Ageing Family Carers Experiences of Future Planning for their Adult Family Member with an Intellectual Disability Living at Home.

By

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Declaration

I, the undersigned declare that this thesis which I am submitting to the University of Limerick is entirely my own work and research.

Signed: ____________________________________________

Rebecca Cummins

30th May 2018
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This research would not have been completed without the support and encouragement of many people. I would like to take this opportunity to acknowledge those individuals.

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Heartfelt thanks to my family, Mam, Dad, Sínéad, Bláthnáid, Jayden, Adam and my extended family for all your support, encouragement and babysitting. I couldn’t have done it without ye.

On a more personal note, to my husband Paul and my son Iarlaith, I must express my deepest appreciation and love for their endless support, understanding and encouragement.

To my guardian angel Clodagh, always in my thoughts, this is for you.
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Abstract

Ageing Family Carers Experiences of Future Planning for their Adult Family Member with an Intellectual Disability Living at Home.

Rebecca Cummins Fitzgerald, B.Sc. (Hons), Nursing Intellectual Disability.

Increased childhood survival of people with complex physical needs, health and medical technology advances, greater recognition and diagnosis of autism and increasing life expectancy of the world’s population have all contributed to advances and growth in the population of people with intellectual disability nationally and internationally. Today, the majority of ageing adults with an intellectual disability in Ireland are being cared for by their ageing family members at home. This changing profile has major implications for service planning; it points to an enduring high level of demand for full-time residential services, the need for support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability. Therefore, this study explored ageing family carers experiences of future planning for their adult family member with an intellectual disability living at home. This qualitative research utilised an interpretative phenomenological approach to explore ageing carers experiences of future planning for their adult family members with an intellectual disability living at home. Semi-structured interviews were conducted with ten participants that were ageing aged 65years + caring for their adult child with an intellectual disability at home. Data analysis was facilitated by utilising Burnard’s (2011) method of thematic content analysis. Participants voices and interpretations provided important research findings which were presented in four themes; a life unforeseen, bearing the cross, reaching a decision and nearing the end. These findings were discussed in relation to national and international literature and recommendations for education, research, policy and service provision were offered. Overall, this research highlighted the importance of providing support and guidance to ageing carers caring for their adult family member with an intellectual disability at home. There is a need for a collaborative approach across services provided to people with intellectual disabilities and their families in Ireland and a requirement for leadership and support within the community in assuming a supportive role to ageing carers and their family members with a disability in their future planning process.
Chapter 1: Introduction
Chapter 1: Introduction

1.0 Introduction

This chapter aims to introduce the topic of ageing and future planning amongst older family carers that are caring for a family member with an intellectual disability at home. With the advancements in health and social care along with the changing philosophies within intellectual disability there has been an increase in the life expectancy of people with intellectual disability (Doody et al. 2013). This increased life expectancy and the emphasis on care within the community has given rise to the number of older family carers caring for their aging family member with intellectual disability (Ryan et al. 2013). While there is an increasing number of older family carers caring for their family member at home there is little known about what plans exist for the future care of the person with intellectual disability or if any plan actually exists (Taggart et al. 2012). The chapter will include an overview of the research topic to justify the commencement of this review and study, and furthermore highlight the anticipated accomplishments of this study. Moreover, the chapter will provide a foundation and thesis structure for the coming chapters.

1.1 Overview of the research topic.

Within Ireland today there are 28,275 people registered on the National Intellectual Disability Database (NIDD) at the end of December 2016, (Health Research board 2018). A person with an intellectual disability can be defined as somebody having an IQ of <70. IQ stands for intelligence quotient which is the standardised method of assessing intelligence. The severity of a person’s intellectual disability can vary depending on an IQ assessment, level of social functioning and if the intellectual disability is discovered before the age of 18. Early assessment of a person’s IQ can help diagnose a person’s level of disability and help identify a course of treatment and early intervention strategies to help to improve persons with intellectual disabilities quality of life (Doody et Doody 2012). Individuals who have an intellectual disability within the range of 50 to 70 are diagnosed as having a mild intellectual disability. They are slower than typical in all
developmental areas, may have delayed language acquisition and poor academic abilities, however can be capable of learning practical life skills and functions of daily life. Furthermore, they can be able to blend in socially. Individuals who have an intellectual disability within the range of 35-50 are diagnosed as having a moderate intellectual disability, they have noticeable developmental delays (i.e. speech, motor skills), may have physical signs of impairment (i.e. thick tongue), can communicate in basic, simple ways, able to learn basic health and safety skills, can complete self-care activities and can travel alone to nearby, familiar places. Individuals who have an IQ of 20-35 are diagnosed as having a severe intellectual disability and can often have considerable delays in development, poor communication, may be able to learn daily routines and may learn very simple self-care, however a person with severe intellectual disability requires direct supervision in social situations. A person with an IQ less than 20 can be defined as having a profound intellectual disability. People with profound intellectual disability require round-the-clock support and care. They depend on others for all aspects of day-to-day life and have extremely limited communication ability. Frequently, people in this category have other physical limitations as well. (British Psychological/Psychiatric Society - BPS, 2007). Having intellectual disability can influence many aspects of an individual’s life, including the ability to live independently, form relationships, and achieve academic and employability prospects. Furthermore, it is also apparent that having intellectual disability may influence health outcomes, as individuals have a reduced capacity to understand and apply health promotion information to their lives. This makes them reliant on family carers, paid carers and support systems to enable them to exert self-determination in making healthy lifestyle choices. The proportion of people with an intellectual disability in Ireland today aged 35 years or over has increased and now represents 42% (11,781) of the overall population registered on the NIDD. Furthermore, of the people with mild, moderate, severe or profound intellectual disability, the proportion aged 35 years and over has been on a gradual increase since one of its first statistics of 28.5% in 1974 to 37.9% in 1996 when NIDD data were first reported to the recent statistic of 49.3% in 2016. The increasing age profile of people with an intellectual disability reflects an increase in lifespan and this changing age profile among people with intellectual disability has been observed over the
past four decades (Ryan et al 2013). Increased longevity in this population is attributed to improved health and well-being, the control of infectious diseases, the move to community living, better nutrition, and an improvement in the quality of health care services (Thompson et al 2004; Ryan et al 2013). More than half of people with intellectual disabilities in Ireland are being cared for at home with 68.7% of people with intellectual disabilities registered on the NIDD (19,416 individuals) living at home with parents, siblings, relatives or foster parents in 2016. Almost one third of people (2,513, 30.9%) aged 35 years or over whom had a mild, moderate, severe or profound intellectual disability lived at home in 2016. This changing profile has major implications for service planning; it points to an enduring high level of demand for full-time residential services, the need for support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability (National Intellectual Database Annual Report 2016; Taggart et al 2012; WHO 2011; WHO 2000).

Research has emphasised the changing needs of ageing family carers over time whereby caregivers are being forced to care beyond their caregiving capacity. Current literature advocates for more emphasis on research that can investigate how ageing carers can be better supported to continue caring for their family member with an intellectual disability (Taggart et al 2012). With their increasing age, parent and family carers find themselves less able to cope with the demands of their caregiving role. This can have an impact on their health and wellbeing and that of their family member with an intellectual disability (Bowey and McGloughlin 2007). Despite this, there is convincing evidence that identifies carers obligation to continue caring and avoid planning for the future possibility of a time that may come when they may no longer be able to provide essential care to their family member due to parental illness or death. (Dillenburger and McKerr 2009). The absence of adequate future plans and support systems can lead to crisis and emotional trauma for all involved, inappropriate placement and unexpected dilemmas for siblings or extended family. Moreover, unplanned transitions are costly for service providers. (Taggart et al 2012).

Planning for the future is one area where crisis situations can be avoided. It involves anticipating changes that may be in store, planning ahead regarding health care, end of life care, daily care,
financial needs and legal arrangements and communicating wishes and preferences (Multiple Sclerosis Society of Ireland 2017). Bowey and McGlaughlin (2007) identified a clear need for accessible information and a supportive process for family carers and their adult family member with an intellectual disability to make informed decisions about their futures. This emphasises a demand for services to relook at their service delivery programmes and to incorporate services to meet the demands of ageing caregivers at home caring for their family member with an intellectual disability and provide a supportive process to plan for the future.

In Ireland most of the services for people with intellectual disability have undergone fundamental changes. From the mid-1800s onwards there was a view that the best way of providing support to people with intellectual disabilities was to care for them in residential institutions, separate from local communities. Over time, the focus of service provision has shifted where services provided to people with intellectual disabilities are driven by the values of equality, the right of individuals to be present in their communities, to have choice, to make their own plans and preferences for their future and to get the personal supports they need to promote their independence (Taggart and Hanna-Trainor 2017). Such service requirements for people with intellectual disabilities are underpinned by national legislation and policy as well as by international convention, and our knowledge of evidence based practice. (UN 2007; DOH 2013). Furthermore, there is a continuing shift away from a more traditional medical model of care towards a more community based social model of care across professional caregivers including the Registered Nurse Intellectual Disability (RNID) whom is at the frontline of caring for people with intellectual disabilities in Ireland today (Doody et Doody 2012). Within existing service provision there is a concern that services are not prepared for meeting the demands of this ageing population caring for their adult family member with an intellectual disability at home. (Taggart et al 2012). However, literature addressing ageing carers experiences of future planning for their adult family member with an intellectual disability is limited (Taggart et al 2012). Therefore, this research study aimed to explore ageing carers experiences of future planning for their adult family member with an intellectual disability living at home. By capturing and representing the voices and interpretations of ageing carers in this study, the findings will yield
valuable information to highlight the status of families need regarding planning for their adult family member with a disability at home. Moreover, to identify where service need and reform is required most. Subsequently it is hoped that the findings of the study will contribute to informing practice and service delivery and consequently may have a positive impact on the quality of life and care of people with an intellectual disability and their families.

1.2 Research Aim and Objectives.

This research study aimed to explore ageing family carers’ experiences of future planning for their adult family member with intellectual disability living at home. To meet this aim, research objectives were identified as follows.

- To explore ageing carers perceptions of future planning.
- To explore carers current circumstances in caring for their child with a disability at home.
- To identify the extent of plans made by ageing carers for their family member with an intellectual disability.
- To highlight factors that facilitated/hindered successful future planning.

1.3 Thesis Structure.

This chapter presented an overview of the research topic and the aims and objectives of the study were outlined. Chapter two provides a literature review where current national and international literature regarding ageing carers experiences of future planning caring for a family member with an intellectual disability at home is appraised. Chapter three presents the methodological research design of the study. A qualitative study utilising an interpretative phenomenological approach is explained, the sampling methods, data collection and analysis methods and rigour is identified. Chapter four illustrates the findings from this study. The findings are presented in four themes which captures participants’ experiences about the phenomena in question; a life unforeseen, bearing the cross, reaching a decision and nearing the end. In chapter five, a discussion and critical analysis of the findings in relation to national and international literature is presented and the limitations of the study are acknowledged. Finally, chapter six summarises
significant findings of the study and presents conclusions and recommendations based on the research findings.

1.4 Chapter Summary.

The majority of adults with intellectual disability in Ireland continue to live with their families with the aid of additional support services (68.7% n=19,416) according to the National Intellectual Disability Database (NIDD 2016). As their caregiver age beyond their care-giving capacity, a wide range of additional support services are required for people who wish to continue to live at home as independently as possible. The voices and interpretations of the participants is fundamental in understanding ageing carers experiences of future planning for their adult family member with an intellectual disability. Through a qualitative study of family carers experiences, review of the literature, presentation of the findings and discussion it is hoped that this study will contribute to national and international services by highlighting the needs of ageing family carers caring for their family member with an intellectual disability at home. This in turn may assist service planning and reform to support practice and service developments regarding future plans. Chapter two will review of current literature on future planning for family carers caring for persons with an intellectual disability at home.
Chapter 2: Literature Review
Chapter 2: Literature Review

2.0 Introduction

This chapter aims to provide a comprehensive report on how the literature review for a research study was conducted. Utilising a thematic approach, the review aims to critique the predominant themes derived from the literature. A literature review is conducted in order to generate what is known and unknown about a chosen topic, it provides the researcher with an opportunity to identify a gap in the literature that may initiate interest for further investigation and research thus providing contributions to evidence based practice (Newell and Burnard 2011).

For the purpose of this review an integrative design that allows for the incorporation of a variety of methodologies including experimental and non-experimental research was utilised. This is a particularly appropriate review method for the nursing/midwifery disciplines as it does not place an over-emphasis on randomised clinical based trials (Kirkevold 1997). There are many forms that a literature review can take and given the popularity of systematic reviews which is linked with the development of evidence-based care it was considered. However, despite its advantage in a portrayal of a rigorous and transparent data and research, it is at a disadvantage for its lack of inclusion of non-experimental designs (Dixon-Woods et al 2006). Thereby a review framework originally composed by Cooper (1982) and a methodology further updated by Whittemore and Knafl’s (2005) was utilised within this review. Cooper’s original framework placed more emphasis on systematic reviews and meta-analyses, while Whittemore and Knafl (2005) focused on specific issues relating to integrative reviews. This framework involved a five-stage process was followed that involved: problem identification, literature search, data evaluation, data analysis and presentation of results (Whittemore and Knafl 2005).

2.1 Problem identification

Aveyard (2010) emphasises the importance of identifying the problem. In doing this it is possible to define the scope of the review, identify keywords, determine the search strategy, provide guidance for selecting papers and guide data extraction and synthesis of results (Bettany-
Saltikow and Mc Sherry, 2016). Clear problem identification and review purpose are required for focus and boundaries (Whittemore and Knafl 2005). Without a clear and focussed research question it can be difficult to know how or what to research (Groves et al. 2013). Defining and refining a research question can be difficult and time consuming particularly for a novice researcher (Doody and Bailey 2016). However, a clearly defined research question supports strategic targeting of information, so that the literature can be reviewed in depth generating comprehensive results (Wakefield 2015). PEO is a widely used tool for identifying the component parts in qualitative research (Bettany-Saltikov and McSherry 2016) where P identifies the population or problem, E identifies the exposure and O identifies the outcome. The PEO framework (Population, Exposure, Outcome) supported the development of the research/review question for this study Table 2.1 (Kahn et al 2003).

An initial scoping search of the literature was conducted to generate an understanding of research in the topic area and establish if this question had been addressed in a recent review of evidence. The scoping search enabled the identification of the broad range of terms within the literature including; intellectual disability, learning disability, aged, aging, ageing, family, family carer, parent, future plan, forward plan.

Table 2.1. PEO framework formulating the research question (Kahn 2003)

<table>
<thead>
<tr>
<th>P-Population</th>
<th>Family OR Family Carer OR Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>E-Exposure</td>
<td>Ageing carers for a person with Intellectual disability OR Learning disability</td>
</tr>
<tr>
<td>O-Outcome</td>
<td>Future Plan OR Forward Plan</td>
</tr>
</tbody>
</table>

- 10 -
2.2 Literature search

A literature search is conducted to examine the current knowledge on the topic area, consequently this identified what sources to review in more detail (Wakefield 2014). A systematic search of nine academic databases relevant to nursing and healthcare was performed to identify relevant articles: PsycINFO, Cochrane, Medline, CINAHL, Web of Science, Embase, Psycharticle, Academic Search Complete and Scopus during the period June 2017-Nov 2017. These academic databases are relevant to nursing and healthcare (Wakefield 2014; 2015) and search terms generated from the PEO framework were used to ensure a comprehensive search (Wakefield 2014). Boolean operators AND/OR were used and truncation* to promote comprehensive search results. Databases were searched by title and abstract and the search terms used are presented in Table 2.2.

*Table 2.2 Search terms and process*

<table>
<thead>
<tr>
<th>Area</th>
<th>Terms</th>
<th>Search</th>
</tr>
</thead>
<tbody>
<tr>
<td>P</td>
<td>A - Family OR Family Carer OR Parent</td>
<td>S1</td>
</tr>
<tr>
<td></td>
<td>B - Aged OR Aging OR Ageing</td>
<td>S2</td>
</tr>
<tr>
<td>E</td>
<td>Intellectual disability OR Learning disability</td>
<td>S3</td>
</tr>
<tr>
<td>O</td>
<td>Future Plan OR Forward Plan</td>
<td>S4</td>
</tr>
<tr>
<td></td>
<td>Process</td>
<td>S1 and S2 and S3 and S4</td>
</tr>
</tbody>
</table>

Hand searching of reference lists of relevant published papers was also conducted known as ‘ancestry searching’ (Cooper 1982). The search was limited to the years 2006-2017, as 2006 was the earliest published paper found to meet the inclusion criteria. An additional search for relevant publications and policy documents was undertaken within the following websites, Department of Health, Health Research Board and World Health Organisation. This was conducted based on
Hopia et al (2016) recommendation that comprehensive search strategies involve a combination of both database and hand searches. As a failure to search for literature beyond databases could result in bias (Hopia et al. 2016). This search resulted in a large body of published literature which was initially screened in terms of 1) title, 2) abstract and 3) full text. This process in conjunction with specific inclusion criteria (Table 2.3) enabled the selection of relevant literature pertaining to the topic under review and the use of the PRISMA flow diagram enabled a visual presentation of the process (Figure 1)

**Table 2.3. Inclusion/Exclusion criteria**

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Types of studies:</strong></td>
<td></td>
</tr>
<tr>
<td>• Reviews</td>
<td></td>
</tr>
<tr>
<td>• Primary Qualitative Studies</td>
<td></td>
</tr>
<tr>
<td>• Primary Quantitative Studies</td>
<td></td>
</tr>
<tr>
<td>• Primary Mixed Method Studies</td>
<td></td>
</tr>
<tr>
<td><strong>Types of participants:</strong></td>
<td></td>
</tr>
<tr>
<td>• Family carers, male or female</td>
<td></td>
</tr>
<tr>
<td>• Ageing Family carers</td>
<td></td>
</tr>
<tr>
<td>• Caring for their child with an intellectual disability.</td>
<td></td>
</tr>
<tr>
<td>• All living in the family home environment/community.</td>
<td></td>
</tr>
<tr>
<td><strong>Focus of studies:</strong></td>
<td></td>
</tr>
<tr>
<td>• Studies related to concepts and variables identified in <em>Table 1</em>.</td>
<td></td>
</tr>
<tr>
<td>• Must refer to future planning</td>
<td></td>
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<tr>
<td>****</td>
<td></td>
</tr>
<tr>
<td>• Studies published prior to 2006</td>
<td></td>
</tr>
<tr>
<td>• Studies published in countries outside of Western Europe, Australia, USA and Canada</td>
<td></td>
</tr>
<tr>
<td>• Non-peer reviewed studies</td>
<td></td>
</tr>
<tr>
<td>• Studies that do not speak about future planning</td>
<td></td>
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</tbody>
</table>
Figure 1: Prisma Flow Diagram.
2.3 Data evaluation

Data evaluation involved two types of extraction in order to help critique the literature. Firstly, it involved the methodological details of each study being extracted and assessed for quality and rigour; this was then followed by common data being extracted for subsequent analysis (Whittemore and Knafl 2005). To evaluate the data a data extraction table was devised (See appendix K) to include; author, year, title, country, care setting, aim of study, methodology, sampling, data collection, data analysis, summary of findings, limitations and quality score. Within this process the reviewer read and reread each article highlighting relevant details for extraction. This process enabled data to be extracted or summarised for extraction easily and presented a clear synopsis of each study so comparisons or evaluation of the total evidence could be made. Complexity is added where research of varying methodologies is being assessed in a single review (Whittemore and Knafl 2005). The quality of the methodological data was assessed and evaluated through the utilisation of a quality review tool devised originally by Caldwell et al (2005). This tool allowed for the assessment of both qualitative and quantitative studies which was helpful when undertaking the integrative review due to the variety of research involved. Moreover, the reviews that met the inclusion criteria were assessed using the CASP assessment tool for systematic reviews and all studies and reviews were graded into low, medium or high quality.

No papers were excluded based on quality score as there is no gold standard for assessing methodological quality (Whittemore and Knafl 2005). However, it is noteworthy that all papers included within this review scored medium or above. The scores for each paper are detailed in appendix K allowing for a comparison of quality assessment for all research included in this review and the assessment forms utilised for each paper included within this review are included in Appendix J & K.

2.4 Data analysis

Data analysis in an integrative review requires that data extracted is coded, organised, classified and then summarised so that a conclusion can be reached (Whitmore and Knafl 2005). To
facilitate data analysis data from each research paper included was ordered, coded, categorised and summarised into a unified conclusion (Whittemore and Knafl 2005). Challenges exist in obtaining accurate data from primary research (Whittemore and Knafl 2005) and this review was guided by the constant comparative method which has been used to analyse data for this integrative review. This process involves extracting data into systematic categories and formulating patterns, themes and relationships (Glaser 1978, Patton 2015). These coded categories were then compared for further analysis and synthesis resulting in a unified conclusion (Cooper 1998). This approach is very suitable for data analysis in an integrative review as it allows for iterative comparisons of data across multiple primary sources (Whittemore and Knafl 2005). Data were extracted from the 18 papers that met the inclusion criteria (two quantitative, six qualitative, eight mixed methods and two systematic reviews) and analysed to develop themes to present the findings. Within the process the findings of included papers were read and reread line by line, notes were made from statements extracted from each paper and initial codes generated. These codes were reviewed and organised into subthemes according to similarities and differences. As patterns and relationships emerged in subthemes and subthemes connected to become themes (Vaismoradi et al. 2016).

2.5 Presentation of results

Presentation of results involved presenting the synthesised evidence of the reviewed papers under themes and highlights gaps in the research evidence. Through the analysis process evidence within the literature was documented as codes. Codes were grouped to form subthemes. Through grouping the subthemes higher order themes emerged to produce four findings for this review. Within this review the four themes that emerged were; Concerns about the Future, Extent of future planning, Barriers to future planning and Solutions to future planning which are presented below and Figure 2 presents the themes (yellow), subthemes (blue) and codes (green).
Figure 2: Themes, Subthemes and Codes.
2.6 Concerns about the Future

Planning for the future care of adults with an intellectual disability after the main carer ceases their care, continues to be a sensitive and difficult topic for lifelong parental carers. Limited research has been undertaken on this topic because until recently, people with intellectual disabilities usually pre-deceased their parents (Taggart et al 2012; Weeks et al 2009; Gilbert et al 2008; McConkey et al 2006).

Mansell and Wilson (2010) utilised interviews through focus groups and a questionnaire to study issues relevant to the current concerns of carers for the future. 151 participants took part with a response rate of 23%. Participants cited anxiety about the future as a priority key issue, (“what will happen when I’m no longer here to care”). One particular family/parent in Mansell 2010’s study identified the importance of getting their child into supported housing now as soon as possible to avoid having too much an adjustment at a later more crucial stage. Another participant added that they would like to see their child happy and settled within another service or support scheme in order for them to know that they are safe, happy, loved and secure which is a common desire amongst all families interviewed and spoken to within the literature. The possibility of living with an uncertain future proved very stressful for some carers in this study.

Weeks et al (2009) reported an awareness among participants about the need to make some sort of arrangements for their family member with an intellectual disability for their future. The parents identified concerns about their own aging and about a time that may come when they may be no longer able to continue caring for their family member. Carers were worried about what would happen their family member after they had gone, however many carers did not know what they were going to do, some knew what they hoped would happen. Their hopes included not only physical care, but also an environment where their son or daughter would be accepted and loved. Many parent carers envisaged that their other family members would be able to provide care for their son/daughter with ID. Some parents had a tentative plan in place that often-included other family members, such as their other non-disabled children providing care.
in the future. However not all families wanted to rely on other family members to provide care, and in some cases, there was no other family member available to provide care.

2.6.1 Ageing and increasing caregiving difficulties.

An ageing population is a transitional demographic phenomenon in social, economic and political implications. Over the past century, the life expectancies for the general population have dramatically increased. Similarly, life expectancies for people with intellectual disabilities have also significantly increased (Emerson et al 2012). Ageing adults with an intellectual disability are more likely to be living with an ageing family carer who themselves have additional support needs (McConkey et al 2006). These carers constitute a non-normative group as their caregiving role begins at birth and continues through childhood long into adulthood. In some cases, caregiver’s roles can span up to decades ending only upon their death (Cairns et al 2012). The proportion of people with an intellectual disability that live with family members can vary across countries (Taggart 2012). In the United states, estimates of near three-quarters of people with intellectual disabilities live with ageing family caregivers of which 25% are aged 60+ (Heller et al 2006). In the United Kingdom, 60% of people with intellectual disabilities live with their families of which one-third are over the age of 60 years old. Moreover, in Ireland more than half of people with intellectual disabilities in Ireland are being cared for at home with 68.7% of people with intellectual disabilities registered on the NIDD (19,416 individuals) living at home with parents, siblings, relatives or foster parents in 2016. (NIDD 2016). It’s noteworthy to mention the majority of ageing caregivers reported across the literature tends to be female (Cairns 2012; Taggart et al 2012; Dillenburger and McKerr 2009). The reasons for such variation in family caregiving in intellectual disability have not been well explored but they are likely to reflect the individual wishes of parents. With caregivers increasing age and infirmity, parents find themselves less able to cope with the demands of their caregiving role. This can have a negative impact on their health and that of their relative with intellectual disabilities. Despite this there is quite a convincing account of literature that suggest that families still feel it is there responsibility to continue caring for as long as possible. (Grey et al 2015; Bibby 2012; Taggart et al 2012; Chou et al 2009).
Taggart et al (2012) employed a mixed method design examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. This study has been a key factor and definitive piece of research among the topic of ageing carers’/parents caring for their child with an intellectual disability in the family home. It also plays a huge factor for the commencement of this literature review as it has introduced the need to highlight the difficulties and challenges that parent carers are facing as they age while continuing to care for their adult child with an intellectual disability at home. Stage 1 collated information via questionnaire on the health, demands of caring of 112 carers. A high percentage of careers reported suffering from anxiety (40%) and depression (31%), however 71% of these parents indicated their anxiety and 46% highlighted their depression was related to their caregiving. Similarly, the caregivers also contributed sleep problems (46%), back problems (33%) and weight issues (18%) to the caring of their family member. No significant differences were found for these health problems regarding gender and whether you were alone/dual carer. However, slowing down, sleep, back and cardiac problems were found to be significantly different for those aged 72+ years. Over half of carers reported caring to be both physically and emotionally demanding. Behavioural problems of the person with an intellectual disability have also contributed to such demands involved within caregiving. No significant difference was found across the subscales of care-dependent relationship, physical demands of caregiving and total stress for age, gender and lone/dual carer.

Similarly, Dillenburger, et al (2009) reported on carers psychological health in a study completed with 29 parents and carers who were an average age of 65.17 years of age. The study identified as participants aged their stress levels has been increasing due to tasks becoming too difficult and demanding. This was experienced at two levels. First, as carers’ own physical health and strength decreased it was becoming increasingly difficult to complete caring tasks, especially if they involved physical lifting or social supervision. Second ageing sons and daughters themselves developed increasing care and/or social needs. The study identified that participants in the study were more than twice as likely to experience psychological ill-health than the general population.
Demands on caregivers have been found to vary accordingly due to the severity of the family member’s disability (Iacono et al 2016; Chou et al 2009) and presence of co-existing conditions such as mental health problems or challenging behaviours (Weeks et al 2009), and whether the person with a disability and the carer cohabitate (Knox and Bigby 2007). These care demands can lead to high levels of stress and family burden (Eley et al 2009). For carers of adult children with an intellectual disability, age and health related conditions for both carers and adults with a disability as well as the concern for who will take on the role when the parents are no longer able adds to the stress of caregiver’s responsibilities. Furthermore, this level of stress has consequences for carers mental health and wellbeing. Depression, has been associated with the same variables that predict stress, such as carer age (Llewellyn et al 2010), co-residency with the care recipient and the amount of time spent caring (Llewellyn et al 2010). Iacono et al (2016) highlighted the negative impact that caregiving had on some caregivers indicating their use of alcohol and benzodiazepines to attempt relieve their stress and apprehension.

Furthermore, Grey et al (2015) explored the experiences of families seeking out of home accommodation for their family member with an intellectual disability and furthermore highlighted the physical and psychological strain of caregiving resulting in lower energy levels was one of the main reasons for seeking out of home accommodation for their adult son or daughter.

