community care depends upon achieving a balance between the needs of carers and the people they care for and that respite services represent an important means by which this goal can be achieved. The remainder of this literature review will focus on the recognition and development of respite services both in practice and in Irish policy and legislation.

3.3 The Development and Definition of Respite Services

One such family support service that has developed in the wake of the deinstitutionalisation movement is that of respite services. Internationally, respite care services are the most widespread type of family support offered to families caring to a relative with intellectual disabilities (Freedman et al., 1999). Cotterill et al (1997) in tracing the development of this type of family support notes that traditionally respite services emerged to assist carers with a view to supporting and

maintaining people with intellectual disabilities to remain living at home (Nolan & Grant, 1992 as cited in Cotterill et al, 1997).
The underlying policy rationale was to keep families together for longer and in so doing postponing the need for full time residential care (Chesson & Westwood, 2004).

Support services, such as respite, play a vital role in maintaining a family's ability to provide this care. The role of a carer impacts not only the individual carer(s), but also the overall family. The intensity of care needed by the family member with a disability as well in conjunction with other life responsibilities places large demands on the carer(s) (van Exel *et al.*, 2007). Consequently, respite care services are viewed as a *necessity* and *essential* for families throughout several international studies (see, for example, Folden and Coffman, 1993; MacDonald *et al.*, 2006). Although it is difficult to ascertain what exactly respite care encompasses due to the fact that there are several different models of respite in operation and there are a broad range of services regarded as respite care, however it can be broadly defined as short breaks, either in or out of the family home whereby the person with a disability is cared for by persons who are not the main/ primary carers (Neufeld *et al.*, 2001; McConkey *et al,* 2004).

The definition of respite has broadened over the decades to encompass a range of service aims and objectives. As Cotterill (1997) points out that the roots of respite services began as a service directed in the main at supporting carers, wider conceptualisations including aims of supporting the person with intellectual disabilities began to emerge. Over the years studies began to highlight the wider role that families want respite to play in their lives. Oswin (1984) in her study on short-term respite care found that a definition of respite should hold a focus on both carers and those being cared for. Her study found that while regular short breaks for a person with intellectual disabilities away from parental care can be very helpful for families, it needs to be of high quality and of benefit to the family member with disabilities too if parents are to use the opportunity for relief of stress or worry (Oswin, 1984).

In-home respite is often provided by informal supports for example family, neighbours, and friends but can also be provided in the form of formal supports. Formal Respite which is provided by non-family members or professional providers are short breaks in the form of day care, buddy systems, over nights, weekend breaks, and holiday breaks (Neufeld *et al,*, 2001). The latter is the form of respite that is mainly addressed in completed studies and is typically addressed as formal overnight short breaks (ibid, 2001; Folden and Coffman, 1993; Hanrahan, 2010; Lindsay *et al.*, 1993).

In recent years, the term 'short breaks' has been emphasised in both literature and public discourse in this area to describe respite services (SCIE, 2004). Cramer & Carlin (2008) argue that the term 'short breaks' is more apt in describing the role of this service as 'respite care' implies connotations of the temporary removal of the burden of care. They feel this suggests that caring for a family member is a negative experience for the carer and is derived from the problem focused medical model of disability. They propose the term 'short breaks' to more accurately describe the role of respite as experienced by the families that use it, in that it denotes an activity that can be a positive experience for both the carer and the person with a disability and in turn, is more in keeping with the social model of disability (ibid, 2008).

The governing policy body in the area of disability in Ireland, the National Disability Authority (2004a), while using the term 'respite' supports a definition of respite that reflects this dual purpose for both carer and the person with a disability. They define respite care as; *"Temporary residential care, based either in a centre or community based, that is intended to support the maintenance of people with disabilities in their own homes. It can cover a crisis period, take place on a periodic basis to enable a carer to have a break, or can provide the person with disability with medical, therapeutic or support services*" (ibid, 2004a: 212).

Also of significance in this definition is that it clearly articulates a model of respite care that is centre or community based and it is not clear whether the term ‘community based’ encompasses the family based models of respite care that will be discussed later in this chapter.

3.4 Benefits of Respite

Many studies have highlighted that caring for someone with an intellectual disability often impacts on the carer’s physical and psychological and emotional health (Chan & Sigafoos, 2000; Forde et al., 2004; Hirst, 2004; Herring et al., 2006). Dunst & Trivette (1994) write that family support developed with the aim of *“enabling and empowering family members by enhancing and promoting individual and family capabilities that support and strengthen family functioning”* (ibid, 1994, p. 31). The care of a person with a disability can have large impacts on the carer as an individual, their own well-being and their inner-circles i.e. family, relationships; social networks (van Exel *et al.*, 2007; Redmond and Richardson, 2003). Carers have reported that the main benefit of respite care is the opportunity to have a break from caring during the period of respite (Robertson *et al.*, 2010), allowing parents cope better with the *burden* of care (van Exel *et al.*, 2007) and a chance to re-energise in order to provide an appropriate standard of care for their dependant person (Levin *et al.*, 1994). Research has demonstrated that access to regular high-quality respite care has been shown to have a beneficial impact on a carer’s ability to continue in their caring role (Mansell & Wilson, 2009; Catherall & Iphofen, 2006; Cooper, 1997; Willkie and Barr, 2008). Other benefits noted in the literature that families experience from using respite services include that it enables them to make time for other family members (Sines 1999), to do a wider range of activities as a family (Marc & MacDonald 1988) and can serve to refresh the emotional bond between caregivers and those being cared for (Levin et al. 1994).

3.5 Models of Respite Care

Traditionally respite care services in most countries have been provided to people with disabilities in residential settings, first in long-stay hospitals and later in smaller community based residential centres (Cramer & Carlin, 2008). In recent decades these smaller residential centres have continued to provide care alongside a number of different forms of respite care which have developed to reflect the broader definition of respite as previously discussed. These models typically include informal help from family and friends, formal respite care in the service user's home, recreation and holiday breaks and family based residential respite services (Merriman & Canavan, 2007).

As this research study is focusing on community based residential respite services and family based respite services it is these two models that will be discussed further in this review.

3.5.1 Community Based Residential Respite Services

As stated previously this model of respite care is now commonly provided in community based centres or units. In Ireland the bulk of respite provision for children and adults takes the form of short-term admissions to some form of this residential model (McConkey et al, 2010).

This form of respite care is planned, formal and usually long term (Merriman & Canavan, 2007). Merriman & Canavan (2007) in their review of the literature around this model note that there is a lack of detailed research into these more formal settings of respite care however it can be assumed that they provide for the basic needs of service users as well as activities, outings and opportunities for interaction with other service users.

Bain's (1998) study on residential care for children with disabilities, while not focusing specifically on respite, does highlight some of the benefits of this type of staff grouped care. He found that rostered staff carers resist 'burn out' and often develop a familiarity and attachment with the residents. He also highlights that staff are specially trained and as such this model of care can provide a sense of security for families and parents (ibid, 1998). McConkey et al's (2004) U.K. study echoes some of these findings in that the features of this model of respite care noted by parents of those with intellectual disabilities found to be most valued were when it is provided in small, homely services in pleasant surrounds with a person-orientated approach, high standards of care and a low risk of abuse.

This model of respite care has tended to provoke similar criticisms that community care services in general have received. These have tended to surround the gaps in service provision in terms of availability of regular respite breaks and the long waiting lists that families can experience in accessing this service (Cotteril et al, 1997; Sines, 1999).
The most common criticism of this model of respite care has been that of unmet need in terms of responding to the demand for this type of service (Merriman & Canavan, 2007).

Since 2000 in Ireland this model of respite care has received increased funding from the government and a commitment in policy as part of the National Disability Strategies to improve and develop these community based facilities and the training of staff within them (N.D.A., 2004b; N.D.A.; 2010a). However, as of yet no Irish research has been undertaken on the improvements in these services since this time. The National Intellectual Disability Database has, however, indicated that there has been an increase in families accessing these services over the decade (Kelly et al, 2009).

McConkey et al (2010) in their quantitative longitudinal study on respite service provision in Ireland found that although increased funding in the area of community based respite care has led to a rise in the number of people receiving respite, they found that this has also led to increased inequalities in the availability of provision across the country. Woods (2006) argues that this has historical links to the fact that the majority of respite services in Ireland are run by the voluntary sector and this had meant that service provision has developed in pockets throughout the country.

3.5.2 Family Based Models of Respite Care

Since the mid-1970s, family based models of respite care have grown and developed in many countries (Cramer & Carlin, 2008; Hanrahan, 2010). This model of providing respite to people with disabilities was pioneered in Canada, America and Britain and has developed internationally as an alternative to traditional residential models of respite provision (Stalker, 1990; Robinson, 1994;

Carlin et al., 2004). It involves recruiting host family carers who are then assessed and subsequently linked with a person with disabilities. This host family then provides personalised short breaks to the individual in their own home (Hanrahan, 2010).

Initially, most family based respite services provided a host family who would care for a disabled person overnight. Over time, the nature of these schemes developed to meet more diverse needs and may offer day-care, a sitting or befriending service or a support service to enable a disabled person to access community or social activities (Merriman & Canavan, 2007).

Hanrahan (1996) notes that traditionally in Ireland this model developed as 'host family' schemes that recruited volunteer families who were then paid a stipend to provide a fixed amount of respite breaks over an agreed amount of time. The family based scheme run by the C.S.O. in this research is one such example of this type of host family service.

More recently, however, successful schemes have emerged in Ireland that have built upon the host family scheme that recruit contract families (Murphy, 2009 cited in Hanrahan, 2010). The core difference in this scheme is that host families instead of volunteering would agree contractually to provide a specific number of respite sessions in the course of any month. An allowance is then paid to the host family per break which depends both on the length of the respite break and the needs of the host person availing of the break (Murphy, 2009).