### 2.6.2 Financial concerns and funding

Financial concern is a major issue across the literature for ageing carers caring for their adult family member at home with an intellectual disability (Iacono 2016; Hole 2012). Financial considerations cover a range of issues for carers including paying for services they receive, and there is a link between what parents feel that they need and what they are able to afford (Taggart et al 2012) Weeks et al 2009) demonstrated that caring for a family member with an intellectual disability can lead to a negative effect upon the financial situation of the while family. There may be higher costs of specialized equipment, transport, clothing and higher laundry costs, but in addition to this the care needs may affect the parent’s ability to make up paid employment. The
family capacity to generate money is therefore reduced in a situation where there are increased financial demands (Mansell and Wilson 2010).

Iacono et al (2016) conducted a mixed methods study in Australia to understand the varied experiences of caring and the role appraisal amongst family carers of older adults with an intellectual disability. Qualitative data was received from focus groups and sociodemographic characteristics were obtained regarding employment status. The findings reported that a small number of carers were in paid employment (15.8%), some carers were a full-time housewife/carer (26.3%) and most were retired (57.9%). Sources of financial support included carer allowance/care payment (27%), age pension (21%), department of veteran affairs (5%) and other financial support (11%). Nearly half of participants received no financial support from the government (42%). Most participants had annual incomes ranging from 18,200-33,777 Australian dollars, excluding pensions. Five (36%) of the care recipients lived with a participating carer. Clearly the reality of the income this population were receiving was proving difficult for carers to fulfil their caregiving roles and responsibilities.

Many of the families in Weeks et al’s (2009) study reported concerns in relation to finances. Parents discussed the strain they experienced because of the continuous care required to look after their family member with an intellectual disability. Many parents suggested that they needed funding for either in home-respite or programs outside of the home. Moreover, additional concerns included parents identifying the lack of finance available to meet medical expenses not having enough for extras, not being aware of financial entitlements and the high costs of caring for their son/daughter with an intellectual disability at home. Concerns about the reduction in public forms of financial assistance or low levels of financial assistance were also provided.

Similarly, in Taggart et al (2012), financial concern was a prominent issue in relation to continuity of care and security not only for the present but for when the parents and carers could no longer carry out the caring role. One participant added that “we’re all thinking as we are getting older what is going to happen, in my case, my daughter, when we die, and we’re not here. There needs
to be a system in place where we don’t need to worry about that”. Another participant identified that she as a mother of an adult child with an intellectual disability is aware of what future her child would like to pursue with regard to training and education however lack of funding and finances is preventing her from achieving her goals. Similarly linked to this was security of tenure where one parent highlighted that her daughter would enjoy supported housing however access to these services were problematic due to funding. In reality, the difficulty of accessing service is thought to be a consequence of ongoing financial constraints and the uncertainties of the current financial climate will not help to resolve carers fears (Bibby 2012; Dillenburger et al 2009). The issue of lack of service continuity heightens the level of anxiety that carers expresses over the long-term care of the person with a learning disability. Several pieces of research have emphasised the extent that a lack of financial resources was having on future planning for their sons/daughter by highlighting that they knew exactly where or what their child would like to be but access to respite and services were problematic due to funding placing their children with a disability on endless waiting lists (Taggart et al 2012; Weeks et al 2009).

A study done by Dillenburger et al (2010) reported 24% of families in the study had made no alterations to their homes despite their intentions putting it down to financial costs. Davys et al (2007) recognised the increased financial costs of having a child with a disability, i.e., parents have to pay for the services they receive as well as the cost of specialized equipment, transport, care, etc which can make it all the more stressful for parents to financially plan for the future.
2.7 Extent of future planning

Inevitably, there comes a time when other arrangements are required. The health of the person with an intellectual disability, including their physical and mental health as well as chronic and enduring behaviours that challenge may lead to carers reluctantly exploring alternative care options for the future as they can no longer provide long-term care. (Gilbert et al 2007). More problematic are situations when family care ends due to parental illness or death. The absence of adequate future plans and support systems can lead to crisis and emotional trauma for all concerned (Knox and Bigby 2007), inappropriate placements (Weeks et al 2009) and unexpected dilemmas for other family members (Taggart et al 2012). Furthermore, unplanned transitions are costly for service providers, some family carers may be unknown to services and may come forward only in times of desperate need (Gilbert et al 2007). Despite the rational arguments for proactively supporting family member carers to make future plans, the literature identifies that this unfortunately not the case and many cases future planning is deemed more aspirational than definitive (Bowey and McGloughlin 2007).

Unremitting apprehension emerged as a significant and evocative key theme when talking about planning for the future for many carers interviewed in Taggart et al (2012) study. Many of those carers interviewed found it difficult to articulate on the topic, becoming uncomfortable, distressed and emotionally upset speaking about their “fear for the unknown future care” for their relative. The extent of family and carers planning were cited as being a large area of concern for families in this study. There were two types of plans explored in this study, definitive and aspirational planning. A total of only 10 participants reported that they had already made definitive future plans that involved both living arrangements and legal and financial planning. Yet, despite such plans, few, if any of these plans were developed with personnel from statutory or voluntary organisations. A few carers had planned that their relative would move into a residential facility with other people with intellectual disabilities. However, for some carers that reported future plans made, when explored further plans were found to be aspirational with future plans identified as not having been discussed or any practices put in place to help fulfil the transition of the preferred planning option. Some carers identified their inability to cope with the
thought of the future and panning and highlighted that their future preference was to outlive their son/daughter. Many of the carers expressed their feelings of hopelessness and anguish of the desolate future that lay ahead.

Hole et al (2012) did a qualitative study interviewing 11 ageing adults about their perspectives about the future. The study identified that only three families had engaged in future planning. However, family members expressed the importance of proactive future planning, for them the need of a plan to provide some stability in the event that the future changes. The need for secure and stable living arrangements, the need for attending to legal issues, the importance of financial security, and the value of choice and self-determination were key points emphasised regarding proactive intentional future planning. Moreover, the participants spoke about transition planning and the importance of being around to help with transitioning their loved one into a new living arrangement, families wanted to see their loved one settling into a long-term stable living situation. Another dimension of proactive planning was the need to attend to legal issues particularly the importance of ensuring that ageing adults with intellectual disabilities had an advocate and that their legal rights were protected. One family had obtained a court appointed advocate, another had pursued a representation agreement and several family members spoke of a micro board which involved individuals that come together to create a non-profit society to address the support needs of an individual. The families also related this method to addressing financial plans for their family members future. Despite many participants not having a formal plan in place, most acknowledged the importance of financial security for their loved one. Finally, choice and self-determination was another dimension of proactive future planning. Participants explained that when ageing adults were able to exert choice and independence in the face of age-related changes or crises, they were better able to live the lives they desired. One adult and her child with an intellectual disability were registered with an online registry for personal planning tools which outlines preferences for the future. The registry is a way that third parties can find out who has legal authority to act on behalf of the registered individual. Finally, family members highlighted the importance for opportunities for meaningful activities for their loved one and the value of connections with others.
Weeks et al’s (2009) study reinforced Taggart et al’s (2012) study. The study was conducted in one region of the United Kingdom with a sample of 112 family carers aged between 60-94 years old. The findings of the study reported a lack of future planning among participants 56% of carers had no plan or are willing or ready to make one with the remainder 6% in the process of planning, 13% recognise the need to start planning and only 26% have agreed a future plan. Unlike the previous study Bowey and McGlaughlin (2007) did not identify or further discuss the nature of the plans made. It may be possible that many of these plans were aspirational and were not a definitive plan with an ongoing assessment of the situation and life plan with others. 61% said that they did have an emergency plan, with thirteen turning to the usual short-term break service and twenty-five turning to family. A further four carers assumed that the local residential home would provide emergency care but had made no concrete plans and furthermore 32% of carers had no plans at all for emergency care. Moreover longer-term, 58% had discussed plans for their adult child’s future with another person. 18 of these had discussed this with their social worker, five with day-service staff, 3 with a community nurse and 10 with a family member. However, the remaining 42% reported that they had not yet discussed future plans with anyone.

McConkey et al (2006) completed a study with a sample of 387 participants made up of a sample of family carers. Participants were asked about plans regarding a move for their child, 6% of carers thought a move would be necessary within the next two years and a further 29% thought it could be required within a five-year period. However, when asked about whether plans had been made across the 4 studies, 4% had been placed on a waiting list for accommodation list in study 1, 12% on a waiting list in study 2, 16% were on a waiting list for accommodation in study 3. A number of older carers commented that they didn’t want to talk about the topic, “even though I know I should” said one participant. Surprisingly the highest proportion of parents with plans were those of school leavers in study 4, 20% reported having made plans, one would question whether there were some liaison services in school to help inform and prepare families for the future, something that may be worth investigating in the future?

Bowey and McGlaughlin, (2007) examined the views of the older carers of sixty-two adults with a learning disability about planning for the future providing data about their experiences and
perceived needs. All participants were given the opportunity to either complete a questionnaire or to be interviewed. Six carers opted to be interviewed and the remaining fifty-six carers completed a questionnaire in their own time. Participants were like that of Taggart et al’s (2012) study with an age profile of 70 years+. This paper reported on the views of carers, and attempts to highlight the extent to which they have made plans, their preference for future housing and their experiences of, and barriers to, making such plans. The study highlighted carer’s desperation in identifying that one might feel forced to prefer their son/daughter to die before they do so that they do not have to worry who will take over the caring role when they are gone. It is also important to recognise that parents who have made future plans mostly rely on sibling or other family members to care for their son or daughter with disabilities only few make plans including formal residential care or support in the present family home.

Interestingly some studies have shown a majority of parents anticipating their adult child with a disability to live at home which would identify a perceived need to focus service delivery on supporting the family and the individual with an intellectual disability in the home environment, (Weeks et al 2009). Nevertheless, many family carers stated that they did not want to burden their other siblings with this caring role therefore felt there was no other choice other than to opt for a residential facility (Gilbert et al 2007; Taggart 2012). However, some siblings had agreed to become the main carer upon the death or severe illness of a parent who could no longer provide appropriate care. Among this group, the carers were aware of their own mortality and therefore wanted to face their fears and make future arrangements with their families. In contrast, when some carers who reported they had made future plans, when explored further, these plans were found to only be aspirational. These parents had not directly discussed their future plans with other family members. It became apparent that they were either hoping or expecting that these nondisabled siblings would take on the care-giving role when they died.

Dillenburger et al (2010) study strengthened previous findings from other studies. The study consisted of 29 family caregivers, 20 mothers, eight fathers and one sister 72% of participants had not made any plans for the future care of their sons or daughters with disabilities and only few who had made plans were clear about what would happen to their child when they were no
longer able to provide care. Moreover, 3% were worried about the future and 24% were worried about their own health and well-being. Participants had not discussed future planning with their son or daughter with a disability. Most participants had not even discussed future provision with social services (66%).

Shockingly some carers could not cope with the idea of planning ahead for their relative with intellectual disability and highlighted that their future preference was that “they would outlive their son”. This was a common mutual feeling across many of the parents/carers in the study expressing their anguish and feelings of hopelessness of the desolate future that they believed lay ahead (Taggart et al 2012; Mansell et al 2010; Weeks et al 2009). The study highlighted carer’s desperation in identifying that one might feel forced to prefer their son/daughter to die before they do so that they do not have to worry who will take over the caring role when they are gone.

2.8 Barriers to future planning

Despite the rational arguments for proactively supporting family carers to make future plans, available evidence suggests that this is not the case and that in many cases future planning is more aspirational than definitive (Bowey and McGlughlin 2007). Various explanations have been proposed for these ageing parent’s reluctance to relinquish their caregiving roles. Future planning is an emotive topic. Carers may not make plans as a result of their denial about the inevitability of their own mortality and the realisation that they will no longer be able to continue providing care indefinitely. Moreover, they have difficulties in letting go their loved ones as it may mean increased loneliness for them and an end to their role in life. Also, carers may harbour deep concerns and anxieties about what will happen to their relative in alternative out-of-home placements (Gilbert et al 2007). They find the subject too painful to broach and do not make firm plans until it becomes unavoidable (Bowey and McGlughlin 2007; Chou et al 2009; McConkey et al 2006).

2.8.1 Guidance and Support

Planning for the future when carers can no longer care are among carers worries of intellectually disabled adults. Having supports in place is essential. Despite this, most find it a difficult subject
to face and only a minority discuss it with their child. Similar to the study by Gilbert et al (2007). Few parents, when it came to future planning, some carers identified the importance of their extended families. Some carers identified that their non-disabled child could take on the caring role. In contrast the majority of carers in a study by Gilbert et al (2007) were adamant that other children should not take on the care of the disabled sibling with carers reporting a desire for a better life for their children and not wanting them to carry their burden. Some carers had difficulty talking about the future to their other children, many of whom did not enter discussions on the future of their sibling.

Families are feeling marginalised and are looking for information and help (Bowey and McGlaughlin 2007; Gilbert et al 2007; Taggart et al 2012). Participants spoke about avoiding the painful journey as a result of not knowing what to do. Some participants spoke of their “denial” about having to relinquish their caring role, of “not wanting to let go”. Surprisingly many of the participants recognised the crisis that might arise of not making future plans on them, their families and the person with an intellectual disability. Participants shared their anguish and apprehension over the lack of accessible information, not knowing where to turn or where to look for help and practical supports to help explore future care options.

Another area of concern for parents is the fear of inappropriate placements, in particular the use of older people’s homes for younger people with learning disabilities (Mansell et al 2010). In a study conducted by Gilbert et al 2007, participants shared their anguish and apprehension over the lack of accessible information, not knowing where to turn or where to look for help and practical supports to help explore future care options. Furthermore, carers agonised over the quality and suitability of housing options that are available, many expressing negative attitudes towards both intellectual and non-intellectual disability residential facilities (Gilbert et al 2007). Dissatisfaction with services was the strongest theme in a study conducted by Davys et al (2007), this theme incorporated a number of elements including anger at service providers, a sense of having to fight to get what you want, distrust of services, a sense of parents and service providers being on opposing sides and feeling that services provided are not what parents want and lack quality. Weeks et al (2009) also added that families were unhappy with government personnel,
feeling that they do not understand their situation and need and deliver support in an inadequate way.

Hole et al (2012) reported that those who were engaged in future planning spoke of a support person, a champion, who facilitated planning and accessing resources, supporting other research’s recommendations for greater input from services (Grey 2015; Cairns 2012; Taggart 2012; Weeks et al 2009; Bowey and McGlauthlin 2007; Davys et al 2007; McConkey et al 2006). McConkey et al (2006) conducted four studies in Northern Ireland to ascertain carers views on future accommodation and support needs for their relatives with intellectual disabilities. Using three different methods, carers response was greatest for individual interviews in the home and least for questionnaires and attendance at group meetings. Ironically in all four studies, this appeared to be the first time that carers who were known to the health and social services had been actively consulted about future options. Moreover, many carers reported that they had no ongoing contact with a social worker or a care manager with whom care options could be discussed and who have the responsibility for under-taking formal assessments of care needs which suggests a critical need for service review.

A study conducted by Dillenburger and McKerr (2009) which interviewed 29 parents caring for their adult children with disabilities were asked about present care and service arrangements, health issues, family support and futures planning. The research reported here identifies complex network of relationships as well as virtual absence of structures futures planning was one of the key issues. 90% of participants were full time carers which furthermore involved physical care in 86% of cases. 67% of participants relied on informal family arrangements in case the main carer fell ill, 48% of cases surprisingly had no adequate substitute care arrangements. Only 14% of participants received help from friends or neighbours and 31% did not have any family support. It has also been identified that carers can often be ignorant and unaware about services available to them and recognise that their knowledge of services is based on what is available to them at a local level to them emphasising that parents need to be told about, and to see at first hand, a range of supported living arrangements and examples (McConkey et al 2006).
2.8.2 Access to services

From a historical perspective, it is clear that real and significant tensions exist between parents and service providers. According to Chou (2009) older parents caring for an adult child with an intellectual disability had their wishes and needs ignored by statutory services despite providing a lifetime of care and support. As a generalization, there appears to be a lack of trust in services (Bowey and McGlaughlin 2007). Dissatisfaction with services was the strongest theme in a study conducted by Davys (2007), this theme incorporated a number of elements including anger at service providers, a sense of having to fight to get what you want, distrust of services, a sense of parents and service providers being on opposing sides and feeling that services provided are not what parents want and lack quality.

Grey at al (2015) similarly cited dissatisfaction of services and lack of trust in housing and social services as a key component to their study. The study focused on nine families who lived across six local government areas in Wales and detailed on the families’ experiences of seeking out of home accommodation for their adult child with an Intellectual disability. All participants were ageing between 52-70 years old. The participants all shared the common goal of wanting to plan to transition their sons/daughters to independent living. Disillusion with housing systems was cited as one of the prominent themes. Parents reported a mismatch between rights versus reality highlighting that policy is recognising the rights of people with intellectual disabilities to exercise personal agency and become autonomous members of society, however families reported that that the housing system did not deliver on this promise. Families felt that because they were able to support their family member at home and were not currently in a crisis situation that their needs were viewed as low priority by housing services. Moreover, the process of acquiring housing arrangements was reported to have lacked openness and transparency. Families felt that information was being withheld about offers of property and spoke of difficult relationships with housing and social services staff. One participant highlighted the pressure they felt to take an unsuitable property while recalling a conversation they had with a housing manager who assured them that if they did not take the accommodation offer that there would be many other families who would take their place. These negative relationships with service professional can prove very
stressful and can have a damaging effect upon the family self-esteem and well-being. Weeks et al (2009) also added that families were unhappy with government personnel feeling that they do not understand their situation and need and deliver support in an inadequate way.

Similarly, Gilbert et al (2007) reported family carers views on the accommodation needs of relatives who have an intellectual disability, the study described carers contrasting views on access to services. A number of family carers reported very grateful for the help received from social services naming individuals who were extremely helpful. However, many carers made comments about closures of residential homes, reductions in social service help and limited resources. Family carers reported that they no longer see social workers as they once did and their disillusion with having to fight for everything. Moreover, carers in this study describe their challenges in availing of services due to the inappropriate costs. Two lone family carers in the study reported not availing of respite services because of the financial cost attached. Carers were upset that they were expected to pay, as it was a big expense from their weekly budget. Three other respondents mentioned the difficulty and lack of flexibility accessing respite care that were no longer available, i.e., annual day trips or holidays, as well as availability of residential care for a week or two per year.

The stress and worries that parents had to deal with were particularly evident in a focus group among in Mansell and Wilson’s (2010) study. It was evident that shortfalls in service provision and lack of support exacerbated their concern. The risk of carer and stress burnout is more likely when carers have unaddressed worries or concerns. Services should therefore aim to better support this neglected population while researchers should see to work with carers, parents and their families to help highlight their concerns and evaluate models of good practice in this area. Participants reiterated “I want somewhere that’s going to love her and look after her the same as I do”. Another participant added a note of despair indicating her fear of getting older as she realises the day will come that she will no longer be able to care for her daughter and having to rely on services for support for her child emphasising how “awful” services are and asking the question, “what is going to happen her?”. This particular question was echoed by many of the focus group participants. Bowey and McGlaughin (2007) have identified dissatisfaction with
services as a main explanation as to why informal caregivers may not seek support, however one would question what types of services have these participants utilised to have witnessed such dissatisfaction. Perhaps it may be the shortage of service availability or awareness of accessing services that may be providing negative views on services. McConkey et al (2006) also documented carers fears of their child been abused in facilities which they felt newspapers and media has fuelled. Moreover, it may be issues such as programmes, staffing and care within the structure of the services themselves that require updating and further refurbishment, something that may be work clarifying and further researching.

Mansell and Wilson (2010) also looked at accessing service provision/professional support along with respite care and independence/quality of life. The issue of lack of service continuity heightens the level of anxiety that carers expressed over the long-term care of the person with a learning disability. In Ireland the demand for residential places, exceeds the current supply with many ageing parents having to struggle on in a caring role (McConkey et al 2006).

Deborah Cairns et al (2012) who conducted a qualitative study carrying out eight in depth interviews with 6 mothers and two fathers who had cared for their children since birth. Participants were aged between 65-89 years old. Six of the parent carers were widowed and two were married. The interview aimed to identify carers experiences, concerns and future perspectives on caring for and continuing full time responsibilities caring for their child with a moderate to severe learning disability. After sifting through results, 4 main themes emerged from the interviews including: “a life not foreseen” dealing with when carers first realised their child had a disability, “going it alone” which revealed the uncertainty and unforeseen future they faced and continue face, was very much dependent on the support and information they received, “reaching a decision”, this describes a stage that was at the forefront of most of these parent carers’ minds. Some wanted their children to remain at home for as long as possible, they considered their relationship with their offspring to be reciprocal which was captured under a subtheme “wanting to continue”. Other participants in the study had seriously began to question their abilities to continue the caring role due to their age, health and this was captured under the subtheme, “time to let go”. However, despite their concerns these latter parent carers had no
choice but to continue as there appeared to be no alternative. They had tried and failed to secure suitable accommodation and support for their loved one but were unable to do so because of lack of sufficient information, support and accommodation. Parents also remained the primary caregiver for their offspring due to lack of trust in others to provide sufficient care as well as lack of awareness of services.

Current provision of services in Ireland for people with an intellectual disability and their families is a growing concern particularly for many families who are willing and looking to get help trying to plan for their child’s future. Few investigations have been undertaken into decision making around long-term placement outside of families and these have largely been centred on elderly persons (McConkey et al 2006). There is a huge need for research here, however it is important to recognise that raising the issue of out of family placements and support services may create extra demand for housing and support services without the services to meet the identified needs and in doing so, cause families extra anguish. However, justification for extra resources has to be supported by evidence of need. Moreover, failing to consult with families will not prevent the crisis of finding alternative accommodation that arises when carers suddenly fall ill or die which can result in fitting people into unsuitable accommodation at a time where they are also dealing with the trauma of a bereavement of a loved one (Hole et al 2012).

2.9 Solutions to future planning

After investigating carer’s perceptions of caring for their adult child with a disability at home, Dillenburger et al (2010) drew attention to the level of stress and apprehension participants were exposed. This study illustrates the difficult contingencies to which older parents who care for adult sons/daughters with disabilities are exposed. An explanation for their stress and difficulties is to be found in these contingencies, and consequently, solutions for the problems they face are to be sourced from within the social, cultural and political environments in which they find themselves. The author cited behaviour analytic concepts of ageing and caring which behaviour is viewed as the intersection of person and environment rather than interpreting behaviour as being caused by some hypothetical internal or cognitive factors. This approach ensures that the
blame for difficulties in coping and planning is not laid at the foot of the individual, but is found in the contingencies to which the individual is exposed. The behavioural concept of supply and demand was also mentioned, i.e., whereby in demanding situations and low supply, conflict and stress are very common and practically inevitable. This particular research revealed necessary networks that will break this vicious cycle of low supply/high demand including extended family, friends, financial security, accommodation, statutory bodies, employment and day care.

*Figure 3: Parent/Child Network of support - Dillenburger and McKerr 2010, pg 39*

Figure 3 illustrates a support mechanism that Dillenburger and McKerr (2010) recommended that would alleviate unnecessary stress for parents/carers of adult sons/daughters with disabilities. It recommends that if the family is placed in the center of the network of adequate support while they are able to care for their loved one, this network of support will hold even when the parents are no longer able to care. However, Dillenburger and McKerr (2010) go on to emphasize that these mutual interrelated relationship networks cannot be built overnight or in a crisis situation and require planning and long-term assessment between all participants involved to ensure that in the case of a crisis situation or when the need arises that there will be a safety net of support for the son/daughter with a disability.
Dillenburger and McKerr (2009) recommended an early intensive behavioural intervention to help teach and develop these basic life skills among children with disabilities to help make them as independent as possible. Furthermore, this research highlights a huge and worrying lack of planning for the future of carer’s sons and daughters with disabilities, there is a growing need for more emphasis for forward planning for the future of families living in the community to investigate and highlight what exactly is going to happen to their sons and daughters without a plan. While it was important to investigate access to and service arrangements, the study did not truly investigate future planning and determine what exactly is going to happen to the participant’s child when they are no longer able to care for him/her.

Many researchers have proposed an individual review of the needs of family carers and their relative, using one of the person centred planning methods that are available. Furthermore, this personal contact with family’s need to be maintained over a period of time and with skilled personnel who are available to support ageing caregivers as they face issues of separation and their own mortality.

Furthermore, it has been recommended that service professionals need to rebuild this trust by sign posting parent carers to sources of advice, as well as ensuring that assumptions are not made about parent carers knowing all about their rights and entitlements (Cairns et al 2012; Davys et al 2007). Taggart et al (2012) identified a huge need to develop future planning resources for families particularly in determining which members of the statutory services should accept responsibility to initiate early intervention future planning and support them and their relative through this lifelong emotive journey. The author highlights a wider network of social and health care personnel who could potentially fulfill this role, such as those working in nursing or short break facilities or day care services who have built a relationship with the person if not necessarily with the family. However, the author further illustrates a huge need for staff to be further educated about the changing needs of these parent and sibling carers and the person with intellectual disabilities as they grow older together, and of the emotional, practical and informational support they could offer to them. Research also identifies another option which is for paid staff to support the carers within the family home and to build a trusted relationship
with both the carer and the person with intellectual disabilities. A method of identifying and paying staff is the use of consumer directed payments that allow family carers to define, choose and direct their own supports giving them increased control over the services most suitable for their relative with intellectual disabilities and also the family’s requirement. Money can be allocated or used to pay for personal supports, domiciliary care, day care, transport, supported employment, home modification and respite care. (Caldwell 2007; Doty and Flanagan 2002). There is growing evidence to suggest the success of this scheme of support across the UK and US (Heller and Caldwell 2006).

‘Safe and secure’ is another programme that was developed in Canada (PLAN 2008), and then adapted for use in Scotland by equal futures: a carer led voluntary organization (Etmanski et al 2011). This programme comprises of a six-step guide for future planning for families with a relative with an intellectual disability with topics covered such as clarifying your vision, relationship circles, housing, legal and financial advice, and supported decision making and making a will done through methods of meetings, one to one discussion and workshops. Etmanski et al (2011) also highlighted another approach developed in the US, Canada and Scotland called ‘circle of friends’, this approach involved a group of people coming together in the community to support a person with disabilities on a regular basis.

One of the families within Hole et al (2012) study spoke about a different dimension of planning they utilized called micro boards. Micro boards are composed of individuals such as family and friends who come together to create a non-profit society to address the support needs of an individual. Micro boards are designed around principles of person-centered planning, empowerment and customized approaches to support and provide security for loved ones as well as facilitate future planning. (See: Vela Micro Board Association, http://www.microboard.org/). Research investigating the efficiency of such interventions has demonstrated positive results, specifically demonstrating gains in facilitating self-determination in the lives of ageing adults, decreasing the burden on caregivers, and articulating concrete plans for the future (Heller and Caldwell 2006). There is huge potential for the utilization of empirically and practically supported resources to contribute to the quality of life of ageing individuals and
their families is an area that warrants further exploration and investigation. However, it is worth emphasizing that although future life-planning programs have proliferated and are generally appreciated by participants, some of the programs have had limited success in having participants develop and execute future plans (Hewitt and Lightfoot 2010; Etmanski 1996; Preston and Heller 1996). Some have not included the person with the intellectual disability or his/her siblings in the process (Heller et al 2000; Heller, Miller, Ksieh and Sterns 2000; Sutton, Sterns and Schwartz- Park, 1993), whereas others have provided future life planning training and peer support to adults with an intellectual disability but have not included the family, (Heller 2000). The future planning programme with the most positive empirical evidence is, The Future Is Now: A Future Planning Training Curriculum for Families and Their Adult Relatives with Developmental Disabilities. Based on this model Heller and Caldwell (2006) developed a peer support intervention to support ageing caregivers and adults with developmental disabilities in planning for the future. The intervention was based on a model of peer support: The intervention consisted of a legal/financial training session followed by five additional small-group workshops. Pretest and 1-year follow-up surveys were conducted with 29 families participating in the intervention and 19 control families. Outcome measures included future planning activities, caregiving appraisals, discussion of plans with individuals who have developmental disabilities, and choice making of individuals with developmental disabilities. It was identified that the intervention significantly contributed to families completing several steps in the planning process whom had not previously done so including, letter of intent, taking action on residential planning, and developing a special needs trust. Care giving burden significantly decreased for families in the intervention and daily choice-making of individuals with disabilities increased.