Many research studies have highlighted both the social and emotional as well as the monetary benefits that this model of respite care can provide (Stalker, 1996; McConkey & Adams, 2000; Kelleher, 2001; Merriman & Kavanagh, 2007; Hanrahan, 2010). The benefits noted include that people with intellectual disabilities benefit from the one-on-one attention that this model of respite can provide without the upheaval of staff changes and rotas. This model also provides an environment where relationships between host family and service user can develop as well as providing an opportunity for relationships to develop with other members of the host family (Kelleher, 2001; Merriman & Canavan, 2007; Murphy, 2009). Robinson et al (2001) in their study found that while families were generally positive about the care provided by family based short breaks, some families reported that they had to wait a long time to be matched to a carer and they felt that they were unable to obtain frequent or long enough breaks to manage using model of respite care alone.

A number of research studies have shown that family based models of respite care are reported as the preferred option of parents over other community based residential types of respite breaks (Oswin, 1984; Robinson & Stalker, 1993; Cotterill et al., 1997; Sloper, 1999). However, it must be noted that these comparative studies were all carried out in the 1990s and as noted above and as will be discussed in the following section, since this time community based models of respite care and respite service provision in general has received increased recognition in policy and funding in recent years which may have resulted in an improvement in the quality of community residential services that are provided.

Another important aspect of the literature to note is that recent studies have highlighted the growing recognition that families of persons with intellectual disabilities benefit from being provided with a range of respite services. A number of current studies have shown that families place a high value on the need for different forms of respite care including both family based and community based models (SCIE, 2004; Matthiessen et al, 2009; Robertson et al, 2010). These studies argue that family based respite services should be provided as part of this range of respite support services available to families.

3.6 Current Legal & Policy Context

This section of the literature review will focus on the increasing recognition of respite services in policy and legislation in Ireland and what impact this may have on developments in respite services in the future.

Towards the end of the 1990s both international and Irish policy began to place more attention on the development of respite services. The backdrop to this was both the continued emphasis on community care but also a move away from a medical model of understanding disability towards a social model of disability. The social model of disability sees the world as causing disability by the imposition of barriers in society rather than as a focus on physical or intellectual impairments as the cause of disability (Quin, 2003).

The social model gained popularity alongside a more rights-based approach in policy and service provision. The social model has been empowering for people with intellectual disabilities and their families in that it has placed an emphasis in policy on matters of rights, equality, consultation with both those with disabilities and their families and the main-streaming of disability services (Quin, 2003; Woods, 2006).

In 1996 The Report of the Commission on the Status of People with Disabilities published a fundamental review of the conditions necessary to allow people with a disability to participate, as fully as possible, in economic, social and cultural activities. This comprehensive report was influenced by a decade of policies and papers (Dept. of Health, 1984; Dept. of Health, 1991) underpinned by an emphasis on equality for people with intellectual disabilities and argued for a rights approach to the provision of services. The Report (1996) acknowledges that respite care is a crucial element of community support services for people with disabilities and put forward that respite services *"should be flexible, including a range of options including home support, organised holidays and residential care"* (ibid, 1996: 164).

This report led to the establishment of the National Disability Authority in 1998 which acts as the main policy advisor on disability to the government. Under their auspices the government published the National Disability Strategy in 2004 which put in place a plan of policy and service development for people with disabilities in Ireland. Respite care is listed among a range of specialised services for people with disabilities in the strategy. This provided for investment in disability services for the period from 2006 to 2009. Alongside this strategy the government produced the Department of Health Sectoral Plan (2006) which together showed a commitment to increased funding and the development of respite services.

The 2004 Strategy also led to the enactment of The Disability Act in 2005 which while not addressing respite services in their own right, does establish that every person with an intellectual disability is entitled to an independent assessment of needs, an official statement of these needs along with a time-scale for the delivery of services to meet these needs. It has been argued that respite can be included in this assessment (Merriman & Canavan, 2007).

However, a major criticism of the Act is that while the assessment of needs can describe the ideal level of resources that a person might need, the statement of needs is bound by the availability of services and so is limited in its scope (ibid, 2007). This assessment of needs came into force for all children under five in 2007 but it is yet to be rolled out for all persons with disabilities so it remains to be seen if it will lead to the increased development of respite services for all persons with disabilities.

There have also been a number of developments on an international level which have given further momentum with regards to the development of adequate family support services in Ireland. The two most notable of these developments are, at a European level, the Madrid Declaration (European Union, 2002) and internationally, the recently ratified UN Convention on the Rights of Persons with Disabilities (United Nations, 2006). While neither of these declarations mention respite services specifically they do outline the rights of families to be adequately supported in providing care to people with disabilities and also to have access to mainstream support services (Merriman & Canavan, 2007). Together these place further pressure on Irish policy and legislation to promote the rights of people with disabilities which include family support services.

However, towards the end of the last decade the economy in Ireland experienced a significant downturn and this resulted in cuts in the funding to the voluntary sector. Significant cuts were experienced with regards the funding of respite services with further cuts forecasted (Inclusion Ireland, 2011). Current policy reports are concerned with providing cost effective, value for money services while simultaneously supporting the full inclusion of all people with intellectual disabilities in society (Hanrahan, 2010; N.D.A., 2010b). This has led to the publication of a number of policy review documents by the N.D.A. which highlight the high cost of running residential community based respite while simultaneously reiterating the importance of supporting family carers (N.D.A., 2010b). These cutbacks to community based respite provisions have been seen to have left a new gap in respite provision for family based respite services to fill (Cramer & Callan, 2008; Hanrahan, 2010).

A number of current studies have called on the government to endorse the host family model of respite as a viable choice for service users and release funding to develop these services (Hanrahan, 2010). Merriman & Canavan (2007) in their review of best practice in the provision of respite services for people with intellectual disabilities and autism recommend that respite services should be designed to facilitate the service user in building relationships in their community and argue that both community based and family based respite services can help service users achieve this.

3.7 Conclusion

This literature review has traced the development of respite services in Ireland back to the move to community care through to current service provision in a climate of scarce economic resources and has identified two models of respite services that have sprung up following this move. This review of the literature has presented the development of respite services as something that could be argued has been in the past at the mercy of economics, with the move to community being in part emphasised by the state's acknowledgement of the cost of running residential care facilities for people with intellectual disabilities. This has developed along side a growing emphasis on the social model of disability and the rights of those with intellectual disabilities to live equal and inclusive lives in the community. Respite services have been acknowledged as a service that has the potential to both enhance the lives of those with disabilities and also those of their carers and families. The literature has shown the potential beneficial aspects that both community based and family based models of respite care can provide for families and persons with intellectual disabilities if they receive the appropriate funding to provide their services adequately.

The increased emphasis on family based respite services as a more cost effective option for respite in current Irish policy reports suggests that this may be the way that government funding might swing in the future. Treneman et al (1997) argue that the first steps in developing support services should involve ascertaining the most important needs of carers and whether current provision is meeting those needs. The following chapter will present the perceptions of families using two different models of respite services and will explore these perceptions and how they fit in light of the current policy climate.

Chapter Four: Findings

4.1 Introduction

This chapter presents the findings from the primary research carried out through ten semi-structured interviews. These are outlined with regards to the research questions posed and as such are broken down under four headings: list 1, 2, 3, 4. Themes that emerged through the analysis will then be explored in light of the existing literature on the topics and implications for provision, practice and service users will be highlighted. To preserve anonymity, interview participants will not be referred to by name.

4.2 Findings

The findings have been outlined under the following headings; Rationale for Using Respite, Accessing Services, Evaluation of Respite Models, and Service Gaps Identified Through the Research.

4.2.1 Rational for Using Respite

Concurring with the literature (Cotteril et al, 1997) regarding the definition of respite as including the needs and wishes of service users along with those of carers. Half the participants spoke about how they accessed respite services initially as a break, not only for themselves as carers, but also as an experience for the family member they were caring for. For example, participant 1 explained this stating *"Just to give him a break, get him used to other surroundings and give us a break as well, and be with our other child as well".*

When asked about their decision to use respite care services initially, the majority of participants responded by saying it was a time when they needed a break. When elaborating on this further, participants mentioned a range of events that led them to look for respite at a particular point in time. These responses ranged from wanting to go on a holiday break, needing a break from the responsibilities of being a carer and also for some it was a time of great stress on the family.

Participant 6 talked about how they had never been on holidays and *"it came to the stage were we said we would love to go for a break and I made enquires [about respite] at the workshop."*

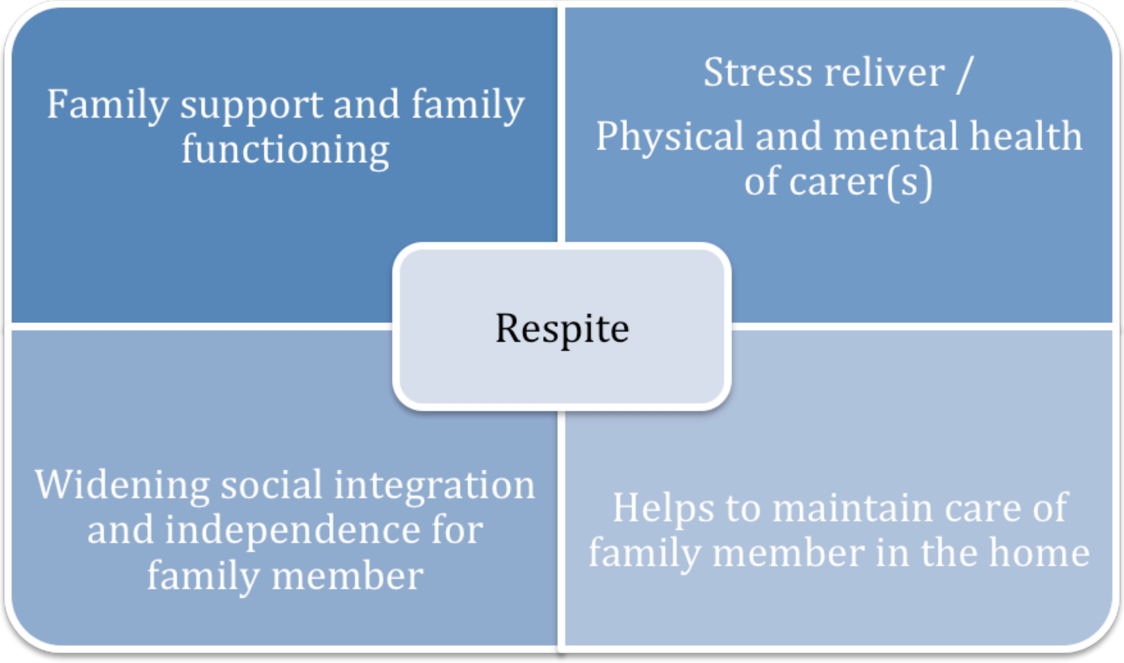
Three participants explained how it was a time of great pressure on them as carers and as a family. Participant 9 remarked *"I just felt it was it was a lot of pressure on us*". One participant (8) talked about how their child's health had deteriorated rapidly and how this had resulted in both parents becoming physically and emotionally ill and had turned to look for some respite *"As at that stage I couldn't cope".* Participant 2 explained *"when we were first introduced to respite was when we had this you know…we were wrecked from her literally and we couldn't manage her…. couldn't manage her straight up we just couldn't manage".* These findings are in line with the benefits of respite highlighted in the literature in that being a carer can often impact on a carer's physical, psychological and emotional health and that access to respite can support and strengthen family functioning (Dunst & Trivette, 1994; Chan & Sigafoos, 2000). Participant 4 elaborated on this further stating that respite *"is the key to caring".*

Participants also stated the benefits of respite for the person who receives it. For example, participant 1 stated *"it makes him more independent and gets him used to other people"* with Participant 5 adding it helps *"his own development, for separation and independence".* Respite was also identified as a link to integration into the community and participation in social activities

The majority of participants also identified the benefit of respite to the overall family outlining the ability to spend more time with the other children in the family, giving the other family members a break and being able to do normal family things, with Participant 9 remarked *"if we didn't have respite first and foremost I don't think our marriage would of lasted".* Over two-thirds of participants stated that respite has allowed them to remain as the full-time carers of their family member with disabilities and all hoped that this will continue for as long as possible. Participant 4 stated *"I think if we hadn't the respite... certainly at this stage of life I would of thought of... having [family member] in somewhere from Monday to Friday*".

All of the participants also recognised their ability to participate in some form of social activities as a result of respite.

Figure 4.1:



It is clear from the analysis under this theme that the participants in this study find respite a hugely important and beneficial family support service for them and one that, if not available or accessed when needed, can impact on the well-being and social life of both caregivers and those being cared for. Participant 2 affirmed *"its hard going like it is hard [caring] and you need a break for your own sanity"*. Figure 4.1 represents a summary of the main reasons that carers in this study identified as those that brought them into respite services initially as well as the benefits they have received from using these services.

4.2.2 Accessing the Service

A recurring response when asked about how they found out about the respite services available participants reported that they had to go looking for information about services themselves as and when they needed it. The majority of participants (9) stated that they were never told about respite from the services prior to needing support and enquiring about a service that might help them.

All of the participants stated that they found out about respite through informal sources or word of mouth through other parents, parent-run support groups, or other services such as the day services or schools. Participant 6 remarked that she felt that she found out about what respite services her child would been entailed too after she needed them *"I did find out that there was a lot of services that were there, that well I don't know whether I had my head in the clouds [...] or what but I just didn't know about them".* While participant 2 remarked "*they are very slow with coming over with information and telling you that you can have this, this and this you know [and] that it is even there".*

In general participants either contacted the day services or schools that their family member attended in order to find out information about respite services available. While for other participants they found out about the services through other parents in similar situations. Participant 10 remarked "*It's down to parents themselves, and we have with other parents set up a support group in the area like to kinda inform each other and everything because it's the only way".*

While accessing respite services initially is not explicitly identified in the literature it has implications for the findings mentioned already in the first theme discussed where respite was noted to play an important role in supporting family functioning (Dunst & Trivette, 1994) and as such if families are unaware that such supports exist this may have detrimental effects on families' well being. One participant mentioned that had they known respite services existed they may not have reached the crisis point they had as they would have attempted to access these services earlier. If respite services are to fulfil their brief of supporting carers and service users then it could be argued that giving families information about the family support services available prior to needing them might encourage families to access services earlier.

In short these findings around the issue of accessing services highlight are two key implications for respite providers:

- Firstly, some families identified that there was some unnecessary suffering and stress for their family where they required support but were unaware of the existence of respite services.
- Secondly, the available respite services may need to re-evaluate how to collectively advertise the existence of its respite services to increase awareness around its services and to ensure timely support and care to families in this area.

4.2.3 Evaluation of Respite Models

All ten participants were asked about the specific benefits and gaps they experienced with regards to the particular respite service they used. These findings are presented under the different models pertaining to this study namely, the community based residential model and the family based respite model. As previously mentioned, there was a division between participants in the sample regarding the modelled used; four using the Home Share Clare family based model only, three using the community based residential model while the remainder three used both models of respite.

Community Based Residential Model

A total of six of the participants interviewed used the community based residential model (CBRM) of respite, and of these, three also used the family based model. A common response when asked about the benefits of CBRM model of respite was that it provided their family member with a chance to socialise with other people their own age and a chance to do social activities in the community. Participant 2 echoed the sentiments of this group stating *"they take them on outings or that sort of thing [...] take them bowling, take them to the pictures or like if it was summer time bring them off to the beach you know they were always doing something and then in the house, it was a beautiful big house and loads of rooms in it a play area [...] and sure like they played with their own pals*".

Three participants also commented on how they found the high quality of care provided in this model of respite provision.
A number of participants (3) remarked on the positive and close relationship their family member has with the respite staff and their family members. Participant 10 remarked that *"they're lovely and they love the bones of the children in there"*. Similarly participant 7 commented on the group home their family member accessed respite in as *"well staffed with young [people][...] who very much love and enjoy [their work] and deliver a high standard of care [...] they know what [the family member] needs and they relate to him as a person of that age"*.

When asked about their thoughts on the differences between each model of respite, Participant 3 felt that one benefit of the community based model over the family based was that they did not have to worry about the residential staff being sick or cancelling their shift, whereas in the family based model, they felt they had to be more flexible if their host family carer needed to change a shift. They explained: *"in an employee situation where they are on duty and that's it, where in a family situation so that is more flexible, and you [as carers] have to be able to change on short notice, like the other day [the host family carer] was called into work but she couldn't basically take [our child] and I suppose that's more likely to happen"*.

Four participants also highlighted the importance of this model of respite care as preparing their family member for the future, a time when they envisaged that their family member would be living full time in a house that replicated this service. They saw this model of respite as a *"transition into that [full-time care]"* (Participant 4). The role this model of service plays in terms of preparing their family member for future care is something that emerged from the primary research. This may have implications for the future roll-out, or development, of Home Share Clare as families may be reluctant to move from using CBRMs as they may worry what effect this may have for the full-time care of their family member in the future. This will be discussed further in the section 4.3 of this chapter.

An identified disadvantage of this service model highlighted by all participants using it stated that if they wanted respite on specific dates they would need to inform the service long in advance to ensure availability.

The model of service was also deemed unavailable in last minute (non-emergency) situations. However, five out of the six participants that use this CBRM highlighted that in the case of an emergency they felt the service would do all in its power to accommodate families.

These findings are significant as the literature review identified that there are few current reviews of community based residential models (Merriman & Canavan, 2007) and as the participants identified they find there are many benefits to this model of respite care. This suggests that the developments in these services as laid out in the National Disability Strategy (Author, 2004), which included increased funding to these services, as well as improvements in accommodations and staffing, may have resulted in improvements in this model of service over the past number of years.

Family Based Respite Model

All seven participants that used a family based model of respite stated that a significant benefit of this model is the close, trusting relationship that can develop between them as carers, their family members and the host family carer. Commenting on this network of relationships Participant 5 reflected that her family member has become like a sister in her host family. Participant 9 stated *"[our host carer's] been with us so long her, ya know, her life is with us [...] like [our daughter] would be very close to her host family like her parents, her aunts and uncles, nieces and nephews, she knows them all!"*.

A common benefit also noted by participants was the flexibility this model of respite offers in terms of being able to organise your respite hours as a carer rather than this choice being limited by service availability as in the community based model. A number of participants highlighted how this model allowed them to coordinate their respite breaks with the host family to fall over the summer holidays, a time when they found that community respite services tended not to be available. These benefits are consistent with those highlighted in the literature (Merriman & Canavan, 2007; Murphy, 2009) and in Kelleher's (2001) study that found that this model of respite care can expand the social network of the service user as well as that of the carer and that this model is found to be more flexible than staffed institutional care.

Three participants talked about how the relationship with their host family had been established through the pool of people already working with their family member. The benefit of this highlighted by the participants was that the relationship with the host family had already been developed between them and their family member. This was important to participants as they felt they had already established a trusting relationship with the host carer and were comforted knowing that they were able to provide a high level of care to their child *"we wanted someone that knew [family member] [...] we wanted to be comfortable to leave [family member] with someone that knows what to do in the event of an emergency*" (Participant 8).

Participant 5 also identified the benefits to the host family and society in general that family based respite schemes provide and felt this was a positive move towards community integration. "*They [the community] learn an awful lot about disabilities and the more we separate people with disabilities from society the less people have contact with it and they don't know how to handle it or behave around it, but also they miss out on the beauty of the contact* (Participant 5).