Research suggests a reform of health and social care services and personnel highlighting a huge need for older parent carers who have been caring for their adult child with disabilities for a prolonged period of time are given information, advice and support as quickly as possible to help them continue in their caring roles (Bibby 2013; Taggart et al 2012; Cairns et al 2012; Davys et al 2007). It is clear that there are solutions to combat this ageing epidemic among the ageing population of families with adult children with intellectual disabilities through different types of
interventions. Most of the research done on utilizing future planning interventions has been utilized and trialed outside of Ireland. In Northern Ireland, the need for reform and modernization of the health and social care system has been recognized some time ago (McGimsey 2008).

Whilst support for carer’s has been set as a priority area by national and local government (Department of Health, 2001, 2008, 2009, 2010; 2013), services are still very much dependent upon service availability as opposed to overall need. Bowey and McGlaughlin (2007) and Mansell and Wilson (2010) stress the importance of proactive planning that sets out to avoid the need for crisis intervention.

There were two major Government spending initiatives in the United Kingdom aimed at dealing with the growing concern. The White Paper ‘Valuing people: A new strategy for learning disability for the 21st Century’ (Department of Health 2001) resources of over £300 million were invested to improve the accessibility of mainstream schools and to improve provision for children with special educational needs more generally with the explicit commitment to: improving early identification and early intervention; supporting parents and carers; improving the Special Educational Needs (SEN) framework; developing a more inclusive education system; developing knowledge and skills; working in partnership. Research reported here shows the importance of including policies on early intervention and early planning. These and similar findings (Keenan et al. 2007) should be used to enable governments to spend resources wisely. More recently, the Carer’s Strategy (Department of Health (DOH) 2008) has identified the importance for carers to be afforded short breaks for respite, supporting carers to enter or re-enter the job market, and improving support for young carers. However, despite the fact that the Carer’s Strategy was underpinned by £255 million, recent reports allege that, for example, much of the £150 million that were to be spent towards planned short breaks for carers, seemed to have been ‘lost into the general budget of primary care trusts’ (BBC, 2009). Research reported here shows that these funds should be freed and commitments.
Furthermore, while research has been done on different interventions that might assist families in future planning across the world. It is important to recognise that these interventions are unique to these countries with unique results based on different types of service provision. It would be most beneficial to establish an intervention related system for families in the community and investigate the benefits or implications the system may have on families preparing for the future. Proactive planning is a fundamental requirement for families where a person has a learning disability and will require carers to have a comprehensive list of options. Such planning may take years or months to achieve rather than weeks or days and is understood to be stressful process for both parents and the adult child (Jokinen and Brown 2005).

As revealed by the literature the demanding role faced by carers is not fully recognised by health and social care professionals and government officials, partnership working is an exception rather than the norm, parent carers neglect their own health and needs by prioritising their offspring with learning disabilities, parent carers are unable to think ahead to their own future and their own needs, and finally the absence of suitable care alternatives to substitute the role that parent carers are doing prevents carers from moving on it is therefore critical that practical services plan for those who will be caring long term. Information and advice agencies need to plan for advising parent carers who are at the end of caring, helping them to plan for the future of their offspring and also for their own future, the consequences are too great at an individual and societal level to ignore. If we do, then a vulnerable group in society will continue to be segregated from society.

2.10 Chapter summary

This literature review has systematically examined the body of knowledge that exists in relation to this topic. It has collated the appropriate studies and examined, analysed and synthesised their results to identify what is known about the topic and recognise where further research is required. A description of ageing caregiver’s concerns for the future have been presented. A review of the research in terms of the extent of future planning and the barriers and solutions to future planning were described in accordance with the literature.
Conclusions from the literature review indicate that ageing carers are very concerned with their own ageing and their ageing needs of their family member with an intellectual disability. Caregiving is becoming more challenging for caregivers as a result of their ageing and there is a common worry among the literature of what is going to happen to the person with an intellectual disability being cared for by an ageing family member at home when that person is no longer able due to illness or death.

Literature indicates a level of dissatisfaction among carers with the level of supports they are receiving as carers in the home. Inadequate services, financial assistance and a lack of guidance and support from service providers and professional personnel were highlighted as major factors attributed to caregiver’s concerns for the future. Literature has identified a perceived lack of trust among family carers in the services available to them and an identification of a sense of marginalisation by service professionals.

Literature identified a lack of future planning for the most part among ageing caregivers caring for their adult family member with an intellectual disability. Avoidance, denial, lack of awareness, reluctance to plan and lack of support are all factors that have been identified as contributing to a lack of planning in the literature amongst ageing carers.

From an Irish perspective there is very little published research regarding ageing carers perceptions of future planning for their adult family member with an intellectual disability. This research study will address this dearth by exploring ageing carers experiences of future planning for their adult family member with an intellectual disability living at home. An interpretative phenomenological approach to the study will give ageing carers an opportunity to voice their experiences and it is hoped that findings will contribute to a greater understanding and add to the body of knowledge in this area.
Chapter 3: Methodology
Chapter 3: Research Methodology.

3.0 Introduction

The previous chapter gave an overview of the body of research exploring ageing family carers experiences of future planning for their adult family member with intellectual disability living at home. A research study has been conducted to address the gap in research and knowledge in this area from Irish carers perspective and this chapter will outline the research design. A rational for the chosen research paradigm and methodology for this study will be offered in attempt to justify the chosen method as well as intending to create a logical link between the research questions and the methodology (Polit and Beck 2013).

Conclusions from the literature review indicated that ageing carers are not prepared in terms of future planning for their adult family member with an intellectual disability. There are inherent links between the level of services and quality of supports available to ageing caregivers caring for their adult family member with an intellectual disability at home and the quality of future planning they have engaged in. Therefore, the research study aimed to address this dearth of knowledge.

In this chapter the aims and objectives are outlined. Justification for choosing the research methodology is presented. Ethical considerations are explored. Clear details regarding sampling and access to the sample are provided. Details of the data collection, piloting of the study and data analysis are described and procedures taken to ensure rigour of the study concludes this chapter.

3.1 Research Aim

To explore ageing family carers experiences of future planning for their adult family member with an intellectual disability living at home.
3.2 Research Objectives

- To explore carers current circumstances in caring for their child with a disability at home in the community.
- To identify the extent of plans made for the future care of their son and daughters.
- To identify factors that facilitated/hindered successful future planning.

Exploring parent carers future plans and plan preferences for the care of their children, yields valuable information for government supporting bodies and services particularly as this group of individuals are facing ageing beyond their caring roles. The gathered data highlights current status and circumstances of families caring for their adult child with an intellectual disability at home. It aims to support the provision of service planning amongst those being cared for in the home. Moreover, it aims to identify where services and reform is required most. Subsequently it is hoped that the findings of the study will contribute to informing practice and service delivery and consequently may have a positive impact on the quality of life and care of people with an intellectual disability.

3.3 Research Design and Paradigms

The research design is the key mapping system for a study. It informs the exact research approach best suited to answering the research question. The choice of research design is influenced by the purpose of the study, taking particular consideration of the research questions, aims and objectives (Moule and Goodman 2014). The research design promotes a logical explanation of the research question and the chosen methodology which consequently allows the reader to gauge the validity of the research findings (Polit and Beck 2013). Therefore it is imperative that a research design must be fit for purpose and successful in answering the research question (Newell and Burnard 2011).

The initial design of a research study originates with the identification of the research topic and the research paradigm (Moule and Goodman 2014 ). The research topic for this study was identified within the literature review. A research paradigm is a worldview, a framework of
beliefs, values and methods within which the research will take place (Taylor 2014). All research is guided by the researchers set of beliefs and feelings about the world and this influences how the researcher thinks the world should be understood and studied (Taylor 2014, Creswell 2013, Polit and Beck 2013). There is a difference of opinion in the literature as to what constitutes a paradigm and no absolute definition or categorisation of paradigms exists (Parahoo 2014). All research is guided by the researchers set of beliefs and feelings about the world and this influences how the researcher thinks the world should be understood and studied (Creswell 2013, Polit and Beck 2013). The positivist and naturalistic paradigms will be considered here as they are the most commonly referred to in nursing research. The positivist paradigm is a philosophical paradigm commonly used in scientific research with its origin from the 19th century. The positivist paradigm assumes that there is an absolute distinction between what is true and what is false (Polit and Beck 2013, Newell and Burnard 2011).

The naturalistic paradigm began as a counter movement to positivism and its thinking was that multiple interpretations of reality exist in people’s minds. The goal of researchers working within this perspective is to understand how individuals construct their own reality within their social context. Research carried out within the naturalistic paradigm usually yields subjective findings as a direct result of an interaction between the researcher and the participants (Creswell 2013, Polit and Beck 2013).

For the purpose of this study the naturalistic paradigm was deemed most appropriate as this study explored ageing family carers experiences of future planning for their adult family member with an intellectual disability living at home and it was assumed that multiple realities will emerge within each participant’s social context. The positivism paradigm was deemed inappropriate due to its rigidity that one single truth exists.

3.3.1 Research Methodologies – Quantitative and Qualitative research

In modern research two distinctive designs exist; quantitative and qualitative and both approaches have theoretical perspectives in the attainment of knowledge (Polit and Beck 2013).
Quantitative studies are closely allied with the positivist paradigm and qualitative studies are closely allied with the naturalistic paradigm.

Both qualitative and quantitative methods are common approaches to research used in nursing, one method of research can be chosen over the other based on the nature and suitability of the research in question. A qualitative/quantitative debate does exist and there are many arguments for and against the use of both designs (Burns and Grove 2009).

A Quantitative approach is often used in nursing research, it is a formal, objective, systematic process of obtaining information, using numerical data and statistical analysis. It is deductive, meaning that data is gathered and predictions develop from that data, (Newell and Burnard 2011). Quantitative research utilises numerical data to authenticate facts and quantify or measure findings and phenomena (Taylor 2014, Burns and Grove 2009). Generally quantitative findings are presented using graphs, mathematical models and statistical tables (Parahoo, 2014). A major criticism of quantitative research is that it promotes an idea that the world can be understood and explained in terms of universal laws and objective truths, which apply irrespective of place and time (Polit and Beck 2013). One of the most important differences between quantitative and qualitative research is the relationship between the researcher and the participants (Burns and Grove 2009). While quantitative approaches are considered valuable to healthcare research for providing sound and reliable knowledge bases to guide nursing practice, it is criticised and has been referred to as depersonalising as it fails to grasp what is important in human life and oversees unobservable values including moral and ethical relationships (Polit and Beck 2013). Consequently, a quantitative design was not chosen for this study as it was deemed unsuitable, as this method would not create a logical link between the research questions and the aims of the study. As this study explored ageing family carers experiences of future planning for their their adult family member with an intellectual disability living at home and did not aim to authenticate facts, quantify or measure findings and phenomena, data collection was not formal or objective and the findings are not suited to a numerical or statistical representation. Furthermore, the study was inductive in nature and
multiple realities of participants did exist. A qualitative approach was deemed more suitable and thereby the chosen methodological approach for this research study.

Qualitative research has the ability to illuminate the particulars of human experience in the context of a common phenomenon, it involves a variety of focuses, involving an interpretative, naturalistic approach to its subject matter, and combines the scientific and artistic nature of nursing to enhance understanding of the human experience (Moule and Goodman 2014, Newell and Burnard 2011). It enables the researcher to make sense of reality, to describe and offer explanations and seeks to understand by means of exploration, human experience, perceptions, motivations, intentions and behaviours (Parahoo 2014). While quantitative research often explains why something has occurred, a qualitative approach seeks to understand the interpretations and motivations of the person involved (Creswell 2013). Qualitative research is based upon the belief that no one singular truth or answer to a particular matter exists (Burns and Grove 2009), that reality is subjective and multiple realities exist (Creswell 2013). Qualitative studies are inductive, meaning that they gather information and develop hypotheses about the data. Qualitative research employs flexible methods of data collection which allows the researcher to explore the subjective complexity of human relationships and interactions (Polit and Beck 2013).

A qualitative approach was the chosen methodology for this study as it is deemed most appropriate to give the researcher the flexibility to revel the depth and diversity of carers experiences and the answer the research question (Newell & Bernard 2011). The study explored carers future plans for their sons and daughters with a disability; the findings were subjective as reality existed in the mind of the person experiencing it. Moreover, multiple realities and unique perspectives to each participant arose in this study (Newell & Bernard 2011). Lived human experiences was the type of data collected in this study which help to uncover and understanding the motives that lead to certain perceptions or behaviours.

Within the qualitative paradigm, there are several methodological schools each with the ability to uncover different aspects of human life, therefore an examination of the philosophical schools
within qualitative research was required to determine the most suitable philosophy for this study and phenomenology was chosen.

3.3.2 Phenomenology

There are many approaches to qualitative design, each having their own individual approach and answering individual research questions. Some common qualitative approaches include grounded theory, case studies, ethnomethodology, phenomenology, and constructivism (Maltby et al. 2010).

For the purpose of this study where parent carers views and experiences are explored on their ageing process and future planning for their adult child, the research aim can only be achieved by studying the individuals living this phenomenon, thus phenomenology is the chosen qualitative methodology for the study as it has the ability to discover and understand the unique views and experiences of the phenomena (Converse 2012).

Phenomenology is a philosophical perspective to aid researchers explore and understand everyday experiences without assuming knowledge of those experiences, therefore the researcher can essentially come to the study with an open mind and be ready for whatever may present itself during the study (Converse 2012). Converse (2012) identified the importance of nursing researchers being familiar with the history and philosophical underpinnings of phenomenology in order to assist them in producing a philosophically congruent, phenomenology research design.

Phenomenology originated back to the platonic allegory of the cave where the idea that what people understand to be reality is only a shadow of the phenomena of the true reality (Converse 2012). This concept continued into the 18th and 19th centuries where two philosophers Immanuel Kant and Georg Wilhelm Friedrich Hegel began to develop the idea, one with the theory that a phenomenon is something that appears in the human mind followed by a view that phenomenology was an appropriate way to study the path human consciousness takes to travel from natural consciousness to real knowledge. These concepts were than more explored by Franz Brentano who maintained that his principle of intentionality stated that every mental act is
related to some object and implies that all perceptions have meaning. Finally, two of the most influential philosophers to have developed phenomenology are Edmund Husserl and Martin Heidegger.

### 3.3.3 Husserlian (descriptive phenomenology) and Heideggerian (Hermeneutic or Interpretive phenomenology) approaches.

Martin Husserl, a German philosopher and mathematician, is considered the founder of phenomenology and in particular descriptive phenomenology (Converse 2012). Husserl attempted to understand human thought and experience through rigorous and unbiased study of things as they appear (Dowling and Cooney 2012). The Husserlian approach or descriptive phenomenology is based on the attempt to study the direct experience, from the person or phenomena themselves through a process of coherence, interaction, observation and understanding. Husserl believed that human beings are free and are fully responsible in controlling their own environment (Parahoo 2014). Furthermore, the approach involves a process of transcendental subjectivity and bracketing (Converse 2012). Bracketing refers to the researcher examining his or her own attitudes, beliefs and prejudices and following this transcendental subjectivity refers to the researcher disregarding any preconceptions about the phenomenon under study (Polit and Beck 2013). Hence a pure description of the phenomenon emerges.

Martin Heidegger, a student of Husserl challenged Husserl’s construction of phenomenology as a purely descriptive philosophy introducing interpretation as both a concept and method of phenomenology (Converse 2012). Heidegger sought to answer the question of the meaning of being, he believed that humans are hermeneutic beings with the ability to find meaning in their own lives (Earle 2010). Heidegger developed the Heideggerian (Hermeneutic or interpretive) phenomenological approach using the premises that all humans are interpretative. For Heidegger, the ‘environment’ or ‘context’ in which a phenomenon occurred was of upmost importance. A pivotal difference between the two perspectives is context. Husserl viewed humans independently of their context but Heidegger believed that humans cannot be studied
without consideration of their context and culture (Parahoo 2014; Polit and Beck 2013). For this study, the researcher chose to use an interpretive methodological approach for this study as phenomenology is an appropriate methodological approach to exploring the person views and experiences and in particular for the purpose of this study, carers future plans for their adult child with a disability. The more specific reasons for choosing an interpretative phenomenological as opposed to descriptive phenomenology were as follows:

The researcher aimed to understand parent carers’ perceptions and plans in their social and cultural context. Carers had varied backgrounds, ages and life experiences, were in receipt of varied supports and services each bringing their own unique perspectives and experiences.

The researcher does not believe that descriptive phenomenology and bracketing will yield bias free research findings in this particular study. Secondly the influence of the researcher was an important issue. The researcher in this study is a Registered Nurse Intellectual Disability (RNID) and continues to work with people with intellectual disabilities and in particular their families and has her own perceptions of future planning preferences and the essential criteria to assist in positive planning for people with disabilities and their families. The researcher can see that future planning for people with an intellectual disability is an area that is under developed within community support services and the researcher is interested to see how exactly families are coping regarding planning. Heidegger asserted that it is not possible to achieve true detachment from personal bias as Husserl suggested. Instead Heidegger proposed that these fore-structures be used to construct the phenomenon with the participant (Polit and Beck 2013).

An objective of this study is to provide meaningful results that will highlight service need and reform for families caring for their adult child with a disability at home in the community to governments, supporting bodies and services so that the future provision of services will be delivered based on identified need to assist them in planning for the future. The interpretative phenomenological approach, with its co-creation of meaningful results and acknowledging the subjectivity of the researcher, seems the obvious methodology for this study.
3.4 Access

Any research project that involves human participants is subject to ethical approval by a research ethics committee. In general, ethics committees consist of professionals and members of the lay community with interest in such areas as law, theology and moral practices. The aim of such committees is to protect the rights and interest of the people by scrutinising research proposals before they can be put into practice (Polit and Beck 2013). Human participants must be safeguarded by the knowledge that the research being carried out is in fact ethical. There are ethical deliberations surrounding all forms of research and this includes nursing research (Newell and Burnard 2011). As a nurse, the researcher involved in this study abides and adheres to the national code of conduct set out by the nursing and midwifery board of Ireland (NMBI 2014). This study involved obtaining access to ageing parents caring for their adult child with a disability at home from local groups and services for parents with children with intellectual disabilities. The first step in negotiating access involves seeking approval from the Faculty of Education and Health Sciences Research Ethics Committee at the University of Limerick. Approval was obtained in December 2014 (Appendix A)

Following this, a letter was sent to a local intellectual disability service requesting permission to contact families, parents. The researcher met with the general manager of the service to discuss the aims and objectives of the study and to seek assistance in obtaining a purposeful sample. The general manager agreed to be the gatekeeper for this study where he would distribute information packs to the relevant sample of people on my behalf.

A radio interview was completed with Tipperary Mid-West interview, a meeting was set up with the radio manager and an agreed time slot was given on morning radio to allow the researcher to speak about the topic.

3.5 Ethical Considerations

Ethics is a branch of philosophy concerned with morality (Moule and Goodman 2014). Ethics began in ancient Greek times, it is a branch of philosophy that deals with the dynamics of right
or wrong in our moral lives (Parahoo 2014). The main principle of ethics in nursing research therefore is the protection of the rights of all or any individual who participates in biomedical research. No one should be subjected to torture or to cruel inhuman, degrading treatment or punishment. In particular no one should be subjected without his/her free consent to medical or scientific experiment, (United Nations 2002). Ethical considerations in research can be explained as a set of moral values that are concerned with the degree to which researchers adhere to professional, legal and social obligations regarding human study participants (Polit and Beck 2013). Many international ethical standards have been developed and adopted in health research internationally. The Nuremberg Code 1947 (Merz 2018), Helsinki Declaration 1964 (Wma.net 2018), Belmont Report 1979 (HHS GOV 2018). and the ICN Code of Ethics 2012 (Icn.ch 2018) underpinned the methods and plans for this study.

There is also a national document in Ireland available provided by the Nursing and Midwifery Board in Ireland regarding the ethical conduct of nurse’s and midwives in research (Nursing and Midwifery board (NMBI), 2014) which highlights core ethical principles and considerations to be taken when carrying out research. Moreover, there is a Code of Professional Conduct for each Nurse and Midwife which must be adhered to during research also (NMBI, 2014).

Ethical approval was essential to obtain for this research project as is any research project looking to involve human participants. Ethical approval was granted by the University of Limerick Research Governance and Faculty of Education and Health Science Ethics Committee in February 2015. A vital requirement of all research is that it is scientifically sound and conducted by researchers who are supervised or have the essential skills to undertake the investigation (Parahoo 2014). For this research project, the researcher involved had two highly skilled academic researchers supervising and guiding her work. Moreover, the researcher adhered to all guiding principles that are required to be utilised when formulating and assessing the appropriateness of research studies (Polit and Beck 2014). Core principles of research have been identified as relevant to the conduct of research involving human subjects (Lo-Biondo Wood et Haber 2014), these principles will be explored next in relation to this research.
3.5.1 Beneficence

Beneficence is one of the primary ethical principles of ethics and means to do good or to benefit persons (Lo-Biondo Wood et Haber 2014). The benefit of this research has been the valuable information from the carers/parent’s perspective that has been obtained. The information received aims to voice their current situation regarding future planning as they continue to advocate for their sons and daughters as they both age. Furthermore, this research will create awareness providing evidence based information that is valuable for service providers and government bodies who are in charge of funding and delivery of service provision in Ireland. Moreover, non-maleficence refers to the principal that means to do no harm, (Parahoo 2014). While there were no anticipated risks involved in this research, it is acknowledged that all qualitative research has the potential to raise emotive response in people particularly with the nature of the topic looking into the future where parents will no longer be able to care for their child facing the ageing process and death. In this instance the researcher offered all participants the option that if any time they felt uncomfortable or distressed in any situation, they were free to cease or withdraw at any time thus the study would have terminated and/or postponed. Thankfully this was not the case and participants were able to continue with the study. A counselling service was to also available be offered to participants whom were in need but again was not required. A business card was offered with the contact details of a fully qualified counsellor of whom would have been of assistance if needed. Furthermore, participants were afforded a choice of venue in-order to reduce inconvenience and opportune costs imposed such as travel. Also, when sending out introduction packs which consisted of an information sheet, invitation letter, consent form and reply slip (see appendix B, C, D, and F), a stamped addressed envelope was included for convenience of participants to return forms to researcher. A tea bag and coffee sample was also included in the information pack as a light-hearted gesture which received a warm thankful acknowledgement to take the time to consider participation.

3.5.2 Respect for Persons

This is another ethical principle in research involves many issues within research such as fidelity, veracity, justice, autonomy, informed consent, privacy and confidentiality. The researcher
adhered to The Code of Professional Conduct and Ethics for nurses and Registered Midwives (NMBI 2014). The purpose of the Code is to guide nurses and midwives in their day-to-day practice and help them to understand their professional responsibilities in caring for patients in a safe, ethical and effective way.

The aims of the Code are to:

- help, guide and support registered nurses and midwives in their ethical and clinical decision making, their on-going reflection and professional self-development.
- inform the general public about the professional care they can expect from nurses and midwives.
- highlight and emphasise the importance of the obligations of nurses and midwives to recognise and respond to the needs of patients and families.
- set standards for the regulation, monitoring and enforcement of professional conduct.

3.5.3 Fidelity

Fidelity is where trust is given and obtained between the researcher and participants and involves the researcher maintaining confidentiality (Polit and beck 2013). Each participant was reassured that any information gathered would be kept confidential and that their names would remain anonymous. Furthermore, it ensures to safeguard the rights of the participants (Parahoo 2014). Fidelity was upheld at all times during this research. In order to receive a detailed account of parent carers extent of planning for the future, it was imperative that the participants can trust the researcher and feel comfortable with expressing their own personal experiences and perceptions of the topic. The researcher took care in creating relationships with the participants. There were two points of contact with participants pre- interviewing which gave the participant time to feel comfortable speaking to the researcher. Care was taken to ensure the participants gained a brief background about the researcher and felt comfortable in her surroundings. The researcher ensured that their presence wasn’t at all threatening in terms of files/folders carried, the researcher sat at each participants level and was fully engaged and not taking notes during interviewing. Interviews were kept unstructured and conversational and the recorder was kept
out of sight so that the participant would not feel threatened or nervous. Veracity and the ability of the researcher to tell the truth always was also important in helping to build trust.

3.5.4 Justice

Justice involves the researcher correctly deciding how to distribute resources through ethical methods (Newell and Burnard 2011). It involves fairness from the researcher ensuring to put the needs of the participants ahead of the needs and aims of the study (Parahoo 2014). For example in this study, time will be allocated for participant to act or talk freely about the topic. This was particularly important in this study. It was anticipated that due to the nature of the topic, information obtained may be very personal and sometimes saddening for an individual making them vulnerable, therefore at times the needs of the study had to be overlooked, for instance where the participant went off the initial probing question in order to express concern in another area. The researcher had to be careful to be empathetic and understanding in this instance.

3.5.5 Veracity

Veracity is the responsibility on the researcher to ensure to tell participants the truth at all times and not to lie or mislead others at any expense or cause even if it involves withdrawal of participants (Parahoo 2014; Newell and Burnard 2011). In this study, an information sheet was given in the introduction pack (see appendix c). All aspects of the study were discussed with the participants, ie, benefits, risks, harm etc if any. Furthermore, the researchers contact details were highlighted for any further queries or questions that participants may have at any time.

3.5.6 Autonomy

Autonomy is the principle that recognises one’s own ability to make a free, independent and informed choice (Creswell 2013). Participation in the proposed study is voluntary and participants are free to withdraw at any stage of the research. During the interviews probing questions were used however the researcher was mindful of the demand effect in conducting the study where the researcher searches for more elaboration when none exists; this runs the risk of the
respondent saying things for the sake of saying it or to satisfy the researcher (Newell and Burnard 2011).

3.5.7 Informed Consent

Informed consent refers to a process that protects a participant’s autonomy and encourages professionalism and responsibility for providing information during the research process (Parahoo 2014). In this study, all information will be provided regarding the research undertaken so that participants can make an informed decision based on receiving clear, accurate and unambiguous information about the study, identifying any benefits and risks there may be (Parahoo 2014). In order to achieve this, during the recruitment process an information sheet (see appendix C) via email/letter was sent to provide full disclosure of relevant study information. A consent form (see appendix D) was sent in the introduction pack also with a stamped addressed envelope.

3.5.8 Privacy and Confidentiality

The personal information about clients, whether it is personal notes, address, medical files/information, forms, etc is deemed as confidential private information. Privacy is a basic ethical principal. Confidentiality is the manner in which this personal information about participants are kept private and only disclosed on a need to no basis (Parahoo 2014). It is important in nursing research that researchers take care not to inadvertently reveal information that participants may want to remain confidential (Pilot and Beck 2010; LoBiondo-Wood and Haber 2014).

Closely related to confidentiality is anonymity whereby a subject has a right not to be linked to the information they disclose for data collection purposes (Parahoo 2014). Parahoo (2014) recognise that anonymity may not always be possible as quotations, speech mannerisms and context may provide adequate information for participants to be identified by themselves or others. As small samples were used in this study it was important to recognise that during analysis and recording of data, quotes have the potential of identifying participants so each participant was given a pseudo name and only the researcher has access to the data and audio recordings.
which are stored in a locked press and password protected computer (see appendix G on storage of information). A pseudo name was applied in the presentation of findings and masking was used to hide figures of speech which might identify a person. Only the researcher and the researchers two supervisors has access to the data. Confidentiality and anonymity of participants is guaranteed at all times and written consent was obtained from participants prior to any data collection (see appendix D, consent form.) A promise of confidentiality by the researcher was made to ensure participants that information provided will not be disclosed or reported publicly in a way that will highlight their identity, i.e., within research transcripts, research report or in any publications (Burns and Grove 2009).

3.6 Sampling

Sampling involves how a group of people are picked for the study. It involves selecting groups in terms of specific factors, i.e., education, events, behaviour, activities, etc. There are two types of sampling, probability and non-probability sampling (Nieswiedomy 2008). The sample of interest for this research are ageing parents caring for their adult child with a disability at home in the community. There are two types of sampling which will be discussed.

3.6.1 Probability Sampling

Probability sampling involves randomly selecting individuals from a sample group. In other words, all individuals that meet inclusion/exclusion criteria of the project have an equal chance of selection therefore there is less chance of bias by the researcher (Parahoo 2014). There are four types of probability sample, simple random, stratified random, systematic random and cluster random. This type of sampling was not selected for this research proposal as a specific group of participants were required for this qualitative research.