Participant 4 suggested that consideration be given to the actual physical lay-out of the host family's home when they are being contemplated as a match for a host to ensure they match all the needs, physically and socially, of the individual. Another participant identified the potential risks involved with using this model. This was in relation to the matching of the person to the host family and if this is mismatched it can have a negative impact on the person receiving respite.

Two participants highlighted that a drawback of this family based model of respite is its viability as a long-term respite care option. These participants saw the role of this model as being one that they benefited from presently providing them with a high quality respite option. Whereas, as discussed above, CBRM is perceived as serving a more long-term function of preparing their family member for living in a similar setting to that which they deemed as part of their family member's future e.g. full time care in a residential home.

Figure 4.2

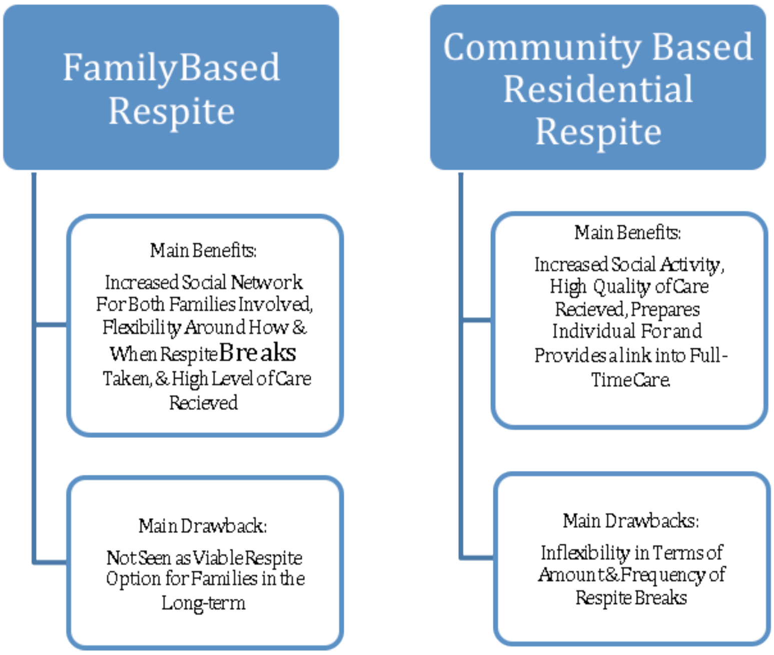


Figure 4.2 outlines a summary of the key benefits and drawbacks noted by participants in regards to both family based and community based respite services. Mansell & Wilson (2010) in their U.K. study echo many of the findings outlined in this section. Their study on the current concerns of informal carers of people with a learning disability found that current issues of concern to carers included quality and quantity of respite and what would happen to the person with learning disability when the carer was no longer able to carry out their caring role (ibid, 2010). Taking this into account, these findings suggest that participants value having *both* models of respite care available to them.

Almost all of the participants that use both services found both to be satisfactory; however, they identified the family based model (HSC) to be more a short-term option to meet immediate needs for high quality respite breaks and the community based to meet the needs of the future in terms of being a link with the full-time care of their family member. There was an expressed fear from a minority of the participants that family based models of respite were an option that was cheaper and therefore these services would replace community based services in the future.

One participant stated *"there is a certain amount of need of residential and I think it is only the services actually trying to cut costs and ignoring the family... and I know they are going in to this integration into society and that all sounds rosy but that is not for [family member]... She needs somewhere very very structured very very safe where she is loved and that is her future"*. These concerns are notable given that the literature review revealed that current trends in Irish social policy suggests that a move towards more cost-effective models of respite is on the horizon. The findings of this study revealed that participants felt that a range of services were needed to meet the individual's needs and emphasised services should meet the needs of the individual, not the individual fitting in to services.

Merriman & Canavan's (2007) recommendations in their Irish study on best practice in the provision of respite services echo the findings presented here in that there is a place for both community based and family based services in the continuum of family support services and that both these models can serve as models of best practice in that not only do they support carers but they can *"help service users to take their place in the community"* (ibid, 2007: 45).

4.2.4 Service Gaps Identified Through the Research

Some common criticisms of respite provision identified in literature review (Cotteril et al, 1997; Sines, 1999; Merriman & Canavan; 2007) included that the demand for these services in general far outweigh the supply. Some of common responses noted by participants regarding community based residential services included not getting enough respite nights to fulfil participants' needs, that nights were allocated by the service and not picked by the participants themselves and in general the unavailability of respite cover during the holiday breaks. Participant 4 commented that if they wanted to secure respite hours in this model of respite on particular dates that *"I would have to book immediately or I might not get it. It's* *getting more difficult to avail of time you really want unless you book months in advance and that is one disadvantage but you must book months in advance because it's popular, more people using it now".*

A number of participants highlighted the differing responses they were faced with when trying to access respite in community based residential services. Participant 10 reflected on her struggle to get a place in a residential service for her child and how she had to turn to the other professionals in order to help secure her child a place, stating: *"we fought so much, different people like the paediatrician and the psychologist fought so hard to get something put in place to actually be a solid support for us to the point where it literally nearly destroyed my family and I can't stress that enough, they nearly destroyed me. I fought so hard to get something put in place because I knew as she was growing, especially as she was hitting the eight mark, I could feel the strength in her."* Participant 2 echoed this remarking *"I just kind of felt it went to crisis, it really went to crisis, before you were offered [respite]".*

In contrast, other participants such as Participants 6 and 7, talked about how the process in securing respite nights in relevant community based residential service was relatively straight-forward. Participant 6 stated that *"…we rang them up and they took her, we went for a week out to the Canaries and they kept her…so it worked out great! They put her down then on a regular basis for four respite nights a month".*

Of note the analysis also revealed that participants felt that these differing responses from services were not linked to the needs of the caregiver or the level of disability of their family member. In general participants perceived that it had not been made clear to them why they received the response they did from respite services (in terms of the amount of respite breaks offered to them).

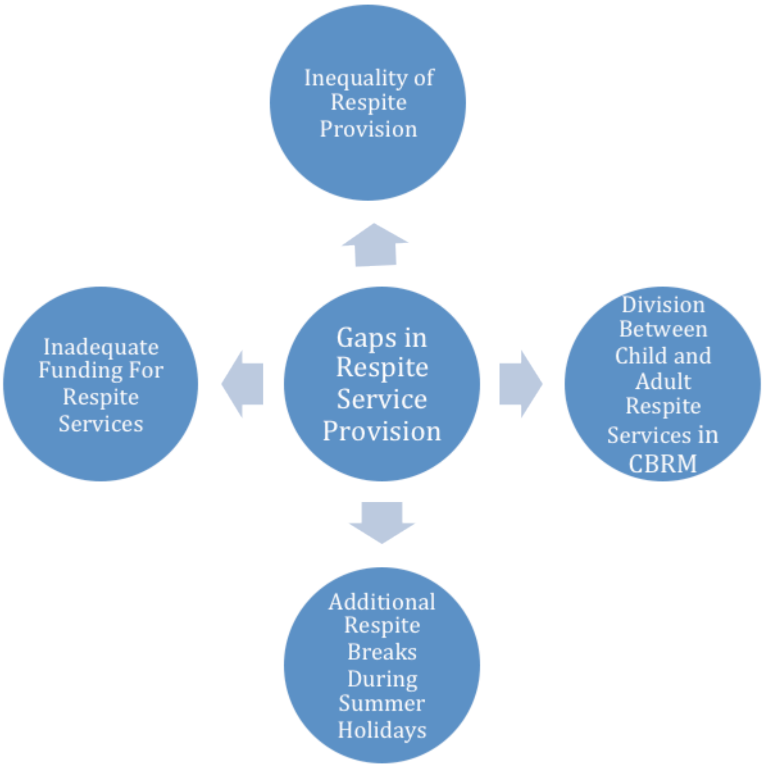
Eight out of ten participants spoke about funding at various times during the interviews. They stated that there was a fear that services would receive cutbacks and envisaged respite to be the first to be affected. They also spoke of the need for the government to give more recognition for respite services through funding. When asked what she would like for the future Participant 5 stated "*more recognition by the government, more funding I don't like how a lot of projects are charity projects and they have to spend so much time in spending money instead of working with the groups they are for and you have to beg for money all of the time the whole idea of it is not nice*".

Participants 2, 3 and 10 pointed out the gaps between child and adult services. The differentiation between Early Intervention, 6-18 years services and adult services were identified generally regarding disability services and specifically in respite. Participant 3 stated *"[family member] needs consistency, you don't want to be chopping and changing too often… you would like the service to be there and continue from [family member's] point of view as well with the people she knows".*

When asked about the transition from child to adult respite Participant 2 commented "*Oh it just stopped, its stops…. its like you are out of the child services now and there is no one there to tell you what happens now how do you get in to the adult services, we were told that would be told to us once she started and that was July, she didn't start in the adult [respite] services until September and there was nothing in between"* (Participant 2). All participants also identified a gap in respite service provision during the summer months as there is no school/day services resulting in, as they perceived, increased demands being placed on respite services.

In summary, the main gaps identified by participants in respite service provision generally include:

Figure 4.3



4.2.5 Conclusion of Findings

Overall from these findings it can be concluded that participants want a range of respite services that offer stability, are adjustable to individual needs, can be easily accessed and will be continuous and seamless, with little disruption to the person receiving respite. The participants feel that this could be achieved through government acknowledgement of the services through providing funding to ensure respite services can operate to meet the needs of the individual rather than the individual fitting in to services. The findings of this study reveal that this would be a move that would go some way to supporting the needs of carers of persons with intellectual disabilities more accurately.

4.3 Discussion

This study aimed to evaluate how family based models of respite care locate themselves within the current climate of respite care provision with a view to informing the C.S.O. involved on the future provision of their family based respite service. The research compared this model to the more traditional model of community based residential respite care through both a literature review and primary research carried out with participants that use both models of respite care.

From this data various themes were identified which portrayed the significant factors impacting on participants' experiences of using respite services. This research found that while both community based and family based models of respite care are identified in the literature, current policy and funding in Ireland is largely tied up in delivering community based models and as a result this has remained the dominant model of respite care available to carers. The literature also highlighted that in the current economic climate there has been an emphasis on providing cost effective services while simultaneously supporting the full inclusion of people with disabilities in society (Hanrahan, 2010; N.D.A., 2010b).

Gaining the perceptions of participants about current respite provision in their locality through the primary research has identified a number of findings that shed light on the research questions posed. In looking at the decision that carers come to in terms of using respite services these were largely in line with what the literature found in that carers use respite services initially for the range of reasons as identified in the analysis. The findings highlighted the importance of respite not only for these participants but also for those being cared for as previously outlined.

In looking at carer's experiences of accessing and using both models of respite a number of issues were highlighted which may have implications for both service provision and policy making. These will now be further outlined.

4.3.1 Accessing Information

Participants outlined that accessing information regarding available respite services in a timely fashion was problematic. Several participants obtained information about respite from informal sources and had to seek out this out themselves rather than being provided with it by professionals running these services. Mencap (2006) identified that families who did not have access to the information needed to obtain respite services resulted in a lack of understanding of services for carers. Power and Kenny (2011) recognised the barriers this caused carers for future planning. Without information carers cannot make decisions regarding the future and it causes a lot of unnecessary anxiety for the carer. Since the establishment of the NDA in 1999 policies and provisions have been outlined to protect and ensure equality to persons with disabilities (NDA, 2004; Merriman and Canavan, 2007). Service providers and professionals in the field of disabilities need to provide carers with relevant information needed to access services. However, it is acknowledged by the researchers that the demand for respite services nationally already outweighs the supply (McConkey *et al.*, 2010) and the provision of information may result in further increasing this demand. As such the importance of increasing the amount of respite services available to families, for example, through the development of initiatives like Home Share Clare is made ever more salient.

4.3.2 Misinterpretation of Respite Services

The benefits of respite that participants in this study identified were not surprising as several previous studies have documented these (Wilkie and Barr, 2008). What the research did reveal was the link participants drew between respite and future long-term care.

Mansell and Wilson (2010) identified carer's worries about the future and their apprehension *'that there would be stable and caring support available to the person with learning disabilities when they were no longer able to care for themselves'* (ibid, p. 29). This fear of the future was a voiced concern in this study. The definition given to respite through the NDA (2004) refers to respite enabling carers to maintain care within the home. As is pointed out in the literature, policy-makers do not envisage respite to be a long-term service or to provide long-term care.

MacDonald and Callery (2004), highlight the variation in understandings and perceptions of respite that can exist between carers and professionals. If carers understand respite to mean a step into future full-time care, implications for carers, services and practice should be noted. Firstly, this could contribute to the increased demand of respite outlined by McConkey *et al.* (2010) resulting in people using respite services that don't necessarily need them presently. Secondly it implies that there may be a miscommunication or misunderstanding among families using community based respite of what these services may be able to provide in the future. The perceived lack of information about respite services highlighted by participants in this study could be a factor in how misunderstandings about what respite services can provide in terms of security in the future may have prevailed.

4.3.3 Ad Hoc Service Provision and Inequitable Distribution

Carers in this study identified that there is little coordination between adult and children's community based respite services and once information is obtained they can prove difficult to access and understand resource allocation. Presently, there is no national systematic criterion outlining respite hour allocation therefore it is at the discretion of service providers (McConkey *et al.*, 2004). The researchers are aware of such a system in the children's residential respite services in this study and participants expressed satisfaction with the same. However, it was unknown by participants how respite breaks are allocated in the adult residential respite services, and as such this system of allocation was perceived as one that is not transparent.

The findings of this study are in line with McConkey *et al.*'s (2010) recent quantitative study which found that there are marked geographical inequalities in the provision of respite services in Ireland and that even with the extra funding received by residential services these inequalities still persist. This could go some way to explaining why the families in this study had differing responses from services when trying to access respite provision. While although the families were all from a particular region in Ireland, there were marked inconsistencies in the amount of respite provision available within this area. Power and Kenny (2011) echo these sentiments arguing that the Irish government have produced policies for the provision of respite without providing the funds to implement them so persons with disabilities are left in limbo with *ad hoc* service provisions (Power and Kenny, 2011).

There is an identified need for collaboration across respite services in the disability sector. It was identified in this study that summer holidays increase a carer's need for respite and therefore puts immense pressure on the respite services during this period. Also the large discrepancies between the different age categorised services (0-6, 6-18, adult) cause implications for the carers and the dependant person. Power (2008) identifies that the transition into adult services can be very difficult and suggests that there should be more cohesion within the services and they should be seamless, transparent and easy. As the findings identified this transition from children to adult community based respite services is something that participants found particularly problematic and a process they feel is not made transparent to them.

Of note, this is a difficulty that is not experienced by those using the family based model who work with both adults and children within the same service and are able to match the service user with a particular carer who can meet their particular needs regardless of their age.

4.3.4 Range of Respite and Recognition

The need for a range of respite service (family based and community based) was expressed by the participants and it was felt that one should not replace the other as both were perceived as playing valuable and complimentary roles in the lives of participants in this study.

Merriman and Canavan (2007) also highlight the need for a range of respite services identifying that no one service can fulfil every persons' needs. As stated previously, there have been recommendations made to the Government to recognise the importance and function of respite and to provide the necessary resources and funding to provide this range of respite.

Although this study found that participants in general felt that family based models should not replace community based models of respite fully, the many benefits that this model holds for the families that use it were identified. These benefits included the close relationship that can be developed between the host family, the person with disabilities themselves and indeed their own family. The flexibility that this model can offer families in terms of organising their respite provision as well as the opportunity this model can hold for community integration of persons with intellectual disabilities were also identified by participants. It is suggested here that this model of respite should receive governmental recognition through funding to provide more family based services, and indeed service users themselves, with stability ensuring the future existence and development of these services.

Guaranteed funding would enable the service providers like Home Share Clare to further roll out this initiative to more carers, potentially increasing the amount of respite breaks available to carers and perhaps reducing the numbers of people using residential respite whose needs may more accurately be met by family based respite, opening the community based residential respite option to those that need it most.

4.4 Conclusion

The following key findings can be concluded from this study:

- ***<u>Range of Respite & Recognition</u>*****:** It is felt that to more successfully meet the individual needs of people with disabilities and their families, this research concludes that a range of available respite services are necessary. All the participants in the study identified that the quality of care and service both models of respite provide for them, once accessed. Participants identified the differing but complimentary roles that both family based and community based respite offers them in terms of meeting their short and long term need for quality respite breaks.
- ***<u>Accessing Information & Ad Hoc Service Provision:</u>*** There was a consensus among all participants that there is a perceived lack of information regarding respite services available to them generally. Participants felt that information on available services was not freely available or provided to them, meaning this was something which they had to seek out themselves. Participants using the adult residential respite services felt there was a lack of transparency as to how the service is distributed.

- ***Misinterpretation of Respite:*** There was also an identified worry amongst participants about the future care of their dependant person. Participants regarded using community based respite as a means to gaining access to long-term care placements for when they can no longer provide full time care for their dependent person. Participants also felt that using this model of respite was important for their family member as it replicated and exposed them to a model of care arrangement they were likely to enter into in the future. This is in contrast to the purposes of respite care.
- ***Inadequate Funding:*** Participants identified the lack of adequate government funding and support for respite services as an issue that requires addressing. All participants expressed awareness of the current economic climate and conveyed their concerns that respite services will become a targeted area for cutbacks. They feel that any cuts in respite services would impact on, and be detrimental to, the level, quality and maintenance of care that they can provide to their family member with disabilities within the home.

Chapter Five: Recommendations and Conclusions

5.1 Introduction

This chapter draws together the key findings from the literature review, interviews and analysed data to answer the core research questions outlined in Chapter One. The recommendations arising identified through the recurring themes that emerged from the data analysis will be outlined. These are made specific to Home Share Clare, respite service providers more generally and policy makers to assist in ascertaining a higher quality of respite provision for carers of persons with intellectual disabilities using the evaluated services in this study.

This study aimed to evaluate how family based models of respite care locate themselves within the current climate of respite care provision with a view to informing the C.S.O. involved (Home Share Clare) on the future provision of their family based respite service. The research compared this model to the more traditional model of community based residential respite care through both a literature review and primary research carried out with participants that use both models of respite care. In doing so the research aimed to understand how carers came to the decision to use respite services, their feelings surrounding this and their experiences of using two particular models of respite care.

5.2 Overview of Key Findings of the Study

Change in Respite Models

Following a review of the literature this research found that while both community based and family based models of respite care are identified in the literature, current policy and funding is largely tied up in providing community based models in Ireland and as a result this has remained the dominant model of respite care available to carers. The literature also highlighted that in the current economic climate there has been an emphasis on providing cost effective services while simultaneously supporting the full inclusion of people with disabilities in society (Hanrahan, 2010; N.D.A., 2010b).

The recent cutbacks in respite services has brought attention towards the high cost of running community based respite services and has led to an acknowledgement of the relatively inexpensive and high quality care that family based models of respite can provide (Hanrahan, 2010).

Rationale for using Respite Care

Feedback from participants about current respite provision in their locality through the primary research has identified a number of findings that shed light on the research questions posed. In looking at the decision that carers come to in terms of using respite services these were largely in line with what the literature found in that carers use respite services initially for the range of reasons as identified in the analysis. The findings highlighted the importance of respite not only for these participants but also for those being cared for.