3.6.2 Non-Probability Sampling

Non-probability samples are made up of individuals whose chances of selection are not known in advance (Pilot and Beck 2013). There are 5 types of non-probability sampling, accidental, purposeful, volunteer, snowball and quota sampling. There are many advantages of non-
probability sampling including that it is economical, convenient and does not require as much skill and resources as probability sampling. Non-probability sampling is the chosen method for this study in attempt to yield a high quality, descriptive, alluvial data.

There are three common methods of sampling in qualitative research, convenience sampling, purposeful sampling and snowball sampling. For the purpose of this study purposeful sampling was used to enable the researcher to gain an understanding of the phenomenon under investigation.

3.6.3 Purposeful Sampling

Purposeful sampling involves the researcher specifically choosing a sample of individuals with certain circumstances that would best meet the requirements of the study and may have something relevant to say in accordance with the research aims (Polit and Beck 2013). In this study the sample was deliberately chosen by the researcher on the basis that these are the best available people to provide data on the issues being researched (Burns and Grove 2009). For this study the researcher chose a sample of parent carers that are ageing and caring for their adult child with a disability at home. The researcher believes that ageing parents as opposed to younger parents with younger kids with a disability will be more in tune with the ageing process and future planning for their sons and daughters.

The researcher chose to access purposeful sample two ways in this study. Primarily the researcher accessed an Intellectual disability service in the local district and arranged a meeting with the service manager to discuss the aims of the study.

The researcher gave the manager an agreed 30 information packs which he distributed on the researcher’s behalf (appendix B).

The researcher also completed a radio interview whereby the researcher was given a 10-minute timeslot to talk to the broadcaster about the study and request anyone who was interested who fit the inclusion criteria of the study to come in contact with the radio station who would distribute my number.
3.6.4 Sample Size

A qualitative study normally involves smaller sample populations usually 10 or less (Polit and Beck 2013). When a sample is chosen properly, the researcher is able to make claims about the population based on data from the sample (Nieswiadomy 2008). For this study 10 participants took part which will be discussed further.

3.6.5 Inclusion and Exclusion Criteria

Inclusion criteria refers to specific characteristics, features or experiences a subject must hold to be eligible to be part of the intended population for the study (Burns and Grove 2009).

The inclusion criteria for this study is as follows:

- All participants should be family carers, male or female.
- All participants should be ageing, aged 65 years plus.
- All participants should be caring for an adult with an intellectual disability.
- All participants should be living in the family home.

Exclusion criteria are the qualities, characteristics and features that cause a person to be excluded or disqualified from a study or the intended population (Burns and Grove 2009).

Exclusion criteria for this study is as follows:

- participants under the age of 65.
- participants that have a son or daughter in full time residential care and not living in the family home.

3.6.6 Participants

After the information Pack were distributed via the gatekeeper and the radio interview was completed, there were 10 respondents interested in taking part in the study, a response rate of 33%. The respondents expressed interest by returning a stamped addresses envelope with a signed copy of the reply slip enclosed which they were prompted to put their contact details on (appendix C). After reply slips were received the researcher contacted the participant thanking
them for their expression of interest. At this point the researcher revised what was involved in the study and what the interviews would entail. Moreover, a date was arranged for the interview to take place at a location which was of most comfort to each individual. All participants chose their own homes. A follow up phone call two days before the interview was also arranged to ensure participants availability.

3.7 Data Collection

Data collection is the systematic method in which information is gathered, relevant to the research purpose of the specific objectives, questions or hypothesis of a study. Data may be collected on participants by observing, questioning, recording to name just a few. A data collection plan details the plan of a study i.e., how data will be collected specific to the requirements of the study and phenomenon (Burns and Grove 2009). The main characteristics of qualitative research investigation are that it can be inductive, interactive and holistic and is carried out by accommodating methods of data collection (Parahoo 2014).

The researcher conducted interviews as it was deemed most appropriate to fulfil the aims and objectives of this proposal. Interviews are particularly useful for getting the story behind a participant's experience. The interviewer can pursue in-depth information around a topic or use interviews to follow-up and further investigate responses or findings (Polit and Beck 2013).

3.7.1 Interviews

Interviews are a method of data collection where the researcher questions participants verbally, they may be face to face or performed over the telephone, and they may consist of open-ended or closed questions (Lo-Biondo Wood and Haber 2014). It was imperative however that the researcher remained mindful of the structure of the interview so as not to cross the boundary to a chat. There are three types of interviews, structured, semi-structured and unstructured interviews.

For this research, in depth, semi-structured interviews were chosen as the researcher wished to get an in-depth account of participants current situations and future plans. As the interviews
advanced it allowed the researcher to utilise probe questions where the researcher felt a more elaborate account of information was required which in turn yielded more valuable information and a more thorough account of where participants were with regard to the topic.

3.7.2 Individual in-depth semi structured interviews

Semi-structured interviews are also more participant friendly in that they utilise a more conversation led interview in comparison to a structured interview whereby questions may seem to be over powering for the participant which can result in participants holding back some knowledge or information. During the interviews the researcher found that the conversational structure that semi structured interviews implies prompted the participant to speak openly and freely without any influence of the researcher as well as making them feel comfortable and oblivious to the fact they were being recorded. In contrast however, semi-structured interviews do provide a little more structure than an unstructured interview which was particularly useful for this study as the researcher was a novice researcher and furthermore there were times during interviewing where participants needed some prompting in relation to topic guidance. A semi-structured interview has control measures in place, such as a semi-structured interview guide which was utilised in this study (appendix D). A guide can probe information providing a direction to the interview which will help to facilitate achieving the aims and objectives of the research.

Individual semi-structured interviews bring the researchers closer than many other methods to an intimate understanding of where people are at in their lives thereby allowing a rapport to develop with the participants, which may assist in eliciting more information in a sensitive and empathetic way (Parahoo 2014). The researcher found in one particular instance, a participant spoke on the topic of future planning they acknowledged, “It’s not an easy thing to talk about, sometimes it’s nice to talk about it with someone that understands…. because you know I do think about it…”. The participant was content in the conversation with the researcher whom was empathetic and sensitive in their approach to the topic.

Semi-structured interviewing allowed questions on the topic to be asked with subsequent questions according to the participants responses allowing the participant to elaborate in order
for the researcher to gain a greater understanding (Newell and Burnard 2011). For example, when one participant mentioned a name that wasn’t recognisable to the interviewer, the interviewer was able to seek clarification that this was a family member and furthermore questioned the family members participation in terms of future planning thus gaining a greater understanding and more alluvial data.

Interviews were non-directed and flexible; and did not follow a detailed interview guide thus enabling the researcher to explore the thoughts and interests of the informants in depth (Parahoo 2014). Probe questions were used to encourage participants to speak openly, frankly and give as much detail as possible to generate further insight into experience and perceptions of participants to get a more in-depth account thus generating rich data. The researcher asked questions that participants could express their opinions, knowledge and share their experience. The individual semi-structured interview is a major source of data collection for phenomenologists and was therefore in keeping with the philosophy and methodology of this study (DiCicco-Bloom and Crabtree 2006).

### 3.7.3 Pre-Interview

There were many factors to consider prior to the interview including, equipment, location, time. A reliable audio recorder was required that allowed for ease of use and transcription after the interviews. Extra batteries were packed as a safeguard. Arrangements for the interview were made in advance including schedule time of interview, interview site. Each participant knew a week and more in advance and there was no confusion. The researcher rang each participant a day before the interviews to confirm they were still able to participate. Each participant wished to have their interview conducted at home. The researcher spoke with each participant on arrival regarding the interview and what it may entail, i.e., types of questions that may be asked thus helped to build rapport with the participants (Parahoo 2014). Consent forms were checked again and brought to the interview.
3.7.4 Peri-Interview

An interview guide was composed peri-interview which acted as a base to commence the interview whereby the researcher had a series of questions at hand to ask or had topics in mind whereby the researcher was prepared to ask probe questions to encourage the interviewee to say more. A decision was made also to not necessarily ask the questions in a particular order but to change them in order according to the respondent’s responses. A copy of the interview guide can be seen in appendix D.

3.7.5 Post-Interview

Following the interviews, the researcher took notes and memos, the data was then transcribed by the researcher who utilised Burnard’s 2011 thematic content analysis which is described in detail in 3.9 data analysis paragraph.

3.8 Pilot Study

For the purpose of this study, a pilot study was conducted. A pilot study is frequently used in research studies. Pilot studies are a smaller version of the proposed study and it is conducted to refine the methodology (Burns and Grove 2009). They are conducted to refine methodology and are often seen as a small-scale trial run of the study (Burns and Grove 2014). Pilot studies can often help identify problems within the design or sample, examine the reliability and validity of the research instruments and develop or refine data collection instruments (Burns and Grove 2009). Moreover, a pilot study also helps the researcher to improve or develop their interviewing skills which the researcher felt important for the success of this study (Polit and Beck 2013). This was the main incentive for the researcher to conduct a pilot study.

Prior to the initiation of this particular study, a pilot study was conducted with one participant. In turn, this participant was excluded from the actual study as repeating interviewing may have elicited different or pre-determined responses. Several issues arose from the pilot study. The participant was conscious of the audio recorder so in subsequent interviews the recorder was placed out of sight. However, it is noteworthy to mention participants still consented to its use
and were aware they were being recorded. The researcher was nervous in the pilot interviews
and on reflection and listening back to the interview it was felt that the interview schedule was
adhered to too strictly and this hindered deep exploration of the topics. The researcher
addressed this in the actual study by being more flexible, allowing participants to clarify and
expand their answers, the use of probing to elicit further expansion and deeper meaning and
generally allowing the interviews to flow more naturally.

3.9 Data Analysis

Data Analysis is used to describe a method of organising and ordering of textual data. The aim of
data analysis in phenomenological studies is to produce a detailed and systematic recording of
themes and ideas that arise during the interview stage and to link similar themes together under
a practical comprehensive category system (Parahoo 2014). For the purpose of this research
study the researcher utilised Burnard's (2011) thematic content analysis which will be discussed
further in relation to this study. This six-stage method has been widely used in published
qualitative studies (Newell and Burnard 2011). It allowed for a large body of information to be
condensed into thick descriptive findings. A description of the steps involved is outlined below.

Stage one: the researcher made memos and notes after each interview to serve as memory
joggers which enhanced the dependability and credibility of the data. The researcher transcribed
the data verbally. As the researcher was a novice, it was felt that human immersion through
transcription would help with data analysis and further enhance the creditability and
dependability of the study. Each participant was given a number, i.e., Participant 1= P1.

Stage two: this stage involved the researcher becoming immersed with the data, themes, notes
and memos that have been previously gathered. It involved a process of reflecting, exploring and
comparing data and transcripts. Initial impressions were noted in the margins.

Stage three: the researcher continues to read and re-read the transcripts again so that as many
headings as necessary are written down to describe all aspects of the content, this process is
called open-coding. The researcher highlighted key words and recorded them in the margin.
Reduction of text was carefully applied and as a result, fourteen category codes were recorded across 10 interviews (appendix F).

Stage four: this stage involved the coding of data and the themes. Themes were organised and noticed that some themes overlapped. The next process involved the organisation/coding of themes that can be lumped together so that some of the other codes can be discarded, this is known as higher order codes. Therefore, a more manageable set of category codes are identified. This resulted in eight higher order category codes (appendix F). The term higher order coding was then discarded and the terms ‘themes and subthemes’ were utilised in its place which are more widely used in research (Newell and Burnard 2011).

Stage five: after achieving a shortened list of themes and subthemes, the researcher was able to return to the interview transcripts to continue with the analysis. Burnard, (2011) identified this process can be done with the help of a qualitative data management programme or it can be done manually working through the transcripts, marking up each part of the text, with the highlighter pens that reflect the category codes. For the purpose of this research study the researcher chose to conduct the analysis manually in order to learn the participate in the full process as a novice researcher. The text of interview transcripts was colour coded until all text was accounted for. Each colour represented a subtheme. The result meant that all quotations related to specific subthemes were recorded in a systematically accessible way.

Stage six: four themes emerged from the organised data. They were; a life not foreseen, bearing the cross, reaching a decision and nearing the end. These themes captured participants experiences of future planning for their adult family member with an intellectual disability living at home and provided the basis for the subsequent findings and discussion chapters. This qualitative research aimed to present truthful illustrations and interpretations of participants’ perceptions. To ensure the accuracy and truth of the research rigor must be established. In the following section the rigour of the study is discussed.
3.10 Rigour

Rigour is defined as achieving standards and quality in research through attention to detail and accuracy but in qualitative research it involves more openness, significance and similarities between method and knowledge. It is the accuracy and consistency of a research design that gives a measure of its quality (Moule and Goodman 2009). It involves taking direct care in the collection of data as well as thorough understanding (Burns and Grove 2013; Parahoo 2014; LoBiondo-Woods and Haber 2014).

Nursing in the past has faced challenges to present the truth and support rigor (Moule and Goodman 2009). For the purpose of this research methodology, criteria developed by Lincoln and Guba (1985) for establishing the rigour and trustworthiness of qualitative research will be conducted and adhered by in this study. There are four key components that will be implemented (Moule and Goodman 2009).

3.10.1 Credibility

Several methods were used to ensure the credibility and reliability of the study. First, the researcher’s experiences and understanding of previous experiences have been clearly bracketed, recognized, and identified as part of the research process. This has helped ensure that any preconceived notions about phenomena did not influence the participants or the analysis throughout the progression of the study. All interviews were recorded and transcribed to guarantee accuracy, and to ensure that the analysis focused on participant responses. Prolonged engagement between the researcher and participants helped gain an accurate understanding of each person’s experience as well as importantly establishing a relationship of trust between the researcher and participant. Furthermore, the researcher spent adequate time ranging from 1- 3 hours with the participants in their homes to observe and to help develop rapport. Member checking was used to validate interpretations and was incorporated throughout the interview process by frequently checking for understanding, clarity, and by asking for assurance that the researcher understood the experience correctly.
3.10.2 Transferability

The researcher was conscious of the transfer of findings to other research and aware that the sites that may wish to utilise the data is unknown. Primarily the purposeful sample of ageing family carers caring for their adult family members with an intellectual disability at home provides initial guidance towards the focus group used which in turn guides readers when exploring the study. The researcher was conscious in providing thick descriptions of the family carers experiences of future planning caring for their adult family with a disability member at home. The researcher utilised and recorded narratives as seen above in the table format from each of the participants in the study to clearly demonstrate their thoughts and experiences and to help provide a logical explanation of the researcher’s journey and interpretations of the research process. Furthermore, the diagramming provides the reader with an understanding to engage and understand the connections among the themes.

3.10.3 Dependability

The dependability of the study was enhanced furthermore by providing a traceable and clearly documented process of the data analysis. The researcher kept a well-documented process from each phase of the thematic analysis taking notes and documenting theoretical and reflective thoughts, utilising a coding framework to highlight themes and documentation of theme naming. Participant narratives and researcher’s interpretations were clearly described and recorded to provide reasoning for theoretical, methodological and analytic choices throughout the study.

3.10.4 Confirmability

Reflexivity was a technique that was utilised to enhance the confirmability of the study. In addition to outside sources for knowledge, the researcher’s direct experience as a registered nurse in intellectual disabilities provided insights into working with ageing adults with disabilities and their families and an awareness of the reality and extent of the challenges of caring for an adult child with a disability at home. Although the researcher took great care to bracket out this prior knowledge through utilising a research journal, and was aware of her potential biases, in many ways these personal experiences on the part of the researcher created a level of sensitivity
and understanding that may not have existed without this prior experience. Furthermore, the researcher began exploring this topic in 2013, and has spent a considerable amount of time building on prior knowledge about ageing family carers experiences of future planning caring for their adult family member with an intellectual disability at home. A pilot study conducted in 2016 explored ageing family carers experiences of future planning at a deeper level than could be gathered through a literature review; thus, the pilot study was essentially a feasibility study to ensure that the research and research questions were valid and warranted further exploration.

3.11 Chapter Summary

This chapter outlined the research methodology for this qualitative research study. The research aims and objectives were outlined and explored in accordance with the study. A concise overview of quantitative and qualitative approaches was offered and the justification of an interpretative phenomenological approach was outlined.

Access to the research site and population was discussed as well as obtaining ethical approval and other ethical guidelines were considered. The utmost consideration was given to participants and their safety was a primary concern at all times during this study. Details regarding the data collection and data analysis were explained. Moreover, a brief description of rigour in research was given, including an overview of how this was achieved in this particular study. The next chapter presents the findings from this study.
Chapter 4: Presentation of Findings
Chapter 4: Presentation of findings.

4.0 Introduction

This study explored ageing carers (n=10) experiences of future planning for a family member with an intellectual disability living at home. Participants of this study were all ageing carers, over 65 years of age, all of whom were caring for their family member with an intellectual disability living at home. A qualitative descriptive phenomenological study utilising semi in depth semi-structured interviews was undertaken with participants, data were analysis using a thematic analysis approach. This chapter presents the findings of the study and the finding will be presented as per the themes elicited from the analysis of the data. The findings reflect the participants’ experiences of future planning as they age continuing to be the frontline carers for their family member with an intellectual disability.

This chapter presents the findings which include the themes and subthemes that emerge from the data. Participants’ statements are included to support the themes. Some of the themes have overlapping elements and some of the statements may highlight one or more theme. Polit and Beck (2013) highlight that narrative material can often contain multiple elements relating to several themes and that data received from paragraphs of transcribed interviews are not necessarily linear. However, in presenting the findings the researcher selected quotes that illuminate the concept most appropriately.

4.1 Findings

The four themes formulated through data analysis were: *a life not foreseen, bearing the cross, reaching a decision and nearing the end*. These themes were formulated by grouping the key statements in each interview into category codes and then collapsing similar codes into subthemes and themes (Burnard 2011). The themes, subthemes and category codes identified in the findings are presented in Figure 4.1. The main themes are presented in the yellow boxes, the subthemes in blue and the category codes in green. The purpose of creating themes was to
provide a means to describe the phenomena, increase understanding and generate knowledge (Burnard 2011).

**Figure 4.1 Themes, Subthemes and Codes.**
4.2 A Life not foreseen

In gaining the experience of participants regarding future plans it was important for some participants to tell their story and they wished to express their experiences leading up to the present day. The first theme captures this experience for participants with some participants identifying the joy when they recalled falling pregnant with their baby, the apprehension they felt over the birth, the anticipation of the gender and the feeling of love for their unborn child and the lack of awareness of what was in store for them. The theme encapsulates participants’ journey in coming to terms with having a baby with an intellectual disability. Dealing with the unexpectedness of being told that your baby has an intellectual disability, the emotions that surrounded the realisation, the issues that they had to face and the unforeseen future that lay ahead of caring for a child with a disability. These areas are addressed further under the subthemes: taking it on and in it for the long haul.

4.2.1 Taking it on

Participants identified all the emotions that they experienced at that time including fear, worry, anxiety and frustration. Participants recalled questioning their ability to cope and their partner’s ability to cope. One participant recalled the look on her husband’s face and it was evident to see that the participant still felt the pain she had witnessed that day.

“I’ll never forget the day that we were told that our baby was going to be down syndrome I thought our world was going to crash down I never forget (husband’s) face the tears just poured down his face and (husband) would never cry now, he was a real, how would you put it, a real man.” P8

Participants identified the worry they had of perceptions of other family members, in particular, other siblings. One participant identified that she had anxiously waited to hear the response of how her children reacted to being told that their new baby brother would have Down’s syndrome, in particular, one of her younger son’s whom she described as being very deep.
“I was so worried, I waited for xxx (eldest daughter) to tell me how xxx (son) had reacted when she told him about xx (son with Down’s Syndrome), I remember the relief she told me that she told him about their brother, and that he looked at her, he thought about it for a split second and replied, then my brother will be the best down’s syndrome there is, and I remember thinking to myself that will do, we’ll be fine, he was my only worry, I wasn’t sure how he would take it.” P10

Another participant identified that having a baby with an intellectual disability had impacted her choice in relation to continuing to family plan “we decided not to have any more after that, we felt we couldn’t take the risk” P5. This was echoed by other participants in the study. Similarly, another participant identified a decision she had made after having a baby with Down’s syndrome at 46 was to get her tubes tied, she recalled booking in for her procedure privately and was adamant that she would have it done despite professional opinion that it wasn’t necessary. The participant expressed that she should have got it done sooner.

“I remember saying it to Dr (name of G.P) at the time, he thought I was gone mad, maybe a bit of depression after the baby I don’t know, he was trying to put me off it but I was having none of it, you know a woman of my age and all that. Well I was getting it done and that was the end of it, I would pay for it and that was it. So, I had it done. I mean you couldn’t take the chance, who was to say it wouldn’t happen again, I thought I was finished with children, I had already 6 before (son with ID) came along”. P10.

Furthermore, the same participant identified feeling perplexed as to why this had happened to her she expressed her dedication to the church, being a good roman catholic, a faithful wife, a devoted mother and a committed caregiver to other ageing family members through the lifespan. Moreover, the participant identified that it wasn’t that she was unaware of Down’s syndrome, she explained that two of her sisters had a child with down syndrome and had expressed that it was “their cross to bear” P10, she identified that she felt being a full time carer to her husband’s challenging family members was “my cross to bear” P10. However, after giving birth to a child with Down’s syndrome later in her life, she felt deflated and demoralised. Another participant recalled her feeling of heartbreak.
“I was heartbroken to say the least, it wasn’t that we wouldn’t love her. We loved her from that very moment, it was in that moment I realised that this baby I was carrying would always need the support and care from her parents, she wouldn’t have the same opportunities as her sisters, you know get married, get a job, have children. That for me was the hardest thing to come to terms with” P2.

It is clear, that the realisation of having a baby with a disability was none other than a huge unexpected ordeal for parents at the time. Even though each of their circumstances were variable, the common experience of a life they had not planned for or foreseen appeared evident amongst all participants. Participants clearly, even in the early days were aware of the lifelong responsibilities that lay ahead.

4.2.2 In it for the Long haul

Each participant had made the decision to take on the responsibility of caring for their child with an intellectual disability. Moreover, participants referred to the outlook they were given on their child with a disabilities life in the early years. Participants had been informed by health professionals that an outlook of a relatively short life expectancy was on the horizons for their child. Moreover, participants expressed that they had not anticipated caring for a prolonged period as a result, and had never envisaged they would be still caring into old age themselves. As well as being faced with a reality of a life that they had not anticipated and the challenges that it entailed they were also faced with a future of caring with no end in sight.

“I don’t know where it will all end” P10

Thus, the uncertainty and unforeseen future that these parents experienced was evident throughout the years of caring ahead of them.

“(son) is heading for 40 years of age now, we never thought he would see that we really didn’t.”, all the things he might not be able to do that’s all we heard” P4.
“People with Down Syndrome didn’t live that long before, my sister’s son, he passed away as a child, he got pneumonia and it took him very quickly. They were devastated, we all were, but now it’s a different story. It’s a different world now,” P10.

Participants highlighted the emotional and physical burden of caregiving. Participants expressed the reality of it being a 24/7 vocation and not something you could walk away or take a break from. For one participant she identified the challenges of trying to multi-task and raise her other children, care for her adult child with a disability and look after her own ageing family members through the years. She expressed that she was now caring for her husband who has Parkinson’s disease highlighting that she would often have to pick him up of the ground, feed him, and bathe him. However, the participant identified that

“it pales beside (son), it doesn’t even concern me so that’s the extent of (son’s) caring”. P10

Despite all the other life challenges that was thrown at participant 10 she identified that they did not exceed the challenges of caring for an adult child with a disability and epilepsy highlighting carers degree of caregiving burden as they continue to care for the long haul.

4.3 Bearing the Cross

The second theme captures the uncertainty and unforeseen future that participants as carer to a family member with an intellectual disability all faced and continued to face. It is noteworthy to mention that the term bearing the cross means to surpass the fear of death continually, it is a religious term that is often used to describe the acceptance of a burden and a difficult situation that must be tolerated and derives from the crucifixion of our Lord. One participant described the burden of having a child with an intellectual disability as bearing the cross. Participants in this study described factors that contributed to easing the burden and assisting them to have a more positive outlook on their futures. In contrast some participants identified other factors that contributed to adding to their level of stress and unremitting apprehension. It was clear that participants outlook on their futures were very much dependent on the support and information they received. This can be captured under the subthemes being supported and being left in the dark.
4.3.1 Being Supported

The subtheme being supported captures the importance of established networks of support for ageing carers in this study. Participants’ experiences of future planning were influenced heavily on the extent of internal and external resources, facilities and support they were in receipt of. It is noteworthy to mention that all participants within this study were all in receipt of some form of day service for their family member with an intellectual disability. The importance of family, friends in helping carers maintain their health and cope throughout their caregiving career was apparent across interviews with participants.

One carer spoke about his daughter who “build a house next door” P6 to “keep an eye on me” P6 after his wife had passed away, he explained that his daughter is very good to look after her sister with a disability advising “she spends more time over there in their sitting room than she does in her own” P6 followed by “she has her own room over in (daughters) house as well so she takes turns in which bed she sleeps in” P6 clearly highlighting the importance of internal supports.

Similarly, another participant identified that her son and his family lived nearby and were there to call on if she needed help, she identified having “a wonderful family and my son is living across the road and he is a farmer, married to a nurse”. Carers expressed their gratitude of having someone to “call on” P8 nearby when they were in need.

While family support was evidently critical, this did not take away the guilt that some parent carers felt about relying on them to deal with the challenges of caregiving or the taking on of the caregiving burden. This was a common opinion shared among participants.

“They both (daughters) have families now, you know they both work and have to pay for somebody to mind their children, there’re busy, it’s different know the woman can’t afford to stay at home, they have bills to pay, the house to keep. There’re great girls and always there when I need them but I wouldn’t ask that of them, you couldn’t. P2

Some participants highlighted the reality of even though their family members are supportive and nearby, they all have their own lives and expecting them to be there full time perhaps is unrealistic. Participants are very vulnerable and dependent on the level of support available to
them from services within the community. Each carer identified in the interviews that their sons or daughters were in receipt of some sort of a day service, it was evident that the service was making an enormous impact on helping carers carrying on caring, easing the burden.

“he’s got wonderful early intervention in terms of speech and language, physio loads of that. We had a disability nurse, disability area co-ordinator I think or something like that, she was wonderful.” P10.

However, the participant went on to explain how in the earlier years she had been quite satisfied with the level of support she was receiving, however as her son had got older she explained that the level of supports had declined and that he had exceeded all the services available to him leaving them feeling forgotten about.

“when he came to 18, that was it”. P10

One participant referred to the service as “a lifeline” P5 indicating the positive impact that it was having on her life.

“it gives me a bit of a break in the middle of the week and you know I don’t really know what I would do without it to be honest, she gets respite one night every second weekend two, it’s great” P5.

Another participant identified how availing of a day service for her son has given her access to socialise and meet people again in the community.

“I feel like I’m finally able to start doing things for myself, it’s a new life for me, I go and get my hair done and set on a Tuesday morning and I go to the active retirement on a Monday and Wednesday, I never did anything like that before. I can even get a cup of tea and a bun after grabbing a few messages in the shops if I want to, the bus takes him home to the door so I don’t have to be rushing back” P9

While some carers clearly relied on the day service they were in receipt of, there remained a discrepancy between participants between the level of satisfaction of the care and services they
felt available to them and their family member with a disability. This will be further addressed under the subtheme *being left in the dark.*

### 4.3.2 Being left in the Dark

The subtheme *being left in the dark* captures participants’ disillusion with trying to receive help and guidance and accessing formal supports throughout most of their caregiving life. Participants were vulnerable and expressed their experiences of feeling ignored and worthless as they recalled instances where they were trying to receive guidance and access to support. Participants expressed that they felt marginalised by the fact they were caring for their family member at home, expressing that they felt ill-informed about the services they were entitled to:

“I suppose it’s a case out of sight, out of mind, when you’re not on their books they don’t have to worry about you”, “I’m sure we’re probably not getting half of what we are entitled to, sure who is going to tell you anyway, I suppose you should look for it but then what do you look for either, we don’t need it” P3.

Similarly, another participant expresses that she had got her son hand rails for her bathroom and when she had been speaking to a friend regarding how beneficial they were, she became aware that she could have received them for free from her public health nurse.

“I don’t even know who the public health nurse is for our area actually, I suppose maybe that’s a good thing, we have been lucky we didn’t need to see one” P8

Many of the participants interviewed reported that they did not know which organisations and professionals to turn to for accessible information and practical support regarding exploring future care options.