Accessing Respite and Ad Hoc Service Provision

In exploring with participants the process of accessing respite care, the research found that participants experienced a number of issues that impacted on their ability to use respite services effectively. There was a consensus among participants that there was a lack of information received by them about respite services. For some this led to them reaching a time of great stress as a family before being introduced to these services. Feedback from participants found that it is felt that information on services was not freely available, or provided to carers, meaning this was something which they had to seek out themselves usually through informal sources. This led to some participants not receiving respite when they felt they would have needed it. This is closely linked to the theme identified in the findings around the inequalities in distribution of respite provision where some participants spoke about the relatively straight forward process in securing a place for their family member in community based residential respite services while others identified how they had to fight to acquire time in similar respite services. Among participants who used the adult residential respite, participants noted a lack of transparency as to how the service is distributed. No two participants in the study received the same amount of respite hours and participants were unaware of how or why they were allocated the hours they receive.

Evaluation of Respite Services

Participants also articulated the need for a range of respite services to meet their families' needs in that both community based *and* family based respite services play an important part in supporting them as carers. Participants articulated how they felt the Home Share Clare model of respite supported their short terms need for high quality respite breaks highlighted a number of benefits they found with the service. The research also found that participants saw the role of community based services as one that served a more long-term goal for them as they felt using this model was important as it replicated for their family member the type of living arrangement that they were likely to enter into in the future. There was an identified worry amongst participants about the future care of their dependant person. Participants identified using community based respite as a means to gaining access to long-term care placements for when they can no longer provide full time care for their dependent person and HSC was not recognised as this gateway in to full time care. This research finds that this is in contrast to the purposes of respite care.

Range of Respite Services

The final research question looks to compare these findings to current policy and trends in respite care provision in Ireland. In relations to this the literature review revealed that recent policy reports have been concerned with providing more cost-effective family support services emphasising the high cost of running community based residential respite services. Merriman & Canavan (2007) provide some words of warning on this issue of respite remarking *"it is not simply a question of using the cheapest form or the traditional form or the one that fits the structures already in place"* (ibid, 2007: 42). As previously discussed the overall findings of this research indicate that participants perceived that both community based and family based models of respite care play important functions in their lives as carers and as such it is argued here that both models should be developed as viable respite services for both carers and persons with intellectual disabilities.

5.2 Recommendations for Service Providers

In exploring with participants the process of accessing respite care, the research found that participants experienced a number of issues that impacted on their ability to use respite services effectively. Participants highlighted the lack of information they received about respite services. The research found that carers felt that services were very slow in telling them what respite was available and this meant that some participants were not receiving respite when they felt they needed it.

- It is recommended here that one way service providers could address this issue would perhaps be to supply carers with the relevant information on available respite service as soon as they enter disability services. In line with some of the suggested recommendations made by participants this could be in the form of a leaflet or that families are made aware of a particular person/service to contact in order to find out about their entitlements with regards to respite services. This information could also contain an explanation as to how respite is allocated to families in order to allow the process to be more transparent for those trying to access services.

- One way Home Share Clare may address this issue is to undertake steps to further market their service, and provide more information on its workings and benefits, making it more accessible to prospective families. The respite services may need to address the use of community based respite as a gateway to future full time care for their family member and also transfer issues within community based respite care explicitly.

- The research has outlined that respite services are experienced as fragmented by carers. The move between age categorised services is identified as one of trepidation by participants, as it causes great disruption to the person with an intellectual disability. This points towards the suggestion that service providers endeavour to ensure that this transition within the respite service is more fluid. This perhaps could be achieved through the collaboration of the adult and children's services aiming for a continuation of provision, resulting in a transferral affect rather than families restarting the process again.

- The inequality of respite distribution highlighted by participants in this study as impacting on their ability to access respite breaks with community respite services may perhaps be addressed in terms of developing family based respite services in order to increase the availability of beneficial respite breaks for carers.

- Through the research a recommendation specific to the community residential based adult respite service was identified. This is to implement a criteria system which will ensure equitable distribution of respite hours for all service users. If one is already in existence, the process of distribution could perhaps be made more transparent to families reducing the unknown about the services for them.

- With regards to the Home Share Clare Service particularly, feedback from participants noted that the identification of a host carer/ family from the pool of people already part of their family members' life was deemed particularly successful and beneficial for their family member with an intellectual disability. A recommendation arising from this study is the suggestion that in identifying potential host carers that this pool of people be considered in the first instance in the matching process.

- Participants of the Home Share Clare service also voiced their concerns over the lack of respite breaks available to them over the summer months and highlighted their preference for coordinating their respite breaks to fall at this point in the year. Taking this into account, it is recommended here that in negotiating weekends when respite breaks may be available that the possibility of these being taken over the summer months is discussed with host families.

- The findings of this research show that participants identified many benefits that this model of respite holds for both themselves as carers and their family member using the service. This research recommends that Home Share Clare continues to roll out their family based service as it is found in this research to be a valuable and viable respite resource that could increase the availability and range of respite services available in this region of Ireland.

5.3 Recommendations for Policy Makers

- It is a recommendation of this study that the Government invest in and provide resources to establish family based respite care as a viable source of respite for families of persons with disabilities throughout Ireland. Other research has also recommended this (see Hanrahan, 2010). This research suggests that if funding was provided to further establish family based respite models, including Home Share Clare, carers may be more adequately supported in providing full-time care to their family member with an intellectual disability in their home having increased respite breaks available to them. Research has previously identified that high levels of family support result in lower rates of admission to full time residential care and that proactive investment and management of family support services, such as respite, result in more desirable outcomes for persons with disabilities in the long term (Murphy, 2009). Providing family based respite services, such as Home Share Clare, with funding would eliminate their need to fundraise and would allow these services to develop and grow with the long-term security received through adequate funding.

- Participants in this study articulated the need for a range of respite services to meet their families' needs in that both community based and family based respite services play an important part in supporting them as carers. In concurring with larger scale studies highlighted in the literature review (Merriman & Canavan, 2007; Hanrahan, 2010) the recommendation is echoed here that policy should explicitly support a range of respite options, including both community based and family based respite services, and that funding should be released to allow services to develop both these models in recognition of the valuable role both services play in the lives of participants in this study.

5.5 Conclusion

This research explored how families of persons with intellectual disabilities in a particular region of Ireland experience the respite services available to them. The perceptions of participants towards two models of respite provision namely community based residential respite and family based respite services were sought with a view to investigating how family based respite care provision locates itself within the current climate of respite provision.

A review of the literature revealed how supporting families in providing care to family members with intellectual disabilities has been a challenge for disability, and respite services, in particular ever since the move to community care in the 1960s. This was primarily due to the lack of funding supplied to this sector in the decades since (Woods, 2006). The model of community based residential respite remains the dominant form of provision in Ireland to date. This has meant that the majority of the funding available has been tied up in the maintenance of these services. This has meant that little funding is left over to develop alternative viable forms of respite services such as family based schemes like Home Share Clare. Through meeting with participants using both models of respite care this research has highlighted how families value the availability of both models as viable resources for them in providing quality respite breaks for both themselves as carers and also for those they care for. The two respite services examined were found to provide different, though complimenting benefits to service users and their families. Participants emphasised the impact that structural inequalities in the area of respite provision has had on their ability to efficiently access respite services which in turn affects the well-being of their family unit.

This research concluded that family based respite services, such as the one run Home Share Clare, are valuable respite services for the families who avail of them and recommended that policy and in turn funding should reflect this to allow the future development of these services. However, the research also concluded that this model of respite provision should form part of a range of respite models available to families as the need for families to be able to access both community based and family based models of respite care was articulated by the participants.

Appendix A

-Interview Schedule-

Introduction { Go through Consent Form with participant & explain process e.g.: the recording of the interview, confidentiality & what will happen with the transcripts}

Opening Part 1 : 'About the family and the respite they use'

(Answering research question (A) How do carers of a person with a disability come to the decision that they need to use respite care services?)

(1) Can you tell me about your family member who currently uses a respite care service?

(Prompts: gender, age, level of disability)

(2) What type of respite care service do you use?

(*Prompts: family based, traditional respite, informal family, private care – do you get any informal respite care support through your family/friends etc.?)*

(3) When did you first become involved with respite services*?*

(Prompts: Length of time with using respite service(s) & frequency- how often do Carers use service?)

(4) Can you tell us about how you came to the decision to start using a respite care service for your [family member / name / son]?

(*Prompts: who made decision? / process / tensions / feelings / worries / etc.)*

Part Two: 'Factors influencing particular respite service being used'

(Answering research question: (B What factors influenced Carers of a person with disabilities to use a specific respite service?)

(5) Can you describe what respite care means to you and your family?

(6) What factors did you take into consideration when choosing this specific respite service?

(*Prompts: what factors influenced you in choosing this specific respite service?)*

Part Three: Carer's evaluation of experience using respite service(s)

(*Answering research question (C) How do Carers evaluate how the respite care service(s) they use is meeting their needs as carers and those of their family, and the person who has a disability?)*

(7) Tell us about your experience of using respite care to date?

(*Prompts: can you describe the service you currently use? How has your experience been?)*

(8)Were you aware of any other respite options / types of care open to you?

(Prompt: both informal supports within family/friends or any other formal respite care services?)

(9) Regarding the respite care service that you use, what have been the benefits for you as carers, your wider family and your family member that uses the service?

(10) How would you say the respite service you use could better meet you and your families needs?

- Closing Part of Interview-

(11) Is there anything else you would like to say/to tell us about your decision to use respite care or your choice of respite care type that we have not covered yet, that you think is important add?

Appreciation and ending process

Appendix B

Dear (Parent/Carer),

We are two Social Worker Students from University College Cork who are carrying out a piece of research on behalf of the [*Name of Service*]. Our research aims to explore how the families of service users make decisions with regards to which respite service they avail of and what influences decisions in this regard.