“Where do you begin, how do you even go about, it’s a struggle to even get respite at times” P7

One participant identified their distress in trying to source information regarding alternative living arrangements when caregiving became increasingly challenging due to their family members increased medical needs and onset of Alzheimer’s. They reported that they had “just carried on” P1. as normal as best they could because they “didn’t know what was out there” P1.
There appeared to be a lack of awareness of where to begin, whom to turn to and what to do. Furthermore, they advised “they might have enlightened us” P1 suggesting that they were unaware of the process involved in securing alternative placements. For others there is a lack of awareness of the long timescales involved in securing appropriate housing and support for people with intellectual disabilities.

“I have him put on the waiting list, but they told me it could be years before he gets accommodation so what do you do” P5

“I want to put him into (name of service) because it’s only over the road but they haven’t a place” P9

Outside of attending day services, participants expressed a feeling of isolation regarding to caring for their family member at home with an intellectual disability. Some participants recalled not having time to themselves or the freedom to be able to leave the house when they wanted due to the extent of their caregiving responsibilities. Moreover, they identified a period of isolation where they did not receive any emotional support or guidance and felt that “nobody came to see us in the early stages till xxx got sick” P1. There appeared to be a shared opinion that support was not readily available and only there in crisis situations. Another participant recalled how the only time they felt like they had support at home was when a family member had surgery and they had support from a public health nurse who put them “on the right track” P3.

It is noteworthy to mention that out of the three participants who appeared to have future plans agreed, the level of a support and guidance received from a service level was minimal. One participant identified that it was two friends that provided them with guidance and direction to seek full time accommodation for their family member, both friends having experience in the field of the health care system and working with people with intellectual disabilities. Participants referred to the bureaucracy in accessing housing and services, when explored further one participant had very frustrating experiences with trying to secure a placement. The participant emotively expressed their experiences relating to contacting services and being told they “fall outside the catchment area” P1 or they wouldn’t be prioritised as their family member was not
“already within the service” P1. Furthermore, the participant’s distress could be easily viewed as they recalled phoning services and offices of professionals in the health care system and being faced with empty responses, no reply, unavailability and outside of office hours. The frustration with the level of support and guidance was particularly evident in this participant’s response.

“it was a hell of a time let me tell you, we were getting nowhere, everywhere we turned nobody wanted to help, the (service providers name) wouldn’t take him because he wasn’t within their service, there’s another one there in (name of place/county), he was on a waiting list for that but we didn’t hear anything from them for about 6 months. Then you have dealing with the locations, of course we were outside of the catchment areas, it was just a nightmare it really was.” P1

Moreover, the timely responses from service professionals and the extent of waiting lists was a common problem shared by those who were engaging in future planning. Participants identified that awaiting responses from services and health professionals was continuous and there lacked a continuity of care within services. Furthermore, another participant identified how she “never stopped fighting” P10 and “if I wasn’t called I would ring and I would keep ringing till I got answers” P10 indicating her level of dissatisfaction and her awareness of the flaws within the services.

Participants expressed significant concern about the quality and suitability of housing options that they knew about. They often expressed negative opinions and attitudes towards residential care and many carers felt that this was the only option available.

“I just don’t want her to have to be in one of those houses, I’d just be afraid, you know would she get the right care, minding her money, and all those things. I’d be afraid she’d go into herself a little bit. Like I’m sure there is good people working in these places but you just can’t be too careful. At least having her here she’s safe” P9

Their views about future housing often stemmed from experiences with respite or short break provision, which was not always a pleasant experience.
“I think he just likes his own space, one of the other boys I think was a little more I feel, a little…. He used to take the controller and change the tv when fair city was on and things like that. He hasn’t done it since. We don’t bother with it”. P4

Similarly, one participant view stemmed from not being entirely satisfied with the level of care that she had been receiving from a day service where her son was attending, she felt a pressure to always having to “keep an eye on things” P1. She utilised the words “it’s a cherry-picking system” P1, referring to the way service users were being picked for various activities outside of the regular schedule. The participant recalled a day where she had popped into the service and had realized that her son had been placed in a different room for activities and some of his fellow class mates and other service users from another class had been mixed and taken out for tea,

“I was furious (son) had missed out in his gardening, again, and it was just by chance I was popping in and met (name of staff member) going out in the bus with the rest of them and (her son) put in another class. It’s not good enough, why couldn’t she take her class?” P10.

However, it is noteworthy to mention that carers did for the most part express positive experiences regarding the day service that their family member was availing of and was very grateful for the service they were receiving, one participant highlighting that a “link worker” P6 for his daughter would always keep him “in the know” P6 and they would have regular contact regarding his daughter. In contrast another carer identified the lack of resources and constraints the services are under regarding allocation of services, two carers identified how their services had been cut from 5 days a week to 4 days a week which left them at a big loss. Moreover, one carer identified her fear of “rocking the boat” P7, despite her disappointment of the cut to services she expressed that she was “lucky” P7 to get what she was given.

Some participants provided many suggestions for the development of appropriate housing, they most frequently mentioned developing small housing options. Other suggestions for the development of the appropriate housing included independent living apartments that are supervised, and a retirement facility that could accommodate both ageing carers and their family member with an intellectual disability.
Participants frustration was evident with the level of support and guidance they received. It was clear that a lack of understanding by government personnel, professionals and the public was a common feeling amongst participants. Many carers felt that the government did not understand their needs, and the government did not provide adequate support.

“they don’t do anything in the health board for your own good let me tell you, none of it is about our children” P10

Furthermore, one participant identified “the famous new directions” P10, and considered the national initiative as flawed and a document of “empty promises” P10 describing her situation where her son had received a cut in his services. The participant indicated that they should be providing more not less suggesting her frustration with the level of funding and allocation of services.

Similarly, participants identified their concerns about reductions in public forms of financial assistance or low levels of financial assistance provided. One participant identified that her family member received his disability money but that there was “no way he could live of it himself if he wasn’t living at home” P1. Another carer identified his fear of awaiting the budget every year to hear the extent of the cuts regarding the financial assistance they were in receipt of. Depending on the state was not sufficient for one carer and she advised that her level of financial assistance was small due to the assets her family had in land and farming. The participant identified having to sell land to ensure that there was enough there to care for her son. The participant proceeded to identify that she always ensured that she had “private health insurance” P10 for her son so that he could have the best treatment available.

“you couldn’t depend on the public system for (son), I mean with his epilepsy I couldn’t face with watching him being left on waiting lists for months and watch him getting worse and nothing being done, I always made sure we had the VHI” P10

It was clear that there was an element of dissatisfaction regarding the care some participants were receiving on the medical card and through the public care system, utilising services outside of the system was mentioned by three participants in this study, clearly this was having a big
financial impact on some participants, however the benefit of the treatment for their family member overshadowed the financial strain of the costs.

“that was all paid for, by myself I may add. We did everything, I would give my last shilling to make sure that (son) had all the support he needed, you couldn’t be waiting in the public system you might never get called. By the time he’d be called he’s scoliosis would have progressed further. I did that, anything he needed I traipsed him the length and breadth of the country to get him what he needed” P10.

Furthermore, another participant identified the flaws and constraints within what should be financial aid for home carers. The participant expressed her disillusionment with the grants available to help make homes more accessible.

“We got a quotation there to build on... somebody came out from (name of place disclosed), an occupational therapist or something I think... We wanted to build on a room for (family member) but the quotations were huge, there was a 10,000 grant or something available but there was loads of regulations to go with it and it would cost a small fortune to do it so we didn't go through it, you also had to take on one of the builders that they give you and they would be charging you thousands more then what it would cost you. sure, wasn’t your man from (name of place) about 40 something thousand, mad stuff! they were adding it on to take it off... All we wanted was a room for a (family member) that he’d have his own shower space” P1

4.4 Reaching a Decision

The third theme reaching a decision describes a point which most participants identified meeting in their lives. The theme captured participants’ experiences in defining their own future planning preferences. Some participants wished for their family member with an intellectual disability to remain at home for as long as possible, others anticipated that another family would take on the caring role, more carers identified a need to secure alternative support arrangements and some participants dismissed the idea of having to make arrangements. The extent of future will be discussed later in the chapter. The journey that participants experienced in identifying their
future planning preferences will be explored under the subthemes wanting to continue and letting go.

4.4.1 Wanting to Continue

The first subtheme captured some participants desire to” keep on going” P1 and continue caring for as long as they could. The theme places emphasis on self-reliance, “managing” P1, and just “getting on with things” P10. In most circumstances, this was a way for participants to cope in their caregiving situation, Carers expressed a duty of care and responsibility to continue caring for as long as possible.

“You just have to do these things, who are you going to ring in the middle of the night when(daughter) is out of the bed and can’t sleep or when she has one of her seizures? you just deal with it, do the best you can, you have to.” P9

Some participants show an element of denial about the inevitability that they will not be able to care indefinitely,

“I mean we have just been getting by day by day, thankfully were still in fairly good health so we didn’t think of it to be honest, we didn’t see the need to be upsetting him” P2

Among other participants there appears to be a lack of awareness of the timeframes and processes involved in securing appropriate housing and support referring to their lack of need of the service “yet”. P8

Some carers wished for their family members to remain at home with them for as long as possible as they were happy with their caregiving role and satisfied with the support they received. One participant mentioned how after his wife’s death, “(daughter) was looking after me more than I was her, she would cook and all so we didn’t starve” P6. They considered their relationships with their family member to be reciprocal. Similarly, another participant addressed their devotion to caring, for as long as possible highlighting how as a married couple they were managing, sharing the caring role and didn’t see a need to change things that were working well. There appeared to a relationship among some participants between their desire to continue caring and their
circumstances including a perceived reduced caregiving burden that led them to have a positive outlook regarding their caregiving role.

In contrast one participant wanted their family member to remain at home and continue caring for them due to lack of trust in others or other services, this participant had a negative experience when her son had gone for a short period to a respite house at an earlier date and was reluctant to try again.

“I think he just likes his own space, one of the other boys I think was a little more I feel, a little... He used to take the controller and change the tv when fair city was on and things like that. He hasn't done it since. We don’t bother with it”. P4.

4.4.2 Letting Go

The second subtheme identified is letting go. In this study some carers’ had begun to seriously question their ability to continue their caring role. Issues that arose included participants’ views on their own ability to continue their caring role for the foreseeable future. Moreover, the realisation that occurred amongst carer’s in relation to their own ageing was common among the interviews. Identification that carer’s were not as physically fit as the years had progressed, “I am getting older and I am not able for it as maybe I was before and either is (name of husband)”, P7. Some of the carer’s had suffered deteriorated health, (name of husband) had his hip done three years ago now”, P4. Similarly, another participant added “I suffer from the arthritis, it gets bad now and then I always find the weather takes its toll on me and I had the gallstones removed there last year” P6. Others, expressed that the extent of caregiving over the years was beginning to take its toll, “I hurt my back years ago carrying son and I suffer with it since” P7.

These carers felt that continuing in such a role was no longer realistic owing to their age and the heavy caregiving demands and to some their deteriorating physical and or mental health.

Some participants expressed a desire to have more time to themselves and felt that they had dedicated their lives long enough and that it was time for their family member to become independent. Some carers expressed an interest to having some time to herself again.
“to be honest I’m looking forward to it. I have dedicated my life to looking after my son and my children” P7

Another participant declared a sense of guilt towards her other children feeling like she hadn’t been able to give the time she desired while being a full time carer, the participant explained that she wanted to give her daughter and her grandchildren more time while she is still able.

“we don't even get up to see the grand children as much as we'd like. we don't get away much now” P2

Two participants had identified how their roles had expanded over time and became more challenging as a compound caregiver. One participant identified her struggle with looking after her husband with Parkinson’s disease as well as her son with an intellectual disability. Another participant highlighted that she looked after her elderly mother for as long as she could.

“She was here, I looked after her for as long as I could but when she broke her hip I couldn’t bring her back home... I just wouldn’t have been able” P5

4.5 Nearing the End

The fourth theme nearing the end captures the unavoidable reality that the participants of this study were facing. Ageing was something that none of the participants had control over and it was inevitable that a time may come that they may be no longer able to care for their family member with an intellectual disability. Nearing the end describes participants extent of plans made. For some carers it involved having secured a future plan and this can be captured under the subtheme being prepared. For other carers a lack of future planning will be discussed under the theme an unforeseen future.

4.5.1 Being Prepared

The subtheme being prepared captured participants future planning arrangements for their adult family member with an intellectual disability. It intends to describe the participants’ plans in which they made or were in the process of making. Future or anticipatory planning means making longer-term plans for a cared-for individual for when you can no longer provide care because of
illness, old age, a change in circumstances or death. Future plans are more in-depth than emergency plans. The people involved in creating the plan are: the carer, the cared-for person and relevant family members, friends and professionals. It's a process which should be developed over time (Care Information Scotland 2018).

Across all interviews participants referred to different aspects of future planning. Financial planning remained the most dominant type of plan among participants with all participants highlighting that they had some sort of financial security in place for their family member. Financial security was identified in the means of a will, trust fund or savings account that was put aside for emergency situations. Participants for the most part remained very disclosed about financial plans and were reluctant to elaborate. However, three participants did reiterate that the level of finance that they had securely put aside for their family member would not solely keep their family member going and reassured the researcher of their need for financial assistance from the state or services.

Participants referred to alternative housing arrangements for their family member with two participants highlighting that they were in the final stages of obtaining a full-time placement for their family member. Moreover, three other participants expressed a desire to seek alternative arrangements for their family member and two participants were currently in the process of looking. One participant identified their desire for their family member to remain in the family home and to continue caring for as long as possible and four participants remained unsure as to what might happen, some with an outlook that a family member may step in.

Similarly, carers were asked about arrangements or plans for temporary care or support of their family member in the event of an emergency. 20% (n=2) of carers identified that they would turn to the respite house that their family member had been attending on short stays which was facilitated through the same service that they were receiving day services. 40% (n=4) identified turning to their families for help in an emergency, 10% (n=1) identified paying for somebody to come in to look after their daughter “if it was only a short while” P3 and a further 30% (n=3) had
made no plans at all. The table below, table 4.5.1 identifies the extent of future plans made by the participants in the study.

**Table: 4.5.1 Extent to which carers have made plans for their family member.**

<table>
<thead>
<tr>
<th>Extent of future planning</th>
<th>Dual carers</th>
<th>Lone carers</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Future plan already agreed</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>In process of planning for the future</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>No plan yet, but want to start planning</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Not/ready or willing to plan</td>
<td>2</td>
<td><code>1</code></td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>4</strong></td>
<td><strong>6</strong></td>
<td><strong>10</strong></td>
</tr>
</tbody>
</table>

The table identifies the extent to which participants had planned. Some carers had given higher priority to planning for the future over others. As the interviews progressed and plans were explored further throughout the interviews, it became apparent that there was an incongruity among future plans with some plans appearing questionable as to how reliable they were. One participant identified that her daughter would take her other daughter with an intellectual disability in the case she would be no longer able to care for her, however later in the interview the participant, when asked whether she had discussed the plan with her daughter expressed that:

“it’s not something you just bring up over tea, I don’t want her to feel under pressure either but she’s a great girl, she’s very good to her sister” P8

For other participants ‘being prepared’ described carers desire to have their family member transitioned successfully into their new accommodation before a crisis occurred whereby something happened to the main carer ceasing their caregiving abilities resulting in the person with an intellectual disability having to be placed in an emergency placement. Having the person transitioned gradually and being able to be part of the process ensuring that the family member
feels safe and secure in their new home are a few of the reasons that carers choose to seek alternative accommodation and make alternative plans even though they consider themselves still of caregiving ability.

“it’s important that I know he will be okay and see that he is happy where he is, I don’t want to put that responsibility on anybody else, I want to see it for myself then someday when my time comes I’ll rest easy knowing that he will be looked after. I mean things will be different but we will still take him home, this will always be his home but I am looking forward to seeing him move into (name of service/alternative accommodation) please god in the next few months, it will be a big relief to me”. P8.

The extent of future plans among participants in the study varied and their perception of being prepared is distinguishable. However, some participants continued to describe their fears, and in contrast a lack of awareness of the possible outcomes that may lie ahead for them. This is explained under the subtheme an unforeseen future.

4.5.2 An Unforeseen future

The final subtheme captures participants unremitting apprehension about what their future had in store for them and their adult family member with an intellectual disability. Participants in general struggled with the initial concept of future planning and found it difficult to articulate their perceptions on what future planning entailed. It was evident that some participants were becoming overwhelmed with the topic of future planning and one participant identified that “I hadn’t really thought about it till now” P5 emphasising a lack of awareness in some cases and moreover one participant expressed feeling inadequate at their quality of response. “maybe we’re not the best ones to be talking about future planning we haven’t really got a plan” P4

Most participants had identified their own ageing and acknowledged that they were not as physically fit as the years had progressed. Participants were clearly concerned about their physical health. “I am getting older and I am not able for it as maybe I was before and either is (husband)” P7. Some of the carer’s had suffered deteriorated health, “(husband) had his hip done three years ago now”, P4 Similarly another participant expressed that he suffers with arthritis
that can pose a challenge, “I suffer from the arthritis, it gets bad now and then I always find the weather takes its toll on me and I had the gallstones removed there last year” P6. Others, expressed that the extent of caregiving over the years was beginning to take its toll, “I hurt my back years ago carrying (son) and I suffer with it since” P7.

Carers were clearly worried about the future and their ability to continue caring with one participant raising the question.

“What will happen him when or if I go, I don’t know?” P10

Participants expressed their emotional stress and apprehension regarding their deteriorating health and the impact it was having on their caring abilities. It was clear that carer’s physical and mental health acted as a tremendous stressor for carers with one participant indicating that they could not afford to be slowing done or becoming ill.

“I was diagnosed with early Alzheimer’s back in February, it was an awful shock to me, I can’t afford to be getting ill, I need to be there for her, I just knew in my heart though something wasn’t right. Of course, my initial thought was(daughter) and what’s going to happen, my own mother died from Alzheimer’s so I knew how quick things can get bad. I had to start planning so she would be safe. P9

Another participant indicated that her mental health was affected with the level of stress and worry she had as being a responsible carer. The carer expressed that she had become so overwhelmed with having to stay in good health that she became obsessed with seeing her G.P on a regular basis and had to be reassured that she was okay.

“I went to the doctor, I thought I was getting something in my head, thank god there was nothing wrong, private insurance, and he looked at me when I came out and do you know what he said, you keep away from the doctors, and you will do the hundred so I’m hoping I will do the hundred”, P10

Some participants showed an element of denial about the inevitability that they could have some plans in place that may assist them in the future.
“we all wear blinkers when it comes to that because there is very little we can do”, P10

Other participants appeared to be dismissive in relation to identifying their perception of future planning. It appeared that there was an avoidance in relation to engaging with topic,

“sure, you can’t really plan too far ahead because god knows what the next day will bring” P2

Other carers spoke of an unforeseen future, due to a failure in securing appropriate placements, inability to identify plans with family members or due to limited resources. Participant one, P1, referred to their failure in trying to secure a place for their family member within a suitable disability service and the pressure they felt to accept a service that was their least preferred option. They recalled the “endless waiting lists”, “wait” for someone to get back to you, “the catchment areas, we didn’t qualify for” and felt that they had no other option but to take a nursing home placement which they had qualified for “the fair deal”. The participant felt under pressure to secure a placement due to the increased strains they were faced with at home caregiving, “we had only two weeks”, “we mightn’t get it the next time”, “we had to take it”.

Some participants had no choice but to continue their caring duties as there appeared to be no alternative. They had either tried and failed to find suitable accommodation and support for their loved ones but were unable to do so because of a lack of accessible information, support and accommodation. Many carers said they had been worried about this for most of their lives, with increasing anxiety as they aged and suffered deteriorating health. One carer highlighted her regular visits to the doctor as she was afraid of anything happening to her,

“I went to the doctor again, I thought I was getting something in my head, private insurance, thank god there was nothing wrong and he looked at me again when I came out, you keep away from the doctor’s and you’ll do the 100, so I’m hoping”.

A lack of security about what would happen should they die or suddenly become ill exacerbated these concerns and worry. Two carer’s were so desperately concerned about the future that they both said they might prefer their son and daughter to die before they do, demonstrating the hopelessness many carers feel about their uncertain future.
“I’m hoping that I will do the 100 years. and deep down and maybe, although I hate saying it that (son) will be gone before I will. You know and that’s a terrible wish for a child, I know.” P10

hope that we can go together or that he will go before me, does that make me awful” P9

For parent carers in this study, the reality that their offspring would outlive them was becoming more apparent. Some participants were so worried about the outlook of their future that they hoped that their family member would die before they do so that they could keep caring for them till the end and know they are okay and not having to depend on anyone or anything else to look after their loved one.

The primary concern for all participants was what would happen to their family member. Some carers did not know exactly what they were going to do but in some cases, knew what they had hoped for and what they hoped not for. Their hopes included not only for their physical care to be looked after but for their family member to be safe and feel secure, happy and loved.

Throughout the interviews it was evident the heartache and worry participants were going through at the thought of transferring responsibility of caring over to someone else. One participant who had not engaged in future planning had become visually upset, the participant had envisaged that her other daughter would look out for her family member with an intellectual disability if anything would happen, but her daughter had recently been diagnosed with multiple sclerosis and now felt that this plan was no longer dependable. The participant described how she was afraid to approach the subject with her daughter, and felt that she would be selfish in putting more stress and strain on her other daughter.

“my daughter, she was always there to rely on, she’s great to look after (son), whenever we were stuck she would always be at the other end of the phone, even with her children, and they’re very small yet. But a few months back she got a bit of news, she’s been diagnosed with MS so that put a change in her life and a damper on things. I suppose I always felt I could rely on her to look after xxx if something you know happened. (pause/emotional). Now how can I she has so much on her plate and I’m afraid to ask. I can’t ask, it wouldn’t be right, it wouldn’t be fair.” P9
Moreover, it appears that relying on somebody else or service professionals to care for their family member with the same love, care and consideration remains a worry. Participants were concerned over the continuity of care if their family member made a transition to alternative care arrangements. Among their concerns were that they may not be able to give the same amount of “time” P9 to their family members or how they would be treated and the fear that they would be overlooked within a service due to the fact their family member may be “quiet” P10 and reluctant to “speak up” P10.

The reliability of future planning appears to be a worry among ageing carers, particularly for those who are relying on other family members to be active members of the plans in question. As life progresses and carers have identified their ageing, another issue is the awareness of their other family members ageing through their lifespan where they are undergoing a series of changes and adaptations. Particularly, where there is expectation that a family member will take on the caring role for their family member with an intellectual disability. Some carers referred to their other family members new responsibilities including children, living locations and work opportunities and worried that whether these commitments might hinder or affect their involvement in being available to help care for their family member with a disability such a time comes where their parent or main carer is not. In some cases, the inevitability of change may influence carers willingness to make future plans.

“I couldn’t say to any of them that now you mind (son) and I’ll give you x or this or that, I couldn’t do it. Because you don’t know will they want to do it, will they be there to do it, will it be a wife, a husband so you can’t do it, (non-disabled daughter) is a physio and she is gone in the morning before 8 she has to try and get the bus up in (name of place) because it doesn’t come down here early enough for her to leave for work, I used take the kids till (son with an intellectual disability) started having his blips you see in the morning. Everything seemed to start happening together of course, and look the rest of them, my son across the road has two children and they both have two jobs, I don’t know, will they have time, it was different before” P10.
However not all families wanted to rely on other family members to provide care, in some cases, there was no other family member to provide care.

“I mean the two boys are off doing their own thing, (non-disabled son) is over London, he has a wife and he’s 2 little boys and xx is over in Saudi Arabia, I don’t know will they ever come home. I mean they do come home alright but it’s a flying visit” P4

Some carers were experiencing substantial inner conflict about the best course of action to take regarding future plans. While they wanted their family member to live with them for as long as possible, they were considering what would be best for their family member in the longer term fearing a crisis occurring capturing the subtheme an unforeseen future.

4.6 Chapter Summary

The four themes emerging from the data analysis are presented above. The themes, derived from analysis of ten participant interviews utilising Burnard’s (2011) framework for thematic content analysis were developing an understanding, extent of future planning, dependability and unremitting apprehension. Participant quotes that illuminated human experience and illustrated findings were included where deemed appropriated. Furthermore, a brief interpretation of the data was offered. A more detailed discussion and critical analysis of the data and findings with regard to current literature will take in chapter five.
Chapter 5: Discussion of Findings
CHAPTER 5: Discussion of findings

This study explored ageing carers experiences of future planning for their adult family member with an intellectual disability. The voices and interpretations of the participants in this study were fundamental to understanding this phenomenon and provided the foundation for this research (Polit and Beck 2013). Four themes emerged following data analysis: a life not foreseen, bearing the cross, reaching a decision, nearing the end. This chapter discusses and critically analyses the study findings in relation to national and international literature. The discussion of findings is presented under the four identified themes.

5.1 A life not foreseen

This theme captured participants journeys in becoming a lifelong carer to their family member with an intellectual disability. It attempts to provide an understanding of carers experiences of coming to terms with having a child with a disability and furthermore caring for a child with an unexpected disability, the emotions and challenges that surrounded the experience and how it impacted their lives. Furthermore, the theme identifies the realisation of the prolonged period that participants had experienced in caregiving. Participant’s had not envisaged this path in their lives and this was captured under the subthemes: taking it on and in it for the long haul. The findings of a life not foreseen by participants in this study can be utilised to attempt to understand participants level of future planning they have engaged in.

5.1.2 Taking it On

The subtheme taking it on captures participants experiences of a life they had not envisaged or planned for. Similar to the findings of Cairns et al (2012), participants indicated that a life unforeseen dates back to the earlier years when carers were faced with the reality that their child had an intellectual disability. The study described carers responsibility in taking on the role as the primary caregiver and described carers experiences in doing so. In this study carers recalled the whirlpool of emotions that surrounded them at the time of discovering their child had an intellectual disability. Through the interviews collectively, participants expressed their initial
concern on how a baby with an intellectual disability would be perceived within their families. The anticipation described by carers who were mothers, as to how their husband would identify with the news of their child having an intellectual disability was evident. Existing studies have identified the impact of having a child with an intellectual disability can have on a relationship and marital status and there is a reported association with having a child with a serious health condition and disability with the increase in the likelihood of divorce or separation indicating the level of strain it can put on a relationship (Namkung et al 2015; Hartley et al 2011; Swaminathan et al 2006). Moreover, participants in this study worried about the impact of having a child with a disability on their other children. Current literature recognises the effect of having a sibling with an intellectual disability indicating that a number of specific child health conditions are associated with poor mental health outcomes of siblings. (Giallo et al 2012; Mulroy 2008; Reichman et al, 2008). Furthermore, it has been proven that peer activities and cognitive development scores are lower for siblings of children with a disability (Di Giulio al 2014; Sharpe 2002). The findings of this study identified that other family’s supportive reactions to having a family member with an intellectual disability had a positive impact on carers willingness to taking on the responsibility in the earlier days.

Moreover, as reported in the literature parents with a disabled child are less likely to have larger families (Reichman et al 2008). Participants in this study reported a reluctance to continue family planning as a result of having a child with an intellectual disability. Most participants did not have any other children following the birth of their child with an intellectual disability. Dealing with the initial shock and coming to terms with the realisation of having a child with a disability generates feelings of loneliness and frustration (Huang et al 2011). Participants in this study described questioning themselves and their religion as to why they were given this burden feeling heartbroken and demoralized. However, despite the conflicting emotions that carers experienced, carers overcame these challenges and focused on the task involved. The findings of this study identify the importance of taking on the responsibility of caring for their family member with an intellectual disability to participants and ensuring the best possible outcomes for their family member with a disability.
5.1.3 In it for the Long Haul

Participants described their life that they had not foreseen under the subtheme in it for the long haul. The theme described parent’s unexpectedness of their prolonged caregiving role that they had not anticipated. Carers described how they had been advised by health professionals in the early years that their child with a disability would have a relatively short life expectancy. Research has identified the dramatic increase in life expectancy over the last century. (Crimmins et al 2016; Kamiya et al 2012). The increase in life expectancy among people with intellectual disabilities has resulted in an increase in the number and share of older people in populations across the world. The rapid ageing of populations in developed countries over the next few decades is expected to increase the demand for long-term care. In Ireland, the proportion of older people aged 65 and over in the population is expected to rise from the current 11.4% to 22.4% in 2041. (TILDA 2016; Kamiya et al 2012). While the projected changes in the population aged 65 and over are striking, changes for the group aged 80 and over are even more dramatic. Between 2011 and 2041, the proportion of people aged 80 and over in the population of Ireland is projected to rise from 2.8% to 7.3% (Kenny and Barrett, 2010). Increased longevity in this population is attributed to improved health and well-being, the control of infectious diseases, the move to community living, better nutrition, and an improvement in the quality of health care services (McCarron et al 2014; Ryan et al 2013; Thompson et al 2004). Inconsistent with current literature’s recommendations to begin future planning early, (Kamiya et al 2012; Kenny and Barrett 2010; McGimpsey 2008), participants in this study had not engaged in early future planning. Participants had not envisaged caring for such a prolonged period of time which may be noteworthy to mention when attempting to address the extent of plans made by this group of participants.
5.2 Bearing the Cross

Bearing the cross is the second theme in this study. The theme captured participants ability to bear the burden of caring for a family member with a disability over a prolonged period of time. In this study participants described the extent of their responsibilities as a caregiver to their family member with an intellectual disability. Participants identified issues such as the mental strain of caring for a family member with an intellectual disability, being fully responsible for somebody else’s wellbeing 24-7, juggling being a caregiver with other responsibilities. Furthermore, caregivers identified the physical burden of caring for a family member with an intellectual disability, identifying issues such as an increase in medical issues such as back pain. Caregivers also cited that their level of social integration in society themselves was restricted due to their dedication to their caregiving responsibilities and the demand that being a 24/7 caregiver involves. The impact of caregiving on parents psychological and physical health and wellbeing has been researched and identified amongst the literature, (Bhatia et al 2015; Rowbotham et a; 2014; IASSIDD 2013; Chou et al 2010.). Effects of caregiving on family carers Research illustrates the long-term effects of caring for a relative with a disability: physical (i.e. arthritis, hypertension, poor mobility, obesity, increased diabetes and cholesterol), emotional (i.e. depression and anxiety), social (i.e. isolation) and being economically disadvantaged (Lin et al 2014; Chou et al 2010; Yamaki et al., 2009). Parents of children with disabilities report greater demands of caregiving than parents of non-disabled children, increased stress levels and poorer physical and psychological health (Yoong and Koritsas 2012; Miodrag and Hodapp 2010).

In this study participants recalled both positive and negative experiences with the level of support they received. The quality of supports that parents receive from informal and formal resources have been identified as reducing the level of caregiving burden thus enabling them to cope with their responsibilities (Dillenburger and McKerr 2010). The impact of feeling supported and the feeling of neglect were two diverse issues that were described by participants in this study and they will be further discussed under the subthemes being supported and being left in the dark. The findings generated rational for the extent of plans made by participants in the study.
5.2.1 Being Supported

All participants within the study spoke of the level of support they were receiving. However, a discrepancy in participants level of satisfaction existed with supports with most carers reporting negative experiences with accessing support. However, those participants that did feel they were supported highlighted the importance that their level of support been given to them was on their quality of life as a caregiver. The findings in this study reiterated the importance of supports to participants to enable them to care for their family member with an intellectual disability in their daily lives. It is noteworthy to mention, participants in this study were all in receipt of a day service for their adult family member with an intellectual disability. Current literature has emphasised the importance of supporting ageing carers caring for their family member with an intellectual disability at home and furthermore to assist them in future planning (Schulz & Eden 2016; Taggart et al 2015; McCarron et al 2014). Ageing caregivers in this study identified for the most part, the positive impact their receipt of day service for their adult family member with an intellectual disability was having. Carers described having time to themselves during the day to be able to go doctor’s appointments and look after their own personal health, for their own socialization and having time to themselves to retract from their caregiving responsibilities. These findings draw similarities to the work of Heykyung & Eun-Kyoung Othelia (2009) where the findings indicated that social support can reduce caregiving burden. Furthermore, a review conducted by Robertson et al (2011) highlighted the benefits of short breaks and respite for families caring for a child with an intellectual disability including: reduction in carer stress; new experiences for disabled children; and carers having time with their other children.

Participants in this study described different resources of support they were availing of. Most participants described the impact of the informal resources that were available to them in the form of support given directly from family members, friends or neighbours. Participants described the feeling of comfort of having someone to rely on outside of office hours and someone to be able to call on in emergencies. A review conducted on the role of natural supports in promoting independent living for people with intellectual disabilities highlighted the importance of these supports in enabling people with disabilities to live at home within their
communities independently (Duggan & Linehan 2013). Moreover, in this study some participants identified the benefit of having someone that you can to talk to or confide in, in terms of a neighbour or a friend. Similar to the findings of Dillenburger and McKerr (2010) participants felt a greater sense of being able to let the emotional guard down and confide in somebody that is not directly linked to the situation and it appeared that some carers found it easier to talk to people that were not involved in the caregiving task or situation. Having a key worker (Henrietta et al 2015), social carer (Deveau & McGill 2016), disability nurse/RNID (Doody et al 2012) is a common possibility among people who are accessing disability services in Ireland today. Moreover, their roles in delivering care that is person-centred around the person with a disability and their circumstances is heavily reported in the literature (Deveau & McGill 2016; Henrietta et al 2015; Doody et al 2012; Sheerin & McConkey 2008). Delivering a person centred plan or approach effectively involves a key professional taking time to really get to know a person, listening carefully and building relationships and rapport over time (National Disability Authority 2018). Based on the findings of this study and taking into account that family carers are heavily involved in an ageing person with an intellectual disabilities lives, it may be noteworthy to explore person-centered planning options that are developed around ageing family carers and there circumstances.

Participants in this study reported a perceived responsibility to be strong for all family members. These findings drew similarities to the findings of Yoong et al (2012) where they identified that upholding a strong front that demonstrates ability to cope and get on with things may be a result of parents perceived responsibility to be a good role model and a protector for all their children, both disabled and non-disabled. In contrast, some carers were luckily enough to identify family members that lived close by to them and this was deemed very positive in relation to feeling supported. A study conducted by Llewellyn et al (2010) with 64 family carers of adults with a learning disability in Australia found that better health was correlated with having an effective family support model (or informal support networks) (i.e. spouse/partner, siblings, extended family members, neighbours). Moreover, Bigby (2002) stressed that a strong family support model was fundamental to a family carer’s well-being. The availability of an effective family
support model allowed many children and adults with a learning disability to remain within their home and also in their local communities. The benefits of these effective family support models for parent carers have been found to increase social support; lead to fewer feelings of loneliness and anxiety; less stress; and improved quality of life (Innes et al., 2012; Heller et al., 2016). However, in this study, even though carers described their gratitude in terms of receiving these informal supports from family members in particular, they identified having a lot of guilt in terms of depending on them and placing the burden of caregiving on them at times consistent with recent research (Taggart et al 2012; Heller & Arnold 2010; Dillenburger and McKerr 2009.). Consistent with other studies participants wanted to protect their other non-disabled children as much as possible from burdening them with caregiving responsibilities (Lunsky et al 2017; Ngangana et al 2016; Thompson et al 2014).

Being supported in this study captured participants level of support received in relation to easing caregiving burden and improving quality of life day to day, however in terms of planning for the future and being prepared, it appeared participants viewed themselves to be unsupported and this can be captured under the theme *being left in the dark.*

5.2.2 Being Left in the Dark

The results of this study add to the current knowledge around issues of concern for ageing carers caring for their adult child with a disability in relation to future planning (Brown et al 2012; Bernard & Goupil 2012; Barron et al 2006). Many participants were unhappy with their interactions with the government, and the results indicate that this was a greater concern than interactions with professionals. Similar to findings of other research, participants in this study reported a dissatisfaction with services available to them, (Taggart et al 2012; Eley et al 2009; Hubert 2006). The participants may have distinguished the difference between the government that develops the policies and allocates the resources and the professionals who deliver services. Participants identified national building grants available to them to make their homes more accessible as unrealistic identifying that the cost was put on to take it off and did not provide practical assistance to them in anyway. Whilst support for carers has been set as a priority by
national and local government, (Department of Health, 2008), services are still very much dependent upon service ability as opposed to overall need (Bowey and McGlaughlin 2007). Participants in this study described their level of day service they were receiving for their family member with an intellectual disability as inconsistent, identifying recent cuts to services as cause resulting in service hours being cut. Moreover, participants in this study identified a reduction in service hours each week due to increased health demands of a person with a disability and the services inability to cope with the demands. One participant advised that services would be available to them according to the level of staff on duty. She described waiting for the phone call as to whether her family member would be going to day service the following day or not. The findings of this study highlight a greater need for services to accommodate individual needs of people with disabilities and their families. Furthermore, it has been reported amongst the literature that district nurse’s rationale for providing support to carers at home has been shown to be largely based on service capacity rather than on carers needs and preferences further intensifying findings of this study. (Gerrish, 2008; Arksey & Hirst 2005. Gerrish (2008) conducted a study with 6 district nurses, the findings highlighted that family carers were not recipients of district nursing support in their own right but were dependent upon the cared-for person receiving nursing care. This in turn was conditional upon others (general practitioners and hospitals) making appropriate patient referrals highlighting an incongruity in the quality of services available to this vulnerable group of ageing caregivers and their family members with an intellectual disability.

The research of this study supports results of other researchers who identified problematic issues that older people face in their interactions with the service system, including a lack of trust, difficulty in finding help and contact, accessing services and emotional barriers such as fighting the service system. (Heller and Caldwell 2006; Taggart 2012; Weeks et al 2009). This study emphasised participants challenges when trying to make plans for alternative arrangements. Carer’s reported their frustration with having to be placed on waiting lists and not receiving any clarification as to whether or not they would have a positive outcome at the end. This has been
evident amongst other studies conducted with similar participants (Mansell & Wilson 2010; McConkey et al 2006; Weeks et al 2009).

Participants in this study have identified the timeframes and lengthy waiting lists that are evident when attempting to secure services and accommodation to help them plan for the future, this has been recognised across other research. (Gret et al 2015; Taggart et al 2012; Bowey and McGlaughlin 2007; McConkey et al 2006). The study identified carers’ challenges on seeking professional help referring to the distress in getting professionals to answer and return phone calls, receiving information and help when it was too late, being placed on hold, personnel being unfamiliar with their case, being placed on lengthy waiting lists for alternative accommodation and in general feeling disillusioned by the timeframes and timely responses from those who they feel may be able to help them. This is a common perception across the literature in the area, (Grey et al 2015; Taggart et al 2012; Dillenburger and McC Kerr 2009; Bowey and McLaughlin 2007; McConkey et al 2006) and intensifies caregivers feeling of marginalisation and isolation (Gilbert and Lanksheer 2008). Some participants spoke of difficult relationships with health and social care staff, reporting that they often felt ignored and an added responsibility in feeling they had to keep a close eye on things. Accounts of conflict and a lack of empathy experienced by families from professional staff within the social care system are consistent with previous research where families spoke of having to fight for service provision on behalf of their family member with a disability, (Grey et al 2015; Weeks et al 2009). These negative relationships with service professionals can prove very stressful and have a negative effect on carers’ well-being (Bhatia 2015; Hole et al 2012). Dillenburger and McKerr (2012) identified that in cases of high demand and low supply, i.e., caregiving burden versus lack of help, conflict and stress are inevitable.

In the present study, some participants were identified as having engaged in reaching the decision to move their family member out of the family home. However, the lack of suitable and available housing resulted in one family carer receiving an unsuitable offer which they felt forced to take for fear they would not get a better alternative. Similar, to findings of research by Bowey and McLaughlin (2007), carers’ found the process of searching for alternative accommodation,
time consuming and wearing. Some carers continue despite their deteriorating health as there appears to be no alternative. Consistent among the literature, carers reported that the process of acquiring services and accommodation lacked openness and transparency (Eley et al 2009; Gilbert et al 2008; Davys & Haigh 2007). Families felt that staff often withheld information and that they were always the last to know. This supports previous research where caregivers reported finding it hard to access information and advice from service providers, (Cairns et al 2012). Similar to the findings of this study, Cairns (2012) reported that all parent carers in the study felt that they were at some point ill-informed about services that they were entitled to, from early in their caregiving experiences to present day. As a result, some felt let down. The findings of this study drew similarities to the findings of Taggart et al (2012) where ageing carers’ were identified as lacking support and information as well as practical resources throughout their caregiving career. Despite policy improvements (DOH 2008; DOH 2001) over the years, participants in this study identified a lack of awareness of where to begin or who to turn to in receiving help and support. Kamiya et al (2012), identified It is not sufficient to wait for carers to ask for this type of information, as many carers are not aware of what services exist or how they work in practice. It appears that presently, society relies on older parents and informal carers to take full caring responsibility of their loved ones with an intellectual disability and thereby making substantial savings (Cairns et al 2012). As a result, the situation is unlikely to change. The huge amount of high quality care given freely and willingly by the parents removes the burden from our government and national stakeholders and reinforces, or increases the likelihood of future inactivity of service providers (Dillenburger and Mc Kerr 2009).

In this study, this appeared to be the first time for the majority of participants even though they were known to health and social services had been actively consulted about future options. These findings would generate questions around how best to inform ageing caregivers and whose responsibility it is to engage with them on the topic. Moreover, many participants reported that they had no ongoing contact with a social worker, public health nurse with whom care options could be discussed and who have the responsibility for under taking formal assessments of care needs. One carer added that she didn’t feel it was the responsibility of the professionals in the
service her son had been attending to. She felt it wasn’t there job and that they had enough to be doing looking after their family member with disabilities without looking after carers as well. Literature has identified that the justification for extra resources must be supported by evidence of need (McConkey et al 2006), therefore it is imperative that social services are consulting with families to determine their preferences in terms of future planning in order to inform service provision of the demands for placements and supports services. These findings suggest that if social service personnel wish to formulate plans for the future housing and support needs, this is best done through an individual review of the needs of family carers and their family member with an intellectual disability, using one of the person centred planning methods available. This personal contact with families need to be maintained over a period of time and with skilled personnel who are able to support ageing carers as they face issues of separations and their own mortality (Richardson and Ritchie 1986). Failing to consult with families will not prevent the crisis of finding alternative accommodation that arises when carers suddenly fall ill or die (Taggart et al 2012; Dillenburger and McKerr 2010; Gilbert et al 2008). Moreover, many family members will lose their home at a time of a bereavement (Bowey and McGlaughlin 2007). It’s also worth reiterating that in situations of high demand and low supply, conflict and stress are inevitable adding to caregivers perceived caregiving burden, with the lack of suitable accommodation, guidance and support and access to information, participants mostly felt unprepared for the future. The lack of suitable accommodation and support services should not be news to service providers. Numerous reports have pinpointed this deficit, (Grey et al 2015; Dillenburger and McKerr 2010; Chou 2007; Bowey and McGlaughlin 2007; McConkey et al 2006). However, where only minimal social support was available during the lifetime of the parents, there will be a severe lack of support for a child or adult with disabilities when parents or family carers are unable to care or have passed away, consistent amongst other studies, those with inadequate networks of support experiences isolation, loneliness, physical and mental problems and heightened stress level, (Dillenburger and McKerr 20).
5.3 Reaching a Decision

The third theme reaching a decision was at the forefront of participants minds. It describes participants own experiences in identifying their future planning preferences for their adult family member with an intellectual disability. Participants described their diverse views in relation to their future preferences. Carers identified their preferences to secure alternative accommodation in some cases, others they described their desire for a family member to take on the role. Moreover, other carers described their preference to continuing caring for their family member with an intellectual disability for as long as possible. Participants identified factors that influenced their decisions for the future. This was captured under the subthemes wanting to continue and letting go, which will be discussed next.

5.3.1 Wanting to Continue

In this study some participants wished for their family member with an intellectual disability to remain at home with them for as long as possible and to continue caring for them. This was captured under the subtheme wanting to continue. Some participants highlighted their duty of care to continue caring and felt a sense of responsibility to keep going particularly for those who were parents. Despite some participants’ awareness of their own ageing needs, they reluctantly dismissed the idea of their family member being anywhere else but home with them. Current literature has linked ageing carers reluctance to view alternative future plans to a perceived sense of denial which can be as a result of a lack of awareness of what lies ahead (Taggart et al 2012). Amongst the literature ageing carers were often identified as unwilling or unable to make plans for the future or just simply had not got around to it especially those who were still coping well (Dillenburger & McKerr 2010; Bowey & McGlaughlin 2007). There is a suggestion that those who have experienced ill health are more aware of the need to plan ahead [Gilbert et al 2008]. Many were fearful of what may happen in the future. Other studies suggest that older carers believe the person with ID would prefer to reside at home as they have lived there all their lives (Bowey and Saul2005). In this study some participants, appeared very happy with their current caregiving arrangements, identifying a relationship with their family member with a disability as mutually
supportive, identifying that they provide help and company for each other. This has been consistent with other studies whereby a reciprocal relationship has been identified as a contributory factor in carers desire to continue to care, (Lara & de los Pinos 2017; Cairns et al 2012; Gorfin & McGlaughlin 2004). One carer described how after his wife had passed away, his daughter with a disability was supportive and was able to help with tasks such as the cooking and cleaning around the house. Inter-dependent relationships have been consistent in the literature in relation to explaining some carers misgivings in planning for the future (Kilic et al 2013; Taggart et al 2012; Dillenburger and McKerr 2009; Bowey & McGlaughlin 2007). Participants in this study described their contentment with their family member with a disability at home for their companionship. In some cases, carers described their joy in spending time with their family member with a disability identifying they had a purpose to get up and go out. Similarly, other participants were satisfied with their lives and happily expressed a level of contentment with their current living arrangements and in their caregiving role as described by Chou (2009). Participants described scenarios of their day to life at home with their family member with a disability, describing routines of the day, obstacles they had overcome, progressions they had made and the day to day items that appeared to give carers a sense of personal achievement. Personal fulfilment has been cited amongst the literature of ageing carers caring for their adult family member with an intellectual disability in an attempt to understand why carers may be reluctant to future plan or make alternative arrangements (Baumbusch 2017; Thompson et al 2014). Participants in this study recalled how far they had come, and most importantly as a unit. It was clear that participants felt a unique bond with their family member with a disability. Similar to that of the study of Cairns et al (2012), participants in this study described a sense of inter and intra personal dimensions. Moreover, participants that had a supportive partner appeared more likely to want to continue caring for their family member with an intellectual disability. They described a supportive situation whereby there was always somebody around to look out for their family member. Participants were less likely to feel tied down or identify psychological factors that portrayed an inability to cope and feel burdened by their caregiving role. Bowey and McGlaughlin (2007), highlighted that Reliable dependents such as having two carers in a
household appears to reduce caregiving burden and creates a sense of ability to continue to care as long as possible. Participants in this arrangement were most likely to have not engaged in seeking alternative arrangements or developing plans. The findings of this study have been consistent with findings from other international studies within a similar field highlighting that the presence of both parental carers reduces the likelihood of ageing carers identifying a need to future plan. (Taggart 2012; Dillenburger and Mckerr 2009). The findings of this study suggest a greater need to inform ageing carers on the benefits of future planning and the outcomes where future plans are absent.

Participants in this study reported some misgivings about alternative accommodation and worried about how their family member would be treated by staff and peers. Furthermore, the literature identified another explanation as to why ageing carers were reluctant to plan ahead was due to a lack of confidence in the housing options available, perhaps after a poor experience during respite for the person with ID (Bowey & McGlaughlin 2008; Gilbert et al 2008; O’Rourke et al 2004). Risks associated with independent living were a concern for carers and professionals when planning for the future (Bowey and Saul 2005). Evidence suggests there is a lack of available information about housing options and not enough practical support to raise awareness of options among older carers caring for their family member with an intellectual disability (Gilbert et al 2008). Older carers reported negative experiences of professional support that could add to the stresses of caring and cause barriers to change (Llewellyn et al 2010; Bowey and Saul 2005). The findings of this study identify a greater need to proactively advertise available services to ageing family carers caring for their adult family member with a disability and to encourage use of short term breaks, respite and stays that may improve carer’s awareness of services and reduce their misgivings.

5.3.2 Letting Go

The subtheme letting go captured some participants willingness to future plan and make alternative arrangements for their adult family member with an intellectual disability. Some participants in this study were particularly concerned with their responsibility of caring for their
family member with an intellectual disability owing to their age and their caregiving demands and to some their deteriorating health. Dillenburger and McKerr (2010) cited similar findings reporting that as health of carers deteriorated, an increased level of worry occurred. Carers reported being very dependent on the level of health that they themselves experienced to enable them to continue their caring role. Consequently, in the case where carers reported to be suffering deteriorating health, likewise in this study, participants became more dependent on external services to enable them to cope with this ageing reality. Participants described the physical and psychological strain of caregiving challenging, highlighting that as they were getting older and reported lower energy levels and underlying health difficulties caregiving had become more difficult. Some participants also reported their own desire for a life outside of their caring role, with some desiring greater freedom to spend more time with other family members particularly non-disabled children and grandchildren. Participants reported a feeling of guilt in their lack of participation in the lives of their grandchildren. Similar difficulties encountered by other carers in providing care as they get older have been highlighted extensively in the literature on family carers of adult children with an intellectual disability, (Grey et al 2015; Cairns 2012; Taggart et al 2012; Dillenburger and Mc Kerr 2010; McConkey et al 2006; Bowey and McGlaughlin 2007). These findings identify a greater need for ageing carers to be supported in their homes to enable them to be able to participate in lives activities outside of their caregiving roles.

Some participants in this study identified the extent of their caregiving burden reached beyond just caring for their adult child with an intellectual disability and identified further responsibility of caring for another family member. The increased caregiving burden in some cases, proved participants to be more willing to future plan. 30% of participants in the study reported caring for another family member, with one carer reporting looking after her husband with Parkinson’s and the other participants looking after an elderly mother. The issue in relation to compound caregiving has been evident across the literature, (Lunsky et al 2017; Perkins & Hayley 2010). Compound caregivers are those parents who are already providing considerable caregiving responsibilities for their sons/daughters with intellectual disabilities, who subsequently becomes a caregiver for an additional family member (Perkins & Hayley 2010). The additional
responsibilities and tasks of being a compound caregiver proves more stressful for caregivers because many difficult decisions about prioritising tasks must be made. Compound caregiving is likely to be an increasingly common scenario for caregivers for adults with intellectual disability, given the increased life expectancy of persons with intellectual disability and the general population (McCarron et al 2014). There is little evidence across the literature regarding compound caregiving (Perkins & Hayley 2010). The findings of this study identify a greater need to further study this group of carer.

5.4 Nearing the End

The fourth theme nearing the end captured the unavoidable reality that the participants of this study were facing. Ageing was something that none of the participants had control over and it was inevitable that a time may come that they may be no longer able to care for their family member with an intellectual disability. Nearing the end describes participants extent of plans made. The level of future planning was variable across participants in this study, for some carers nearing the end involved having secured a future plan and this can be captured under the subtheme being prepared, for other carers a lack of future planning was identified and will be discussed under the theme an unforeseen future.

5.4.1 Being Prepared

The subtheme being prepared captured participants future planning arrangements for their adult family member with an intellectual disability. It described the participants’ plans in which they made or were in the process of making. The level of future planning differentiated across participants in this study. 30% of carers identified future plans that they had already agreed, 20% of carers were in the process of planning for the future, a further 20% of carers had not engaged in future planning but were willing to future plan and finally, 30% of carers interviewed declared a reluctance or a lack of future planning. Some carers had given higher priority to planning over other carers. Current literature while limited, highlights a lack of future planning for the most part among ageing carers caring for their adult family member with a disability at home, (Hole et al 2012; Taggart et al 2012; Dillenburger and Mc Kerr 2009; Gilbert et al 2008).
In this study, there appeared to be an element of hope and aspiration in some future plans made across participants with a discrepancy in relation to how definitive a plan was in terms of how well discussed, planned and finalized it was. One carer assertively identified her daughter as taking on the caregiving role of her family member with an intellectual disability, however when the carer was asked in relation to their experiences of reaching a decision and plan, she was unable to identify that her daughter had entirely agreed to take on the caring role long-term and envisaged that she would due to her current role in assisting her mother when possible. Similarly, a study done by Taggart et al (2012) had identified two types of planning, definitive planning and aspirational planning. Definitive planning referred to concrete plans that were put in place and involved both living arrangements and financial and legal arrangements. Aspirational planning was when carers reported that they had made future plans but when explored further they were found only to be aspirational and some carers were found to be therefore hoping or expecting a plan to happen or take place. Aspirational planning was evident among some participants in this study and plans were found to be based on hope in some cases.

One participant in this study had recently planned for their family member to make a transition into residential accommodation, the carer identified that her family’s needs were getting far too demanding and they were unable to care for their family member at home, however due to their negative experiences and failure with trying to locate and secure suitable preferred residential accommodation for people with disabilities, these carers have been left with no choice but to take a nursing home placement for their family member and they anticipate there family member will make the move in the next few weeks. Research has linked the transition of people with intellectual disabilities into unsuitable accommodation due to ageing carers lack of awareness in the timescales involved in securing placements for family members with an intellectual disability (Bowey and McGlaughlin 2007). Eley et al (2009) review accommodation needs for people with ID in Australia and stress the need for the government to recognise the changing needs of people with ID as they age, they identify a need to ensure people are supported to be independent, as nursing homes are deemed inappropriate by carers. Transitions from the family home into residential or supported living often occur at a time of crisis for people with intellectual
disabilities. As carers age, there are at risk of deteriorating more quickly and furthermore adding pressure to themselves to take placements based on fear of now getting anything else, the likelihood of ageing carers having to placements in a crisis situation are becoming far too common (McCarron et al 2014). Moreover, contrary to the aspiration for person-centred services expressed in government policy (DOH 2013), the inevitability of a crisis situation occurring will result in adults with an intellectual disability being fitted into whatever accommodation is available which in turn may add to the psychological trauma they experience over the bereavement of a loved one (Dodd et al 2005).

Despite some participants identifying that they had made plans or were in the process of making plans, few if any of these plans were implemented or developed in conjunction with help received from professionals from statutory or voluntary organisations. One participant identified that the community public health nurse had come out to see her family member with an intellectual disability when he had returned home from hospital after being treated for pneumonia and after been further diagnosed with Alzheimer’s. The participant reported that it was a pity they had not seen her a bit sooner and felt that she may have enlightened them as to what steps to take. These findings highlight a lack of information, support and appropriate service services and furthermore calls into question, who’s responsibility is it to develop future planning resources aimed at ageing family carers and whose duty is it to make such plans. A vital step in current practice in Ireland is to determine whose responsibility is it to initiate early future planning discussions and support them and their family member with an intellectual disability through the emotive journey. Bigby, (2000) advocated for a key person to be identified to oversee the well-being of the person with an intellectual disability and their ageing family members over-time as opposed to a rigid plan, that may not be realistic or appropriate due to changes that may inevitable occur over time.

There has been a substantial amount of research identify proactive supports that have been developed outside of the republic of Ireland in assisting ageing caregivers in making future plans. Many educational programmes have been successfully developed to assist ageing parents to develop future plans. “Future is Now Programme involves training both the family carers and the person with an intellectual disability to develop a succession plan. Heller and Caldwell (2006)
followed up 49 ageing parents who received this programme and found that these carers were more likely to complete letters of intent, take action on residential planning and develop special needs trust. The family carer also reported decreased carer burden and increased opportunities for daily choice making. “safe and secure” is another programme that was developed in Canada (Plan, 2008), and then adapted for use in Scotland by equal features; a carer led voluntary organisation (Etmanski et al 2011). This programme is based around a six-step approach to planning the family carers future, using one to one discussion and group workshops: ‘clarifying your vision, relationship circles, housing, legal and financial advice, supported decision making and making a will’. Furthermore, a 2-day workshop was set up in Northern Ireland as a resource for carers who wanted to engage or educate themselves in Future planning. The two-day workshop was based upon six core themes: exploring your own future plan; circles of support; person centred planning and emergency plans; signposting housing and support options; making sound financial and legal decisions; direct payments; and supporting a family carer to make a future plan. (Taggart and Hanna-Trainor, 2017). Taggart and Hanna-Trainor (2017) also identified ‘Circle of Support’ which is a group of people who meet on a regular basis to help somebody accomplish their personal goals in life. The Circle acts as a community around that person. The focus person is in charge, both in deciding who to invite to be in the Circle, and in the direction that the Circle’s energy is employed, although a facilitator is normally chosen from within the Circle to take care of the work required to keep it running.