We would like to invite you to participate in our research and are looking to interview parent(s)/ carer(s) who use, or have used, either/ or both the [*Name of Service*] Residential Respite Service or the [*Name of Service*]. We are hoping to carrying out the interviews between March 1rst and March 13th at a venue and time that would best suit you.

Every effort will be made to ensure your confidentiality of any identifying information that is obtained in connection with this study and all personal information will be returned to the [*Name of Service*] on completion of the research.

If you would like to participate in this research please fill in the attached form and return to the above address. If you have any queries please feel free to contact either of us on the numbers below.

We look forward to hearing from you,

Best Regards,

Monica Coll & Siobhan Scully

Appendix C

Participant's Consent Agreement:

1. I am aware that my participation in this interview is voluntary.

2. I understand the intent and purpose of this research.

3. If, for any reason, at any time, I wish to stop the interview, I may do so without having to give an explanation.

4. I am aware that the interview will be recorded using a dictaphone and understand that this recording will be destroyed within a safe time frame of the project completion date (May 2011).

5. Therefore, I am willing to allow the interview to be recorded.

6. I am aware that this recording will be transcribed after the interview and that this transcript will also be accordingly destroyed within a safe time frame of the project’s completion (May 2011).

7. I am aware the project, and therefore the data produced, may become available in the School Off-Print Library and/or the Boole Library on University College Cork campus.

8. The data gathered in this study is confidential with respect to my personal identity and group identity, unless I specify otherwise.

9. If I have any questions about this study, I am free to contact the student researcher.

10. I am aware that I may at any time withdraw all data collected from the interview prior to the submission of the project.

11. I have been offered a copy of this consent form that I may keep for my own reference.

12. I understand that disguised extracts from my interview may be quoted in any subsequent publications if I give permission below:

    (Please tick one:)
    I agree to quotation/publication of extracts from my interview________

    I do not agree to quotation/publication of extracts from my interview________

I have read the above form and, with the understanding that I can withdraw at any time without having to express a reason, I consent to participate in today's interview.

Participant's signature: Date:

Interviewer's signature:

Appendix D

Data Search

Data Bases	Terms Searched	Numbers of Articles Found	Search Dates
Ebsco Host	Respite Care	10	15/12/2010
Science Direct	Parent/Family Carers	13	17/12/2010
	Intellectual Disabilities	14	06/01/2011
	Models of Respite	4	21/02/2011
	Residential Respite	4	24/02/2011
	Family Respite	8	25/02/2011
	Short Breaks	3	27/02/1011
	Deinstitutionalisation	2	03/03/2011
	Social Model	3	08/03/2011
	Medical Model	3	12/03/2011
	Support Services	4	23/03/2011
	Ireland	3	25/03/2011

Some of these searches resulted in the same article being located twice therefore resulting in an overlap. Of the articles found 35 were used. The dates identified above are not particular to the search terms however the date on which specific articles were found is outlined in the bibliography section of this paper.

Bibliography

Bailey, K. (1994) 4th Ed. *Methods of Social Research*. New York: The Free Press.

Bain, K. (1998) 'Children with Severe Disabilities: Options for Residential Care' in *Medical Journal of Australia* **169**: pp.598-600

Beresford, B. (1995) *Expert Opinions: A National Survey of Parents Caring for a Severely Disabled Child* U.K: Policy Press

Blaikie, N. (2003) *Analysing quantitative data*. California: Thousand Oaks.

Braddock, D., Emerson, E., Felce, D. and Stancliffe, R.J. (2001) 'Living circumstances of children and adults with mental retardation or developmental disabilities in the United States, Canada, England and Wales, and Australia' in *Mental Retardation and Developmental Disabilities Research Reviews*, **7**: pp.115-121

Bryman, A. (2008) *Social Research Methods* U.K.: Oxford Publications

Carlin, J., Morrison, J., Bullock, J. and Nawaz, S. (2004) *All Kinds of Short Breaks: A Guide to Providing a Range of Quality Services to Disabled Children and Young People* Bristol: Shared Care Network

Carroll, D. (2010) 'Forward' in Hanrahan, D. (2010) *A Host of Opportunities* Ireland: National Home Sharing & Short-Breaks Network

Catherall, C. & Iphofen, R. (2006) 'Living with Disability' in *Learning Disability Practice* **9:** 5 16-32

Chan, J. & Sigafoos (2000) 'A Review of Child and Family Characteristics Related to the Use of Respite Care' in *Developmental Disability Services in Child & Youth Care Forum* **29** (1): pp.27-37

Chesson, R.A., & Westwood, C.E. (2004). *Making a break: Developing methods for measuring the impact of respite services* Aberdeen: Shared Care Scotland

Cooper, S. (1997) 'Deficient Health and Social Services for Elderly People with Intellectual Disabilities' in *Journal of Intellectual Disability Research* **41**: 4 pp.331-8

Cotterill, L., Hayes, L., Flynn, M. & Sloper, P. (eds) (1997) 'Reviewing Respite Services: Some Lessons From the Literature' in *Disability & Society* **12**: 5 pp. 775-788

Cramer, H. & Carlin, J. (2008) 'Family based short breaks (respite) for Disabled Children: Results from the Fourth National Survey' in *British Journal of Social Work* **38**: pp.1060-1075

Denscombe, M. (2002) *Ground rules For Good Research* U.K.: Open University Press

Department of Health (1965) *The Commission of Enquiry of Mentally Handicapped* Dublin: Stationary Office

Department of Health (1984) *Towards a Full Life: Green Paper on Services for Disabled People* Dublin: Stationary Office

Department of Health (1991) *Needs and Abilities: A Policy for the Intellectually Disabled* Dublin: Stationary Office

Department of Health and Children (2006) *Disability Act 2005 Sectoral Plan* Dublin: Stationary Office

Dunst, C.J., & Trivette, C.M. (1994) *Supporting and Strengthening Families: Methods, Strategies and Practices* Cambridge: Brookline Books

European Union (2002) *The Madrid Declaration: non discrimination plus positive action results in social inclusion*, Available at www.edf.eu

Eyler, P. (2005) 'Out-of-Home – Not Out of the Family: Rethinking the Care of Children with Profound Disabilities'. *Newcastle West, NSW: Disability Advocacy Service Hunter (DASH) Inc.*, [online], Available from: <www.dash.org.au> [Accessed on: 3rd March 2011].

Finch, J. (1990) 'The Politics of Community Care in Britain' in Ungerson, C. (ed) (1990) *Gender and Caring: Work and Welfare in Britain and Scandinavia* London: Wheatsheaf

Flick, U. (2009) *An Introduction to Qualitative Research*. London, Sage Publications Ltd.

Freedman, R.I., Griffiths, D., Wyngaarden, K. & Seltzer, M.M. (1999) 'Patterns of Respite Use By Ageing Mothers of Adults with Mental Retardation' in *Mental Retardation* **37**: pp.93- 103

Forde, H., Lane, H., McCloskey, D., McManus, V. & Tierney, E. (2004) 'Link Family Support- an evaluation of an in-home support service' in *Journal of Psychiatric Mental Health Nurses* **11**: pp.698-704

Gilham, B. (2000) *The Research Interview* London: Continuum

Government of Ireland (2004) *National Disability Strategy* Dublin: Stationary Office

Government of Ireland (2005) *The Disability Act*. Dublin: Stationary Office

Hanrahan, D. (1996) 'Giving an Innovative Lead' in *Frontline* **28**: 10-11

Hanrahan, D. (2010) *A Host of Opportunities: Second National Home-Sharing & Short-breaks Schemes for Children & Adults with Intellectual & Other Disabilities in the Republic of Ireland*: N.H.S.H.

Healy, K. (2005) *Social Work Theories in Context: Creating Frameworks for Practice* U.K.: Palgrave Macmillan

Health Research Board (2009) *Annual Report of the National Intellectual*

Disability Database Committee 2009 [online] Available from: <www.hrb.ie> [Accessed on: 23rd March 2011].

Herring, S., Gray, K., Taffe, J.,Tonge, B., Sweeney, D. (2006) 'Behaviour and Emotional Problems in Toddlers with Pervasive Developmental Disorders and Developmental Delay; associations with parental mental health and family functioning' in *Journal of Intellectual Disability Research* **50**: pp.874- 82

Hirst, M. (2004) *Hearts And Minds: The Health Effects of Caring* Research Summary Scotland: Carers Scotland

Huberman, A. & Miles, B. (1994) *Qualitative Data Analysis* Thousand Oaks, C.A.: Sage Publications

Inclusion Ireland (2011) Available Online At www.inclusionireland.ie [Accessed on 19/03/2011]

Kelleher, J. (2001) 'Family based respite –The experience for children and adults with learning disabilities in St Michaels' House' in *Irish Social Worker* **19:**(2-3), 19-21.

Kelly, F., Kelly, C., Maguire, G., and S. Craig (2009) *National Intellectual Disability Database Annual Report 2008, HRB Statistics Series 6*: Dublin: Health Research Board.

Kelly, C., Craig, S., Kelly, F. (2009) *Annual Report of the National Intellectual Disability Database Committee 2009* Ireland: Health Research Board

Levin, E., Moriarty, J. & Gorbach, P. (1994) *Better for the break* London: HMSO

MacDonald, H. and Callery, P. (2004) 'Different meanings of respite: a study of parents, nurses and social workers caring for children with complex needs'. *Child: Care, Health and Development*, 30(3), pp. 279-288. [online] Available from: <www.ebscohost.com> [Accessed on: 23rd March 2011].