5.4.2 An Unforeseen future

The subtheme an unforeseen future, captures participants worry and unremitting apprehension about the future that lay ahead for them and their adult family member with an intellectual disability. Carers, of all ages, of people with ID do express uncertainty and fear about the future (Mansell and Wilson 2010; Eley et al 2009). These fears include financial concerns, fear of inappropriate placement for the person with ID and fear of what will happen when they are no longer there to provide care (Mansell & Wilson 2010). In contrast to few participants who had made future plans in this study, had engaged in future planning or showed a willingness to future plan, some carers in this study were unwilling to future plan or denied a need to engage in future
planning. Some participants in this study appeared to reject the need to future plan and portrayed a lack of awareness of the reality of the future that may lie ahead. Many reasons were identified as possible factors that contributed to their lack of willingness to future plan including, a perceived lack of lower burden, mutually supportive relationships, reciprocal relationships and companionship consistent with other research findings (Kenny and Barrett 2010; Chou et al 2009). These carers were in the midst of their caregiving responsibility and adapted ways for themselves to cope and appeared content in their roles and responsibilities. Erikson’s (1963) theory of psychosocial developmental, advocated the importance of older adults having to master the developmental tasks of resolving the conflict between ego-integrity versus despair by reviewing life accomplishments, dealing with loss, and preparing for their own death. According to this theory, older parent carers may be categorized as in despair, if they are not able to accomplish these tasks because they are still in the mindset of caring for their child with an intellectual disability. As a result, this type of theory leaves older carers at a loss and may lead to apportioning blame to the older person for not solving the problem or developmental task. This theory may help to explain why some participants did not identify rational to make future plans.

Some participants that reported a willingness to future plan and make alternative arrangements for their adult family member with an intellectual disability described how they had no choice but to carry on as there appeared to be no alternative. Some carers described how they had tried and failed to find suitable accommodation and support for their loved one but were unable to do so because of a lack of sufficient information, support and accommodation which captured their worries for the future. Carers described their worries and fear owing to their age and their caregiving demands and to some their deteriorating health as they face a future unforeseen. The impact of caregiving demands on carers physical and mental health has been prominent across the literature, (Lin et al 2014). Furthermore, in a study by Mbugua et al (2011), 79% of caregivers caring for a family member with intellectual disability were found to be at risk of clinical depression. Moreover, in Taiwan, Chou et al (2010) indicated that between 64% and 72% of caregivers were classified as having high depressive symptoms with an increase in symptoms
evident as caregivers and their family member with a disability aged, identifying the extent of caregiving on some carers.

Similar to findings by Bowey and McGlaughlin, (2007), participants expressed feelings of anxiety related to their perception they hadn’t enough knowledge and awareness in relation to future planning and didn’t know which organisations or professionals to turn to for accessible information. Research has identified that families level of awareness of the support options that could be available to them are often limited. Their views are often stemmed by the provision of services available locally to them. In the republic of Ireland this tends to be in registered residential homes, often these arrangements tend to be in a campus style setting with a number of bungalows or houses accommodating up to 6-8 people. In addition, some, persons are offered places on a 5-day basis and/or for 48 weeks of the year, returning home to family carers at other times. Latterly a number of these placements have been designated as intensive support, either on the grounds of complex medical needs or behavioural problems. In Northern Ireland, the main model of accommodation provision is based on registered nursing homes or residential care home, these homes have an average of 19 residents and they are located mostly in the community setting. (Mulvany et al 2005). Hence parents need to be told about, and to see at first hand, a range of supported living schemes and to have their reservations addressed (Mc Conkey et al 2006). This can start in the teenage years so that parents and young people are aware of the opportunities that are available to them. This would encourage their participation in future planning and should result in more effective support arrangements for the person. There have been recommendations among the literature advocating for early use of respite facilities to prepare both the carer and the family member for living separately and becoming familiar with transitions (Weeks et al 2009). Participants in this study reported a low receipt of short stay and respite services and it was identified that for those participants that were in receipt of those services that it was very limited. According to the Health Research Board’s, annual report 2016, (Health Research Board 2018), area 5 which was the area location that all participants were located in terms of service provision had the lowest rate in terms of use of respite services in the Republic of Ireland with a median of 14 nights being reported. It’s not known the reason for this
lower rate, however identifying the lack of guidance that participants reported in this study perhaps there is a lack of awareness on ageing carers in the services that are available to them. The findings of this study call for review on the level of short stay and respite services available in the south of Ireland.

Some participants in this study envisaged their family member with a disability to be looked after by another family member, (mostly non-disabled child/sibling) when a time came that they would no longer be able to continue caring, expressed their concerns. For some participants it was evident that they had not given this much thought, as when probed by the researcher regarding any discussion that had taken place with their non-disabled family members, participants remained uncommitted to answering the question. For other participants, they identified concerns in relation to the reliability of their family members, highlighting concerns regarding their family members other commitments and responsibilities and worrying whether they would change their mind or find it too challenging. Furthermore, participants identified a sense of avoidance in talking to their family member about their worries as they didn’t want to bring it up and worried about being perceived as being pushy or unreasonable. Communicating wishes and plan preferences with non-disabled family members pose a great difficulty for carers and can be views across relevant literature (Cairns 2012; Dillenburger 2010; Bowey and Mc Glaughlin 2007; Davys et al 2007). The lack of communication regarding plan preferences with family members added to carers not being able to identify definitive plans that were clear to all which further exacerbated carers feelings of worry of an unforeseen future. This study identified participants complete apprehension over the desolate future that lay ahead where it was revealed that a participant identified that she would prefer if her son would go before him. Despite the participant identifying the enormity of her response and highlighting her awareness of it being an awful wish for a child, the participant felt that this was the best outcome in a very challenging situation. Taggart et al (2012) reiterated these findings where it was similarly identified that a participant in the study reiterated that outliving their child would probably be the ideal. The findings of this study identify the extreme pressures ageing caregivers are under and the psychological burden of ageing with a caregiving responsibility.
5.5 Limitations of the Study

This study contributes to current knowledge by exploring ageing carers experiences of future planning for their adult family member with an intellectual disability living at home. However, there are some limitations to the study. Despite the contribution of this study, the findings are limited by the small sample size. Although the small size is acceptable for an interpretative phenomenological study, the views and perceptions of those claimed cannot claim to be representative of all ageing carers caring for a child with an intellectual disability at home. However, it is noteworthy to mention that an in depth semi-structured type interview was conducted therefore generating rich data within the small sample.

Participants were from one region in the republic of Ireland, thus limiting the study further. Furthermore, participants were all connected to a service which may influence their experiences. Moreover, the author of this study was a novice researcher, however the researcher was aware of this limitation and took the necessary steps to fulfil the aims and objectives of this study to the best of the researcher’s ability. The researcher conducted a pilot study to gain experience in conducting interviews, become immersed with the data and develop a familiarity with Burnard’s (2011) framework of data analysis. Furthermore, the researcher engaged in peer checking from her research supervisors.

Findings from the study provide a snapshot in time. To provide more representative views, the study population would need to be expanded to include a larger sample size from more than one location in Ireland and which was not limited to a sample already in receipt of services. Furthermore, the inclusion of perspectives from services and service professionals specifically designed and trained to meet the needs of people with intellectual disabilities and their families would offer a broader viewpoint. Moreover, it would be interesting to include the perspectives of ageing adults with intellectual disabilities themselves. This interpretative phenomenological study was a starting point but more work would be needed to facilitate a greater understanding of ageing carers experiences in future planning for their adult family member with an intellectual disability.
5.6 Chapter Summary

In this study, ageing carers perceptions of their experiences of future planning for their adult family member with an intellectual disability were shared. For the most part, the findings of this study support current literature regarding ageing carers experiences of future planning for their adult family member with an intellectual disability.

- The key findings identified in this study were:
  - Carers are very concerned about what will happen to their family member with an intellectual disability when they are no longer able to care for them.
  - Carers had not envisaged caring for a prolonged period of time resulting in later life planning and in some cases no plans at all.
  - 50% of carers had not made future plans or were unwilling to make future plans. 30% of participants had identified securing alternative accommodation options and remaining participants had identified future plans but when were discussed further some plans appeared to be aspirational.
  - Carers disillusion with accessing services and information was identified.
  - Carers reported a lack of trust in formal services.
  - Inappropriate limited service provision and assistance was reported.
  - The study identified ageing carer’s physical and emotional issues.
  - The study identified a lack or absence of respite options available to participants in the study.
  - Participants reported feeling pressurized to take inappropriate least preferred accommodation/service options.
  - Compound caregiving is a growing concern.
  - There is a need for information and resources on future planning, participants identified that it had been the first time they had been approached on the subject of future planning.
Participants reported the guilt on depending on informal supports from family members, non-disabled siblings and feared relying on them to take on the caring role of their sibling with an intellectual disability.

This chapter discussed the study findings in relation to national and international literature, the discussion was presented under the four themes that emerged during data analysis; *a life not foreseen, bearing the cross, reaching a decision and nearing the end*. The knowledge that emerged from this study will contribute to providing information to highlight areas of need among ageing carers at home caring for their adult family member with a disability which will in turn will provide guidance to services and government departments that are in charge of service delivery on the key areas that need to be addressed and reformed. In chapter six, a summary of the significant findings of the study and recommendations based on the research findings are presented.
Chapter 6: Recommendations and Conclusion
Chapter 6: Recommendations and Conclusion

6.0 Introduction

Globally ageing has been described as ‘a new public health threat’ (WHO, 2016). Increased childhood survival of people with complex physical needs, health and medical technology advances, greater recognition and diagnosis of autism and increasing life expectancy of the world’s population have all contributed to advances and growth in the population of people with intellectual disability nationally and internationally.

Today, the majority of ageing adults with an intellectual disability in Ireland are being cared for by their ageing family members at home. This changing profile has major implications for service planning; it points to an enduring high level of demand for full-time residential services, the need for support services for ageing caregivers, and services designed specifically to meet the needs of older people with intellectual disability (National Intellectual Database Annual Report 2016; Taggart et al 2012).

6.1 Significant Findings of the study

The findings demonstrated that the most significant concern for ageing carers of adults with an intellectual disability is in relation to their concern of what is going to happen to their family member with an intellectual disability when they age beyond their caregiving capacity, through ill health or death. Despite these concerns, 50% of carers had not made future plans or were unwilling to make future plans which points to an enduring high level of carers at risk of falling into the likelihood of a crisis situation occurring as previously supported by other research, (Taggart et al 2012; Bowey and McGlaughlin 2009).

The study highlighted some factors that contribute to carer’s lack of desire to future plan including a perceived lower care giving burden as a result of the presence of two carers and a shared caring role. Some carers felt a reduced sense of need to change when they perceived themselves to be in relatively good health and managing well. The presence of a mutually supportive relationship between the caregiver and the adult child with a disability appears to
have affected some participants willingness to future plan as they are identified as being content in their homes. Furthermore, a lack of trust in others or services in transferring the responsibility of their family member over to them proves difficult from some carers and has been identified as a contributory factor to a lack of desire to future plan.

Moreover, carer’s that have engaged or attempted to future plan have expressed negative experiences in trying to locate help, guidance and support from formal support. Their experiences for the most part was negative with describing the barriers and constraints they experienced with trying to secure appropriate accommodation offers and services including timeframes, waiting lists, inappropriate service options, location boundaries, rules and regulations. Furthermore, they described a lack of continuity of care from service professionals, the challenge of locating a point of contact to access support, response rates, lack of understanding and offices that place you on hold and take you name to get back to you.

Furthermore, the study found that attempting to make plans with family members proved to be just as difficult for many reasons. There was an increased sense of guilt for carers on passing over the caregiving burden to family members in particular other children with caregivers been torn between with the responsibility to protect their family member from experiencing the caregiving burden to the responsibility of ensuring that their family member with a disability was protected and looked after. In some cases, carers feared other family member’s acceptance to take on the role and feared their change of mind due to their other challenges and commitments in their life. Carers identified having to thread carefully with family members, fear of saying the wrong thing resulting in sometimes avoiding the situation and basing their future plans on hope.

This study highlighted that the extent of future planning that ageing carers engaged in varied among participants with some participants identifying an agreed plan, a plan in process, no plan yet but a desire to start planning or lastly a reluctance to plan. However, one similarity across all participants was the lack of a method in approaching future planning. One participant expressed a desire for a guide or a future planning framework that would assist them in planning for the
future and create an awareness as to steps they should be thinking of taking before it gets too late.

In this study participants expressed their views about their experiences of future planning and it was apparent that engaging in future planning was promoted by certain factors including carers own present and personal circumstances including their ability to continue caring mentally and physically, guidance from service professionals, accessibility to services and family involvement, however It was noteworthy to mention the importance of peer support in this listening to other people’s stories and experiences in similar circumstances. This source of support has not been identified in previous studies.

In this study all participants were in receipt of a day service for their family member with an intellectual disability. For the most part, participants expressed positive views about the service they were receiving and the positive impact it was having on their own life as well as their adult family member with an intellectual disability. Despite these carers having frontline access to services that are equipped with supporting people with intellectual disabilities, participants still for the most part identified a lack of support in approaching future planning and there appears to be no direct link between availing of this service and it is having a positive impact on their level of future planning suggesting that services may neither be equipped to support ageing carers in planning for the future and may be worth investigating.

Findings from this study indicate a lack of services for adults with an intellectual disability in Ireland. There appeared to be a common perception among ageing carers of a feeling of neglect and a reduction in the level of continuity of care they were in receipt of from service professionals and primary care team when their family member with an intellectual disability reached adulthood at the age of 18. Carers identified a responsibility on themselves to seek alternative training, employment and education opportunities to help transition their family member into adulthood and from then on accepted full personal responsibility for their family members future.
In this study participants identified the challenges for carers who chose to care for their family member at home and whom now were ready to seek help. Carers identified the beurocracy, location boundaries and obstacles that prevented them from securing services and support. There was a common preconception that the quality and suitability of services available were not geared towards assisting carers who were caring for their adult family member at home. Carers felt unsupported in their homes with their family member with an intellectual disability. Moreover, participants identified a lack of awareness in the process involved in trying to secure alternative accommodation highlighting the extent of timeframes and the lengthy waiting lists that were involved when they attempted to look at alternative housing and accommodation options.

6.2 Recommendations

Based on the finding of this study and supporting previous literature, the following recommendations for education, research, policy and service provision are suggested.

6.2.1 Education

This study reported that ageing carers felt a lack of awareness in relation to engaging in future planning. Participants required guidance or reassurance of the necessary steps to take when trying to prepare for the future. A permissible, supportive interactive strategy is recommended in the republic of Ireland. The development of workshops that provide a positive environment for ageing carers to learn and explore the concept of future planning would be beneficial. Workshops would enhance ageing carers understanding of future planning and provide them with the confidence to be able to take necessary steps in achieving plan preferences. Liaison with professionals that are experienced in dealing with ageing carers and future planning options could provide information to carers empowering them to explore their own future plan, identify circles of support, engage in person centred planning, create emergency plans, offer guidance in signposting housing and support options, promote making sound financial and legal decisions, and moreover support a family carer to make a future plan. Moreover, these types of workshops would encourage ageing carers to have a greater societal participation with ageing carers in
similar circumstances which would furthermore broaden their network of support and provide an opportunity for carers to support each other in an interactive environment.

Considering the findings of an absence of guidance and support from service professionals, it is recommended that there is a need to address the role of service professionals in relation to supporting ageing carers caring for their adult family member with a disability in the community to plan for the future. There is a need for a skilled professional to conduct assessment with ageing caregivers and their family member with an intellectual disability, to implement a person centred plan, to ensure there is a continuity of care and frequent level of engagement and to proactively engage through the lifespan to ensure that carers are supported and have a future plan in place that has been co-ordinated in conjunction with support from the service professional. To do this their needs to be a role re-evaluation and a directive of responsibility to be assigned to existing service professionals or the creation of a purposeful job vacancy to be responsible. Moreover, professionals need to be supported to do this so education in relation to future planning practices needs to be addressed with service professionals requiring training and guidance themselves. The development of postgraduate training courses in relation to supporting ageing caregivers and their adult family member with an intellectual disability would be recommended.

The following recommendations are made;

- Development of Workshops to discuss relevant topics including future planning for ageing carers.
- Organised peer group meetings to encourage ageing carers to have support with carers in similar circumstances where experiences can be shared.
- Professional Role Evaluation and Acceptance of Responsibility within Disability and Health Care Services.
- Early intervention and Continuous planning regarding the future.
- Postgraduate Training in Supporting Ageing Carers and their Family members with an Intellectual Disability.
6.2.2 Research

This study works as a launching place for further research and brings up additional questions regarding these family carers, the services that are designed to serve them, and a system that is supposed to prepare them.

Additional research will continue to benefit and support ageing carers who are caring for their adult family member at home with an intellectual disability. Exploring these issues further may be handled in the following ways:

It is suggested that further research that examines current services in Ireland that are providing care to adults with an intellectual disability be conducted. It is recommended that an exploration be completed on the range of options and services available to families and their family member with a disability and investigate their current approaches in terms of providing assistance and guidance with future planning.

Further research is warranted on the role of professionals that are working closely with this group of carers in the community including public health nurses, doctors and primary care team. Exploring the perceptions of service professionals in relation to their roles, approach and experiences of providing support to ageing family carers caring for their family member with an intellectual disability would help to create an understanding of where services could develop in order to better facilitate ageing family carers caring for their family member with an intellectual disability at home.

The following recommendations are made:

- Examine current roles of disability services in Ireland in relation to providing care to ageing people with a disability and their ageing carers.
- Examine views of working professional in relation to their own personal roles and their experiences in providing care to ageing people with a disability and their ageing carers.
6.2.3 Policy and Practice

In this study participants reported a lack of guidance and support living at home caring for their adult family member with an intellectual disability. Community based health and social care professionals need to engage more with carers and provide the necessary supports. There is a required need for an assigned role to community professionals to engage with ageing carers and their adult family member with an intellectual disability. Service providers and policies need to acknowledge and recognise that families have diverse needs and one size does not fit all. Compound Caregivers have unique caregiving circumstances and all caregivers should be assessed individually and the provision of services to be allocated individually. The development of frameworks to help provide guidance to ageing carers and aid professionals to co-ordinate care is recommended. In-home supports such as home-based respite, home based therapies, and home help would assist ageing carers to continue caring for their adult family member in their home for as long as possible and promote positive ageing among carers.

Caring for an adult with an intellectual disability has been identified in this study as having challenges particularly when carers have their ageing needs to contend with also. In the Republic of Ireland there is a required need for the establishment of a policy that is primarily dedicated to supporting ageing carers caring for a person with an intellectual disability living at home in their communities. Much of the policy available with reference to the republic of Ireland is limited and directed towards Northern Ireland and Great Britain. Policy in the republic of Ireland has not completed a combined report on the needs of ageing adults with a disability and their ageing carers. There is a required need for a strategic development in service design in the Republic of Ireland from our National Health Service.

The following recommendations are made:

- Service reform – role evaluation and designated person’s responsible
- A development of community based care and supports that can be provided in homes of ageing carers and their family member with a disability, i.e., respite, etc,
• A person centred, community model of care, that evolves around the person and their current circumstances.
• Development of evidence based frameworks for future planning.
• Republic of Ireland specific Strategic Plan.

6.3 Researcher Reflexivity

When this inquiry first began, the researcher was heavily influenced by her prior experiences in working with people with intellectual disabilities and their families. These experiences and somewhat rudimentary understanding of ageing carers experiences of caring for an adult family member with an intellectual disability were greatly altered through the course of the research process. This study has worked to enhance the researcher’s personal understanding of the future planning process. Moreover, it has identified the level of responsibility to the researcher that as a service professional she must keep up to date with relevant research and practice throughout her professional career to enable her to deliver care that is in association with service need and demands. In addition, the identification of these ageing carer’s experiences has prompted new thinking around the importance of research from service professional’s perspective into future planning for carers’ caring for their child with an intellectual disability at home. For example, the researcher identified a greater extent of future planning when a greater level of support and assistance was provided to carers’ in this study which is supportive with other current research in the area, (Davy’s and Haigh 2007). While the researcher identified that in the context of the study, support could be received from both internal, (family) and external, (services), sources, there appeared to be a more definitive plan across participants whereby there had been a link or input from services. One would question whether due to the nature of this emotive topic, carers’ may feel more content in discussing their views and experiences with personnel that are not directly linked to the phenomenon in question. Furthermore, as previously mentioned there is a strong stigma amongst this group of carers of wanting to avoid placing a perceived burden upon siblings which may give substance to this debate. The researcher feels it may be worth looking at how well service professionals are equipped to cope with providing information and guidance to
carers’ caring for their family member at home with a disability and looking in current practices that are been implemented in the Ireland of Ireland today to help this vulnerable group of carers that are not only ageing but caring. This has created a desire for the researcher to continue to build upon this research topic.

**6.4 Chapter Summary**

This interpretative phenomenological research study explored ageing carers experiences of future planning for their adult family members with an intellectual disability living at home. Semi-structured interviews were conducted with ten participants that were ageing aged 65 years + caring for their adult child with an intellectual disability at home. Data analysis was facilitated by utilising Burnard’s (2011) method of thematic content analysis, Participants voices and interpretations provided important research findings which were presented in four themes; *a life unforeseen, bearing the cross, reaching a decision and nearing the end*. These findings were discussed in relation to national and international literature and recommendations for education, research, policy and service provision were offered. Overall, this research highlighted the importance of support and guidance.
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Appendix A: Ethical Approval
Appendix A: Ethical Approval.

Dear Owen,

Thank you for your amended Research Ethics application which was recently reviewed by the Education and Health Sciences Research Ethics Committee. The recommendation of the Committee is outlined below:

**Project Title:** 2015_02_11_ EHS  Ageing family carers’ experiences of future planning for their adult family member with intellectual disability living at home.

**Principal Investigator:** Owen Doody

**Other Investigators:** Maureen O’Connor-Fenlon, Rebecca Cummins

**Recommendation:** Approved until February 2016.

Please note that as Principal Investigator of this project you are required to submit a Research Completion Report Form (attached) on completion of this research study.

Yours Sincerely,

Anne O’Brien

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Anne O’Brien

Administrator, Education & Health Sciences

Research Ethics Committee

Ollscoil Luimnigh / University of Limerick

Guthán / Phone +353 61 234101
Appendix B: Invitation Letter to Participants
Appendix B: Invitation letter to participants.

Invitation Letter to participants:

Rebecca Cummins,

Clonbrick,

Limerick Junction,

Co. Tipperary.

Research Study Title: Aging family carers experiences of future planning for their adult family member with an intellectual disability living at home.

Dear______________,

My name is Rebecca Cummins and I am writing to you to ask you if you would agree to become involved in a study I’m about to conduct. I am to investigate ageing carers future plans as they care for an adult family member with an intellectual disability at home. This area of study is of great importance as now ageing carers are caring for their loved ones longer than before as people with an intellectual disability are fortunately living longer. With this trend increasing carers are facing a challenge of their own ageing needs and for this reason I aim to investigate carers future plans as they age and continue to care for an adult family member with an intellectual disability. I would like to study your thoughts and feeling regarding future planning from your perspective. I feel this study will be of benefit in highlighting carers concerns, required
need, extent of plans and areas that need to develop with regard to provision of services and
funding for carers that are caring for an adult family member with a disability at home.

I am currently undertaking a Master’s research degree with the University of Limerick and as part
of that programme I am required to submit a research study. The purpose of my research study
is to investigate ageing family carers future plans as they continue to care for their family member
with an intellectual disability. My background is as an intellectual disability trained nurse and I
am currently working in the Health Service Executive as a staff nurse in the community. I believe
this study will be of great benefit to you and other families along with organisations and staff as
it will highlight a need for service provision.

For this study to take place I will need the participation of family carers who feel they would like
to contribute to this study. I hope you agree to take part in the study and if so would you please
return the enclosed reply slip, which indicates your interest to participate. A stamped addressed
envelope has been enclosed for your convenience. On receipt of this I will contact you in relation
to any questions that you may have. This study will be conducted through interviews conducted
by myself with the persons that respond. The interview will be audio-recorded and will take
approximately 45 minutes. Participation in this study is voluntary and confidential, and your
anonymity will be protected and maintained at all times. The intellectual disability services is
facilitating this study on my behalf by sending this invitation letter therefore no names or
addresses have been given to me in this process. On receipt of this letter you are under no
obligation to respond or participate but if you do decide to respond it is important that you are
aware that you can withdraw from the study at any time if you so wish. I would be grateful if you
would consider my request and return the reply slip to me so we can have a broader discussion
of what is involved.

Remember this study provides the opportunity for you to have your say, highlight your concerns,
identify the challenges you faced and that you are currently facing as a carer.

You are free to ask any questions about the study at any time, please do not hesitate to call or
contact me on the details below:
Email: rebecca.cummins@ul.ie

Or you can contact my supervisor: Dr Owen Doody

Email: owen.doody@ul.ie        phone no: 061-213367

I look forward to hearing from you,

Kindest regards,

____________________________

Rebecca Cummins
Appendix C: Participant Information Sheet

Information Sheet

Study Title: Ageing family carers experiences of future planning for their adult family member with an intellectual disability at home.

What is the purpose of the study – The study aims to identify ageing carers future plans as they age and continue to care for their family member with an intellectual disability.

Who is invited to participate – Ageing family carers aged 55+ that are caring for a family member with an intellectual disability at home. Before deciding whether or not to take part, it is important to understand what the research will involve. Please take time to read the following information carefully.

Do I have to take part - It is one’s own decision to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form and you would be free to withdraw at any time and without giving a reason.

What will happen if I decide to take part – Firstly you must return the reply slip in the stamped addressed envelope. Then I will contact you to outline the study and answer any questions you may have. After this you will have a further 5 days to consider all the information before I will contact you again to organize a date, time and venue that is convenient for you to be interviewed. The interview will last approximately 45 minutes and the will take place at a venue of your choice. The interview will be audio-recorded and you will sign a consent form.
What are the possible benefits of taking part – There may be no direct benefits of taking part in this study. At a broad sense this study will assist in identifying issues faced by ageing while continuing their caring role, the extent of future plans made and areas of improvement.

What will happen to what I say – All information collected will be kept strictly confidential. All information will be collected using an audio-recorder and the recording will be transferred onto a password protected computer and transcripts of the interview will be stored in a locked cabinet in the researcher’s office. All data generated during the research must be kept securely in paper or electronic form for a period of 5-10 years after the completion of a research project as per ethical approval.

What will happen the information gathered in the study – The information gathered in this study will form part of the researchers Master’s thesis to be submitted to the University of Limerick. It is envisaged that the information will also be disseminated through conference presentations or publications to contribute to the knowledge on ageing, carers and intellectual disability in Ireland. Individuals will not be identified in any publication or conference presentation used to disseminate the research findings.

Contact for Further Information –

Name: Rebecca Cummins  Email: rebecca.cummins@ul.ie

Or you can contact my supervisor Dr Owen Doody:

Email: owen.doody@ul.ie  Phone: 061-213367

Thank you for taking time to read the information sheet.

Signed: Date:

____________________________________________

Rebecca Cummins
Appendix D: Informed Consent Form
Appendix D: Informed Consent Form

Informed Consent form:

RESEARCH TITLE: Ageing Family Carers experiences of future planning for their adult family member with an intellectual disability living at home.

Having read the invitation letter, information sheet and after having general discussions with the researcher for the organisation of this interview. I fully understand the nature and purpose of this study. I am willing to participate in this study, with the knowledge that confidentiality and anonymity will be maintained and that I can withdraw from the study at any time should I wish to do so.

The researcher pledges her assurance that confidentiality will be assured at all times throughout the research process. Pseudo names will be used in text when transcribing the interview and where quotes are to be used masking will occur.

I hereby give permission to be interviewed and for these interviews to be recorded through the cause of an audio audio-recorded and note taking.

Name: _______________________   Researcher Name: ____________________
Address: _____________________   Address: _____________________

_____________________________   _____________________________

Phone Number: _________________  Phone Number: _________________

Email address: __________________  Email address: __________________

Date: _______________    Date: _______________

Two copies to be signed by both participant and the researcher and a signed copy to be kept by both participant and researcher.
Appendix E: Interview Guide

RESEARCH TITLE: Ageing family carers experiences of future planning caring for their adult family member with an intellectual disability at home.

Interview:

Introduction

Good afternoon. My name is Rebecca Cummins and I would like to thank you for agreeing to be part of this study, which will involve a relaxed discussion where you feel comfortable saying what you think and feel on the topic of future planning. The purpose is to gain your perceptions/experience/views of planning for the future as you and the person you care for age together. My role is to facilitate the discussion and not give my opinions as it is your perceptions/experience/views that matter and there are no right/wrong, desirable/undesirable answers.

Discuss procedure

I will take notes and audio-record the discussion so that I do not miss anything you have to say. This is so that I can get all the details but at the same time be able to carry on an attentive conversation with you. I assure you confidentiality with regards your comments and I will be
compiling a report, which will contain an analysed version of all the interviewees comments without reference to any individual. The discussion will last approximately xx minutes. It is ok to refer to each other by name, as this will be edited out during transcription.

**Interview**

I’m now going to ask you some questions that I would like you to answer to the best of your ability.

**Interview Guide**

General questions to relax the participant

- How many are in the family?
- How long have you been caring for you son/daughter?
- What age are you?
- Topic questions
- Extent of future plans made?
- What has helped/hindered you in making future plans or what would help/facilitate you in making future plans?

Closing question

- Is there any other information regarding your experience that you think would be useful for me to know?
- Participant’s responses to the questions will be probed.

**Closure**

Thank you very much for agreeing to this interview, your time is very much appreciated and your comments have been very helpful.
Participants will be asked to sign consent form and will be informed of what will occur at the next stage of the research process (data analysis, expected time of results and offer a copy of the results).

**Notes post interview**

- Any other observations of interest.
Appendix F: Reply Slip

Research Study: Ageing family carers experiences of future planning for their adult family member with intellectual disability living at home.

I am interested in your research study and I would like to find out more about what is involved. My contact details are (please give details of whatever means of communication is most suitable and preferable to you).

Name:

________________________________________________________

Preferred means of contact:

________________________________________________________

My preferred times of contact are:

________________________________________________________

All correspondence can be sent to this address:

________________________________________________________
Appendix G: Storage of Information
Appendix G: Storage of Information

STORAGE OF INFORMATION

For the purpose of this study, all confidential information will be stored securely. An identity number will be produced for each participant so the data can be anonymized and will be distinguished via this identity number. The only exception is one document which contains participant’s personal information (reply slip).

Data will be managed in the following way:

1. The researcher will store the document bearing confidential, private information in a locked cabinet with access strictly restricted to personnel working on the study.
2. All computerised data/information will be stored on a password restricted computer that only the researcher has access to.
3. The researcher responsible for the project will be the only person with access to the data/information generated by the study.
4. All computerised data/information collected will be anonymised by using identity number for the participants.
5. The data/information will be stored for the duration of the study i.e. until the work is fully reported and disseminated. It will then be stored in a locked cabinet for 7 years after the study has been completed after which will be discarded appropriately.
6. All electronic files will be stored on password protected USB.
Appendix H: Data Analysis, Themes, Subthemes and Codes
Appendix H: Data Analysis, Themes, Subthemes and Codes.
Appendix I: Caldwell et al 2005 tool.
Appendix I: Caldwell et al 2005 tool.

A generic tool for Appraising research papers—developed by Caldwell et al (2005)

**Does the title reflect the content?**
- Are the authors credible?
- Does the abstract summarise the key components?
- Is the rationale for undertaking the research clearly outlined?
- Is the literature review comprehensive and up-to-date?
- Is the aim of the research clearly stated?
- Are all ethical issues identified and addressed?
- Is the methodology identified and justified?

**QUANTITATIVE**
- Is the study design clearly identified, and is the rationale for choice of design evident?
- Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?
- Is the population identified?
- Is the sample adequately described and reflective of the population?
- Is the method of data collection valid and reliable?

**QUALITATIVE**
- Are the results presented in a way that is appropriate and clear?
- Is the discussion comprehensive?
- Is the conclusion comprehensive?
- Are the results transferable?

**References:**
Introduction

The electronic age has increased the accessibility of information to everyone, whether they are professionals delivering the service or discerning consumers accessing those services. Unfortunately this accessibility often results in the individual being overwhelmed by the amount of information available to them. In addition the quality of some of this information can be questionable. The ability to search, select and then critically appraise the literature is a core skill for all individuals wishing to base their practice on best evidence.

Critical evaluation, appraisal or critique is the ability to analyse the strengths and weaknesses of something. In this instance it is the appraisal of 'the literature or evidence'. Although much of the published material is peer reviewed prior to appearing in a journal, and therefore has met a certain standard, it is still good practice to complete your own evaluation. This will help you to identify the limitations of the paper as well as consider how the ideas presented apply to your practice.

There are different types of literature available derived from different sources. Broadly the literature can be categorized into:

1. Clinical guidelines
2. Systematic reviews
3. Research studies
4. Internet articles
5. Non-research articles

Critical appraisal—how to do it....

It can take 1-2 hours to critically appraise a paper and in some cases a little longer. The first thing you need to ask yourself is what type of paper are you reading. This will dictate the type of appraisal tool you will need to use to perform the critique.

Here are the URLs of some websites where you can obtain critical appraisal tools free of charge:

www.casp-uk.net
www.sign.ac.uk/methodology/checklists.html
http://nettingtheevidence.pbworks.com/w/page/11403006/Critical%20Appraisal%20Checklists

In addition the following site provides access to a comprehensive tutorial on critiquing Internet resources:

http://www.vstutorials.ac.uk/detective/who.html

The SIGN checklists are particularly useful in that they each have an annex explaining what to look for when appraising each section of the paper. It is also worthwhile obtaining a research textbook with a glossary to help you make sense of any research studies you are evaluating.

In addition to this, the following website provides a series of papers to help you to read the different types of literature you are likely to come across:

http://resources.bmj.com/bmj/readers/how-to-read-a-paper/
Appendix J: CASP TOOL
Appendix J: CASP TOOL

CASP Checklist: 10 questions to help you make sense of a Systematic Review

How to use this appraisal tool: Three broad issues need to be considered when appraising a systematic review study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.


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Critical Appraisal Skills Programme (CASP) part of Better Value Healthcare Ltd www.casp-uk.net
Section A: Are the results of the review valid?

1. Did the review address a clearly focused question?
   - Yes
   - Can’t Tell
   - No
   **HINT:** An issue can be ‘focused’ in terms of
   - the population studied
   - the intervention given
   - the outcome considered

   **Comments:**

2. Did the authors look for the right type of papers?
   - Yes
   - Can’t Tell
   - No
   **HINT:** ‘The best sort of studies’ would
   - address the review’s question
   - have an appropriate study design
     (usually RCTs for papers evaluating interventions)

   **Comments:**

Is it worth continuing?

3. Do you think all the important, relevant studies were included?
   - Yes
   - Can’t Tell
   - No
   **HINT:** Look for
   - which bibliographic databases were used
   - follow up from reference lists
   - personal contact with experts
   - unpublished as well as published studies
   - non-English language studies

   **Comments:**
4. Did the review’s authors do enough to assess quality of the included studies?

   Yes  
   Can’t Tell  
   No  

HINT: The authors need to consider the rigour of the studies they have identified. Lack of rigour may affect the studies’ results ("All that glitters is not gold" Merchant of Venice – Act II Scene 7)

Comments:

5. If the results of the review have been combined, was it reasonable to do so?

   Yes  
   Can’t Tell  
   No  

HINT: Consider whether
   - results were similar from study to study
   - results of all the included studies are clearly displayed
   - results of different studies are similar
   - reasons for any variations in results are discussed

Comments:

Section 8: What are the results?

6. What are the overall results of the review?

   HINT: Consider
   - If you are clear about the review’s ‘bottom line’ results
   - what these are (numerically if appropriate)
   - how were the results expressed (NNT, odds ratio etc.)

Comments:
7. How precise are the results?

HINT: Look at the confidence intervals, if given.

Comments:

Section C: Will the results help locally?

8. Can the results be applied to the local population?

   Yes   Can’t Tell   No

HINT: Consider whether
   • the patients covered by the review could be sufficiently different to your population to cause concern
   • your local setting is likely to differ much from that of the review.

Comments:

9. Were all important outcomes considered?

   Yes   Can’t Tell   No

HINT: Consider whether
   • there is other information you would like to have seen.

Comments:

10. Are the benefits worth the harms and costs?

   Yes   Can’t Tell   No

HINT: Consider
   • even if this is not addressed by the review, what do you think?

Comments:
Appendix k: Data Extraction Table of Articles

Included in Literature Review
<table>
<thead>
<tr>
<th>Author, Title, Year</th>
<th>Aim of the study</th>
<th>Sample</th>
<th>Design</th>
<th>Methods (Data collection, Data analysis)</th>
<th>Major Findings</th>
<th>Country</th>
<th>Limitations</th>
<th>Quality score &amp; Tool used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowey, L. &amp; McGlaughlin, A. (2007)</td>
<td>Older carers of adults with a learning disability confront the future: Issues and preferences in planning.</td>
<td>62 families, older carers aged 70+.</td>
<td>Mixed method</td>
<td>Qualitative data: Interviews with 56 older carers (aged over 70) of adults with ID. Quantitative data: 6 more completed a survey. SPSS Nvivo coding thematic was identified as data analysis method used.</td>
<td>Carers not willing or ready to make future plans. Perceived lack of need due to existence of two carers. Lack of awareness of timescales involved in securing housing, difficulties in letting go, a lack of confidence in housing options. Existence of mutually supportive relationships. Reliance on family members to continue caring.</td>
<td>United Kingdom</td>
<td>Only those known to services were identified as part of the sample, families’ unknown to formal services were excluded. Few families did take part that were known to agencies but are not active users of their services. 36 declined to participate creating a possibility of biased results.</td>
<td>CASP High</td>
</tr>
<tr>
<td>Bibby, R. (2013)</td>
<td>&quot;I hope he goes first&quot;: Exploring determinants of engagement in future planning for adults with a learning disability living with ageing parents. What are the issues? A literature Review.</td>
<td>16 papers were reviewed. Inclusion criteria: future planning &amp; learning disability and older carers &amp; the future. Barriers to planning rather than the nature of planning. Perspectives of adults with a learning disability living with older parents. What are the issues? A literature Review.</td>
<td>Systematic review</td>
<td>12 databases were identified as having a health and social care focus: Applied Social Sciences Index and Abstracts (CSA); Care Knowledge; Child Data; Health and Psychosocial Instruments (Ovid); Intute Social Sciences; NHS Evidence; Ovid Online; Lack of confidence in present and future provision 11 Analysis of the papers identified 10 factors which have a detrimental effect on the engagement in future planning for people with a learning disability living with older parents. Difficult relationship with professionals, Mutual care/interdependency, Lack of information, Painful/difficult subject,</td>
<td>United Kingdom</td>
<td>CASP Medium</td>
<td>All carers were white.</td>
<td></td>
</tr>
<tr>
<td>Authors</td>
<td>Study Title</td>
<td>Year</td>
<td>Study Design</td>
<td>Data Collection Methodology</td>
<td>Participants</td>
<td>Findings</td>
<td>Country</td>
<td>Notes</td>
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<td>-----------------------------------------------------------------------</td>
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<tr>
<td>Cairns, D. &amp; Tolson, D. &amp; Darbyshire, C. &amp; Brown, J. (2012)</td>
<td>The need for future alternatives: an investigation of the experiences and future of 8 parent carers aged between 65-89 years old</td>
<td>2012</td>
<td>Qualitative</td>
<td>In depth semi-structured Interviews (n=8). Constructivist methodology used.</td>
<td>Parents lacked support. Lack of information. Some parents continued caregiving despite poor mental/physical health. All parents were concerned with their child’s future.</td>
<td>United Kingdom</td>
<td>A purposive approach was used, sample utilised were extreme cases &amp; either positive or negative. Cannot be generalised to be representative of all older parent carers.</td>
<td></td>
</tr>
</tbody>
</table>

(disability and/or their ageing carers)
| Chou, Y.C., Lee, Y.C., Lin, L.C., Kroger, T. & Chang, A.N. (2009) | Older and younger family caregivers of adults with intellectual disability: factors associated | Grounded theory was utilised as data analysis method. | Taiwan | Cross-sectional study & cannot reveal cause and effect relationships; thus, the results cannot show the direction of any association between the predictive and

| Chou, Y.C., Lee, Y.C., Lin, L.C., Kroger, T. & Chang, A.N. (2009) | Older and younger family caregivers of adults with intellectual disability: factors associated | Quantitative Cross sectional. | Taiwan | Cross-sectional study & cannot reveal cause and effect relationships; thus, the results cannot show the direction of any association between the predictive and

| Chou, Y.C., Lee, Y.C., Lin, L.C., Kroger, T. & Chang, A.N. (2009) | Older and younger family caregivers of adults with intellectual disability: factors associated | Survey. Interviews Data analysis consisted of chi-square tests, correlational tests. | Taiwan | Cross-sectional study & cannot reveal cause and effect relationships; thus, the results cannot show the direction of any association between the predictive and

| Chou, Y.C., Lee, Y.C., Lin, L.C., Kroger, T. & Chang, A.N. (2009) | Older and younger family caregivers of adults with intellectual disability: factors associated | The results indicate that the most disadvantaged group is the one made of caregivers who are old in this study, whom have a lower health status and have a lower level of social support. | Taiwan | Cross-sectional study & cannot reveal cause and effect relationships; thus, the results cannot show the direction of any association between the predictive and

| Chou, Y.C., Lee, Y.C., Lin, L.C., Kroger, T. & Chang, A.N. (2009) | Older and younger family caregivers of adults with intellectual disability: factors associated | Carers of offspring with learning disabilities. The failure to include the perspective of the offspring with ID and of health and social care professionals can be seen as an important omission. | Taiwan | Cross-sectional study & cannot reveal cause and effect relationships; thus, the results cannot show the direction of any association between the predictive and

| Chou, Y.C., Lee, Y.C., Lin, L.C., Kroger, T. & Chang, A.N. (2009) | Older and younger family caregivers of adults with intellectual disability: factors associated | Carers of offspring with learning disabilities. The failure to include the perspective of the offspring with ID and of health and social care professionals can be seen as an important omission. | Taiwan | Cross-sectional study & cannot reveal cause and effect relationships; thus, the results cannot show the direction of any association between the predictive and

| Chou, Y.C., Lee, Y.C., Lin, L.C., Kroger, T. & Chang, A.N. (2009) | Older and younger family caregivers of adults with intellectual disability: factors associated | Carers of offspring with learning disabilities. The failure to include the perspective of the offspring with ID and of health and social care professionals can be seen as an important omission. | Taiwan | Cross-sectional study & cannot reveal cause and effect relationships; thus, the results cannot show the direction of any association between the predictive and

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| Chou, Y.C., Lee, Y.C., Lin, L.C., Kroger, T. & Chang, A.N. (2009) | Older and younger family caregivers of adults with intellectual disability: factors associated | Carers of offspring with learning disabilities. The failure to include the perspective of the offspring with ID and of health and social care professionals can be seen as an important omission. | Taiwan | Cross-sectional study & cannot reveal cause and effect relationships; thus, the results cannot show the direction of any association between the predictive and
with future plans.

Older family caregivers are reported to be counting on themselves for their future care plans for their family member with an intellectual disability. Predisposing factors. Secondly the participants were recruited from just one local government in Taiwan. Thirdly, data was not obtained regarding a number of predisposing factors such as behavioural problems, etc. Fourth, a lack of theoretical framework. Lastly, validity of the instrument scale used to measure perception was used in 1991.
Davys, S. & Haigh, C. (2007) Older parents of people who have a learning disability: perceptions of future accommodation needs. Qualitative Semi structured interviews Data Analysis: content analysis Dissatisfaction with services was the primary theme with the study reporting carers anger at service providers, a sense of having to fight for everything you want, lack of trust, conflict and a lack of quality and suitability. Sibling issues was another issue reported in the study and reported siblings need to have their own lives outside of caregiving but also to have ongoing involvement in the lives of their family member with an intellectual disability. United Kingdom Limitations included: Small group/sample which cannot be considered as generalizable to the general population. All participants were from a white English ethnic background. All interviewees had a partner. Caldwell et al 2005 Medium
Financial issues remained a big concern for carers in this study identifying the financial cost with having to pay for services and the cost of equipment and supplies for the family home.

The difficulty of being a parent to a person who has a learning disability including the physical and mental strain was identified.

Providing support at home for as long as possible was another main finding in the study,
parents wanted to maintain their current situation of caregiving for as long as possible. Finally, awareness of their own ageing was reported.

<p>| Dillenburge r, K. &amp; McKerr (2009) | 40 years is an awful long time: parents caring for adult sons and daughters with disabilities. | 29 parents and carers Average age of 65.17 years living in northern | Mixed methods | Flexible and open-ended interviews. Questionnaire. Interpretative phenomenological analysis. Theoretical framework-behavioural analysis. | A complex network of relationships. Virtual absence of structured future planning. Recommendations are made for professionals working in the field. The study offers a pathway for reform and modernisation. | N. Ireland | Cannot be generalised to be representative of all older parent carers of offspring with learning disabilities. The failure to include the perspective of the offspring with ID and of health and social care professionals can | CASP Medium |
| Dillenburge, K. &amp; McKerr, L. (2010) | How long are we able to go on? Issues faced by older family caregivers of adults with disabilities. | 29 caregivers Aged 65+. | Mixed methods | Semi-structured interviews Interpretative phenomenological analysis. | Issues faced by older family members were identified. A new theoretical approach is necessary to help parents who care for their sons/daughters with disability now and in the future. A need for support nets that are set up at the earliest opportunity to ensure early proactive planning is recommended. | N. Ireland | Cannot be generalised to be representative of all older parent carers of offspring with learning disabilities. The failure to include the perspective of the offspring with ID and of health and social care professionals can be seen as an important omission. | CASP Medium |</p>
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Title</th>
<th>Sample Description</th>
<th>Data Collection Method</th>
<th>Data Analysis</th>
<th>Findings</th>
<th>Setting</th>
<th>Limitations</th>
<th>Methodological Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gilbert, A. &amp; Lanksheer, G. &amp; Petersen, A. (2007)</td>
<td>Older family carers views on the future accommodation needs of relatives who have an intellectual disability.</td>
<td>28 carers Aged 65+ years from a city council in Plymouth, UK.</td>
<td>qualitative Interviews</td>
<td>Thematic analysis</td>
<td>A required need for information about housing options, a lack of practical support and feelings of marginalization.</td>
<td>United Kingdom</td>
<td>Did not include in the design the views of people with an intellectual disability alongside their family carer.</td>
<td>Calwell et al 2005 High</td>
</tr>
<tr>
<td>Grey, J.M., Griffith, G.M., Totsika, V. &amp; Hastings, R.P. (2015)</td>
<td>Families experiences of seeking out of home accommodation for their adult child with an intellectual disability.</td>
<td>9 carers Mean age = 57.2 years</td>
<td>qualitative Semi-structured interviews</td>
<td>Braun and Clarke Thematic Analysis</td>
<td>Families experienced seeking out of home housing stressful and frustrating and would like to see social care housing professionals acknowledge them as a collaborative partner in the process.</td>
<td>United Kingdom</td>
<td>Small sample of participants utilised making it difficult to know to what extent these findings can be generalized to a wider population of families of adults with an ID.</td>
<td>Caldwell et al 2005 Medium</td>
</tr>
</tbody>
</table>
Targeted sample was at families that were at the advanced stages of planning processes and all desired an out-of-home-move and therefore a lack of success in acquiring a placement may be why families were critical of the housing system.

Member checking or participant verification was not conducted as part of quality control and data verification.
| Heller, T. & Caldwell, J. (2006) | Supporting ageing caregivers and adults with developmental disabilities in future planning. | 48 caregivers | Mean age = 63 years old | quantitative | Focus groups/workshops | A peer supported intervention was developed to support ageing caregivers and adults with developmental disabilities in planning for the future. The intervention consisted of a legal/financial training session and pre-test and 1 year follow up surveys. Findings reported that the intervention significantly contributed to families completing letters of intent, taking action on residential planning, and developing a special letter of intent. | Perspectives of individuals with intellectual disabilities were not directly studied with caregivers rating the degree of choice making. Potential sampling bias with regard to the recruitment of the control group, initially individuals were randomly assigned to the intervention and control groups, however due to difficulty recruiting the sample from Caldwell et al 2005. | Medium |
needs trust. Caregiving burden decreased for families in the intervention and daily choice making of individuals with disabilities increased. Within the same agency, different agencies were randomly selected for either participation in the intervention or control.

| Hole, R.D., Stainton, T. & Wilson, L. (2012) | Ageing adults with intellectual disabilities: self-advocates and family members’ perspectives about the future. | 11 family members aged 50+ years in British Columbia, Canada. | Qualitative Semi-structured interviews. Braun and Clarke Thematic Analysis. | Family members concerns for the future centred on ensuring the future security of their loved one with an intellectual disability, addressing legal issues and financial security, and promoting future choice and self-determination. The results pointed to the importance of early and within the same agency, different agencies were randomly selected for either participation in the intervention or control. | Canada The findings cannot be generalized due to the geographic location of the study. Small sample. | Caldwell et al 2005 High |
| Iacono, T., Evans, E., Davis, A., Bhardwaj, A., Turner, B., Torr, J. & Trollor, J.N. (2016) | Family caring of older adults with intellectual disability and coping according to loci of responsibility. | 19 carers Mean age = 71 years | Mixed methods | Quantitative data: Surveys (n=13) Qualitative data: Focus groups (n=19) Data analysis: interpretative phenomenological analysis. | Carers varied in their health and wellbeing. Four overarching themes emerged from the initial interpretative phenomenological analysis of the qualitative data: loci of responsibility, impacts of caring and responses to it on health and wellbeing, transitioning care responsibilities and | Australia Findings may reflect possible patterns only, given they were from focus groups occurring at one time only, without the opportunity for member checking following data analysis. | CASP Medium |
interrelationships around the caring role. Further interrogation of the data according to carers coping strategies revealed three loci of responsibility, providing a point of convergence that related to carer experiences, plans for transition, and relationships within families. These loci of responsibility were having sole responsibility because no-one else could do it better, and sharing responsibility. The loci of responsibility provided a means to
| Knox, M. & Bigby, C. (2007) | Moving towards midlife Care as Negotiated Family Business: Accounts of People with Intellectual Disabilities and their families, “just getting along with 7 families aged between 35-55 in metropolitan Melbourne Australia. | Qualitative | Symbolic interactionism, underpinned by social constructionism theory. Data Analysis: In depth interviews Qualitative data analysis | Participants described care as simply getting on with their lives as @family Business’, characterized by well understood tasks and routines. Family business was underpinned by negotiated, albeit, often implicit, rules that often-reflected family values and were amenable to changes in circumstances. | Australia | Small sample study which limits any ability to make generalisations about families with a middle-aged member with an intellectual disability and has limited experience of more generalized family support or case management programmes. | Calswell et al 2005 | High |
their lives together”.

Future planning was perceived as a sensitive whole family issue. Interdependence among member was key to retaining family independence from formal services that were regarded as ‘top up’.

Geographical location cannot be generalised.

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Study Title</th>
<th>Methodology</th>
<th>Sample Details</th>
<th>Findings</th>
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</thead>
<tbody>
<tr>
<td>Mansell, I. &amp; Wilson, C. (2010)</td>
<td>“It terrifies me, the thought of the future”: listening to the current concerns of informal carers if people with a</td>
<td>Mixed methods</td>
<td>15 carers Aged between 25-64 years old</td>
<td>Issues of concern to carers included access to health and social care information and services, quality and quantity or respite care, suitable educational provision, independence and quality of life and what would</td>
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<td>Data Analysis: descriptive thematic analysis.</td>
<td>Learning disability.</td>
<td>Happen to the person with an intellectual disability when the carers was no longer able to carry out their caring role.</td>
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Mconkey, R. & McConaghi e, J. & Barr, O. &Roberts, P. (2006) Views of family carers to the future accommodatio n and support needs of their relatives with intellectual disabilities. 387 carers sought out in four separate studies. Study1: family carers recorded from a population of people with intellectual disability aged 14+ living with a family carer in one health mixed methods Study 1: interviews (n=45) Study2: Questionnaires (n=2) and telephone interview (n-259). Study 3: interviews at home. (n-45) The majority of carers envisaged the person continuing to be cared for within the family home. the most commonly chose out of home placement was in residential or nursing homes, living with support in a house of their own and in homes for small groups of people. Few carers chose living with another family. In all 4 studies this appeared to be the first time that carers who were known to health and social services had been actively consulted about future options and cannot be generalised. Geographical location: N. Ireland and may not be generalized to other areas. CASP High
and social services boards in N.Ireland. (n=45)

Study 2: family carers recorded from a population of people with intellectual disability aged 14+ living with a family carer in the other three of the four health and social services boards in

Study 4: interviews (n=38). member. However only small numbers of carers envisaged alternative provision being needed in the next two years and few had made any plans for alternative housing arrangements.

The study provided few answers as to the characteristics of carers who are most likely to seek a placement away from the family home.
N.Ireland. (n=259).
Study 3: family carers known to respite services in three districts aged 55+. (n=45)
Study 4: 51 school leavers of two special schools for people with severe learning disabilities in the city of Belfast. (n=38)
'Issues in caregiving for older people with intellectual disabilities and their ageing family carers: A review and commentary'

267 papers generated from initial review, 26 key manuscripts that addressed the main focus & 12 evidence for future planning, 7 were used as evidence base for the provision of support services to older people with ID and Systematic Review

The review was undertaken using a framework adapted from the NHS Centre for Reviews and Dissemination. Papers were identified through the use of databases including CINAHL, Science Direct, PsychoInfo, Blackwell Synergy, the Cochrane

key themes which emerged from the literature and which consequently form the basis of this review include: ageing family carers, future planning and support services. In the context of family caregiving, older people with intellectual disabilities represent a unique group insofar as they are unlikely to be married and therefore have no spouse or dependents to care for them in later life. As a result, parents (usually
their ageing family carers. Inclusion criteria for the review was as follows: Had to address issues including family caregiving for older people with intellectual disability and their ageing family carers.

Library and MEDLINE.

Data Analysis method: CASP assessment tool, Mary Land Scale & PICOS

mothers) have to continue caring for their son or daughter with an intellectual disability as they both grow older, often resulting in a mutually dependent relationship. The caregiving situation is further complicated by poor emergency and future planning and by a lack of appropriate services for this group of individuals.
| Taggart, L., Truesdale-Kennedy, M., Ryan, A. & McConkey, R. (2012) | Published papers in the last 10 years. English language. Expert reports and reviews only. Robust grey literature. | Mixed methods | Quantitative data: Structured questionnaire (n= 112) Qualitative: Semi-structured | Over half of the carers were loan carers, mainly female with many reporting a wide range of health problems. A third of these carers reported that their caregiving resulted in high anxiety | N. Ireland | Stage 1 employed a postal questionnaire, response was based upon a self-selected cohort and therefore the sample could be biased. | CASP High |
| intellectual disability. | interviews (n=19) | Data Analysis: Braun and Clarkes thematic Analysis. | levels. The main preference of the carers was for the person with an intellectual disability to remain in the family home, with either the family and/or paid staff to support them. A minority of the carers preferred the person to move into the home of a sibling, although some favoured the person moving to a residential facility with other people with intellectual disabilities. The majority of carers did not want their relative to move into an older | The limitations of one to one interviews correspond to criticisms of small scale studies, in that the findings may be unrepresentative. Absence of perspectives from people with intellectual disabilities about their future care options and how they were involved in the decision-making process. |

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people's residential nursing facility. In the qualitative data, four main themes were identified around future planning: unremitting apprehension, the extent of caregiving, obstacles encountered and solutions to future planning. Avoidance, lack of guidance and lack of appropriate residential provision were cited as obstacles to making future plans compounded by the emotional upset experienced by carers in thinking about the future.
| Weeks, L.E., Nilsson, T., Bryanton, O. & Kozma, A. (2009) | Current and future concerns of older parents of sons and daughters with intellectual disabilities. | 132 families Parent Carers | Mixed method | Quantitative and Qualitative data: pilot interviews In depth - Interviews Data Analysis: Statistical SPSS Content | Findings indicate a need for emotional, practical and informational supports for this vulnerable group of carers. | Canada | The findings cannot be generalized due to the geographic location of the study. Small sample. | CASP HIGH |
productive active member of society. Key issues identified through quantitative analysis included interactions with the government, the need for respite care and meeting social and emotional needs. Preferred types of housing and care options included small option homes and services that provide care to both older parents who wish to support their sons/daughters with intellectual disabilities at home and to ensure that
desired supports are available in the future when they are no longer able to provide care.