MacDonald E., Fitzsimons, E., and Noonan-Walsh, P. (2006) 'Use of Respite Care and Coping Strategies Among Irish Families of Children with Intellectual Disabilities'. *British Journal of Learning Disabilities,* 35(1), pp. 62-68. [online] Available from: <www.ebscohost.com> [Accessed on: 17th of December 2010].

Mansell, I. & Wilson, C. (2009) 'Current perceptions of respite care: experiences of family and informal carers of people with a learning disability' in *Journal of Intellectual Disabilities* **13**: pp.255

Mansell, J. & Ericcson, K. (1996) *Deinstitutionalisation and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA* London: Chapman Hall.

Marc, P.L. & MacDonald, L. (1988) 'Respite Care- Who Uses It?' in *Mental Retardation* **26**: pp.93-96

Matthiessen, B., Avdagovska, M., Mardhani-Bayne, L., and A. Price (2009) *Respite Care Demonstration Project. Final Report: Summary of The Findings,* Alberta: Disabilities Forum.

May, T. (2001) *Social Research: issues, methods and process* Philadelphia: Open University Press.

McConkey, R. & Conliffe, C. (1989) *The Person with Mental Handicap: Preparation for an Adult Life in the Community* Dublin: St. Michael's House

McConkey, R. and Adams, L. (2000) 'Matching short break services for children with learning disabilities to family needs and preferences' in *Child: Care, Health and Development,* **26:** 5 pp. 429–44.

McConkey, R., Truesdale, M. & Conliffe, C. (2004) 'The Features of Short-Break Residential Services Valued by Families Who Have Children with Multiple Disabilities' in *Journal of Social Work* **4**: 61-75

McConkey, R., Kelly, F., Mannan, H., & Craig, S. (2010) 'Inequalities in Respite Service Provision: Insights from a National, Longitudinal Study of People with Intellectual Disabilities' in *Journal of Applied Research in Intellectual Disabilities* **23:** pp. 85-94

McDonald, G. & McDonald, K. (1995) 'Ethical Issues in Social Work Research' in Hugman, R. & Smith, D. (eds) *Ethical Issues in Social Work* London: Routledge

McNally,, S., Ben-Shlomo,Y. and Newman, S. (1999) 'The effects of respite care on informal carers' well-being: a systematic review' in *Disability and Rehabilitation* ***21****(1): pp.1-14*

McQueen, R. & Knussen, C. (2002) *Research Methods for Social Science* Essex: Pearson Education Ltd.

Mencap (2006) *Breaking Point - families still need a break.* [online] Available from: <www.mencap.org.uk> [Accessed on: 12th March 2011].

Merriman, B. & Canavan, J. (2007) *Towards Best Practice in the Provision of Respite Services for People with Intellectual Disabilities and Autism* Galway: Child and Family Research Centre, U.C.G.

Murphy, T. (2009) *Room for One More: Contract Families Pilot Scheme 07-09* Galway: Brothers of Charity Services Galway with Ability West

National Disability Authority. (2004a) *National Standards for Disability Services* Available at www.nda.ie [Accessed on 11/03/2011]

National Disability Authority. (2004b) *Towards best practice in provision of health services for people with disabilities in Ireland,* Available on www.nda.ie [Accessed on 11/3/2011]

National Disability Authority (2010a) *Models of Residential Provision for People with Disabilities: A Contemporary Developments in Disability Services Paper* Available at www.nda.ie [Accessed on 11/3/2010]

National Disability Authority (2010b) *Advice Paper on the Value for Money and Policy Review of Disability Services Programme: A Contemporary Developments in Disability Services Paper*, Available at www.nda.ie [Accessed on 11/3/2010]

Nolan, M. & Grant, G. (1992) 'Respite Care: An Evaluation of a Hospital Rota Bed Scheme For Elderly People' in *Age Concern Institute of Gerontology*, Research Paper No. 6 London: Ace Books

O'Connor, S. (1987) *Report on Community Care* Dublin: N.E.S.C.

Oswin, M (1984) *Am I Allowed to Cry? A Study of Bereavement Amongst People Who Have Learning Difficulties.* London: Souvenir Press

Payne, M. (2010) *Modern Social Work Theory* 3rd. Edition U.K.: Palgrave MacMillan

Punch, K. (1998) *Introduction to Social Research Quantitative and Qualitative Approaches* London: Sage Publications.

Power, A. (2008) 'It's the system working for the system': carers' experiences of learning disability services in Ireland'. *Health and Social Care in the Community,* 17(1), pp. 92-98. [online] Available from: <www.ebscohost.com> [Accessed on: 8th March 2011].

Power, A., and Kenny, K. (2011) 'When Care is Left to Roam: Carers' experiences of grassroot non-profit services in Ireland'. *Health and Place,* 17, pp. 422-429. [online] Available from: <www.ebscohost.com> [Accessed on: 3rd March 2011].

Quin, S. & Redmond, B. (1999) 'Moving from Needs to Rights: Social Policy for People with Disability in Ireland' in Quin, S., O'Donnell, A., Kennedy, P. & Kiely, G. (Eds.) *Contemporary Irish Social Policy* Dublin: U.C.D. Press

Quin, S. (2003) 'Health services and disability' in Quin, S. & Redmond, B. (eds) *Disability and social policy in Ireland* Dublin: U.C.D. Press

Redmond, B. and Richardson, V. (2003) 'Just getting on with it: exploring the service needs of mothers who care for young children with severe/profound and life threatening intellectual disability'. *Journal of Applied Research in Intellectual Disability*, 16, pp. 205–18. [online] Available from: <www.onlinelibrary.wiley.com> [Accessed on: 8th March 2011].

Report of the Commission on the Status of People with Disabilities (1996) *A Strategy For Equality* Dublin: The Stationary Office

Review Group on Mental Handicap Services (1990) *Needs and Abilities, A Policy for the Intellectually Disabled* Dublin: The Stationary Office

Ritchie, J. & Lewis, J. (2003) *Qualitative Research Practice: A Guide for Social Science Students and Researchers* London: Sage Publications

Robertson, J., Hatton, C., Emerson, E., Wells, E., Collins, M., Langer, S., and Welch, V. (2010) *The Impact of Short Break Provision on Disabled Children and Families: An International Literature Review* Lancaster: Centre for Disability Research

Robinson, C. and Stalker, K. (1993) 'Patterns of provision in respite care and the Children Act' in *British Journal of Social Work*, **23**: pp. 45–63.

Robinson, C. (1994) 'Making the break from "respite care": A keynote review' in *British Journal of Learning Disabilities,* **22**: pp. 42–5.

Robinson, C., Jackson, P. and Townsley, R. (2001) 'Short breaks for families caring for a disabled child with complex health needs' in *Child and Family Social Work,* **6**: 1 pp. 67–75

Robson, C. (2002) *Real World Research: a resource for social science students and practitioner researchers* Oxford: Whiley-Blackwell.

Sarantakos, S. (1998) *Social Research* Basingstoke: MacMillan

S.C.I.E. (2004) *SCIE Research Briefing 5: Short Breaks (respite care) For Children with Learning Difficulties,* London: Social Care Institute of Excellence, Available at http://www.scie.org.uk/publications/briefings/briefing05/index.asp [Accessed on 20/03/2011]

Shaw, I. and Gould, N. (2001) *Qualitative Research in Social Work* London: Sage Publications Ltd.

Sines, D. (1999) 'Identifying the Need for Respite Care for People with Intellectual Disabilities in Northern Ireland' in *Journal of Intellectual Disabilities* **3**: pp.81-91

Sloper, P. (1999) 'Models of Service Support for Parents of Disabled Children: What We Know? What Do We Need to Know?' in *Child: Care, Health and Development* **25**: pp.85-99

Snape, D. & Spencer, L. (2003) 'The Foundation of Qualitative Research' in Ritchie, J. & Lewis, J. (2003) *Qualitative Research Practice: A Guide for Social Science Students and Researchers* London: Sage Publication

Stalker, K. (1990) *Share the Care: An Evaluation of Family based Respite Care Services* London: Jessica Kingsley

Stalker, K. (1996) 'Principles, policy and practice in short-term care', in K. Stalker (ed.*) Developments in Short-Term Care: Breaks and Opportunities*, London: Jessica Kingsley Publishers

Thompson, N. (2002) *Promoting Equality: Challenging Discrimination and Oppression* 2nd edn. Basingstoke: Palgrave Macmillan

Treneman, M., Corkery, A., Dowdney, L. and Hammond, J. (1997) 'Respite care needs, met and unmet: assessment of needs of children with disability' in

*Developmental Medicine and Child Neurology, **39**: pp. 548-53*

United Nations (2006) *Convention on the Rights of Persons with Disabilities*

van Exel, J., de Graaf, G., and Brouwer, W. (2007) 'Care for a break? An investigation of informal caregivers' attitudes towards respite care using Q-methodology'. *Health Policy,* 83, pp. 332-342. [online] Available from: <www.ebscohost.com> [Accessed on: 25th February 2011].

Walliman, N. (2006) *Social Research Methods* U.K.: Sage Publications

Whittaker, A. (2009) *Research Skills for Social Workers* U.K.: Learning Matters

Wilkie, B. & Barr, O. (2008) *The Experiences of Parents of Children with an Intellectual Disability Who Use Respite Care Services* in Learning Disability Practice 11: 5 30-6

Wolfensberger, W. (1972) *The Principle of Normalisation in Human Services* Toronto: National Institute on Mental Retardation.

Woods, Mairide (1997) *Costing the Halo: The Effects of Compulsory Altruism on the Lives of Mothers with Severely Handicapped Adult Children* (Master in Equality Thesis) Dublin: University College Dublin

Woods, M. (2006) 'The Contours of Learning/ Intellectual Disability' in McCluskey, D. (2006) *Health Policy*

World Health Organization (2001) *International Classification of Functioning, Disability, and Health.* (2001) [online] Available from: <http://www.who.int> [Accessed on: 3rd March 2011].