

Exploring mutual care between people with intellectual disabilities and their family carers in Scotland

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Abstract

Background: A significant number of adults with an intellectual disability (ID) live with a family member who often cares for them. ‘Mutual care’ has been defined as both the family carer and person with intellectual disabilities (ID) caring and supporting each other, and includes an element of practical and tangible support as well as potential emotional support. In situations where mutual care is occurring, both the person with the ID and the family carer have taken on a caring and supportive role, and are often interdependent on each other. However there is little research on mutual care in this population, or on the perspectives of health and social care professionals working with this population.

Focus of Project: This project explored the experiences of adults with an ID and family carers in relation to mutual care. This included the language used to describe mutual care, types of care adults with ID provided to their family carer, and how their mutual care developed. It also explored supports used, and barriers to getting support. This thesis analyses a subset of the data.

Method: Semi-structured interviews were used to explore the experiences of three adults with ID and three family carers. Interviews were recorded and transcribed. The data were analysed using Interpretative Phenomenological Analysis (IPA).

Results: For adults with ID, two master themes emerged; ‘Experiences of living with my ageing family carer’, and ‘Supports & Challenges’. Subordinate themes included; ‘Changes in my role’, ‘Changes in my parent’s abilities and health’, and ‘Barriers and difficulties’ - such as a lack of knowledge of available supports. For family carers, the two master themes that emerged were ‘Our roles living together over time’ and ‘Support, barriers and difficulties’. Subordinate themes included ‘Changes in our roles’, ‘Shared tasks’, and ‘An uncertain future’.

Discussion: Key findings are summarised, along with reflections from this project. Finally recommendations for clinical applications, and future directions for research are discussed.

Key words: Intellectual disability, mutual care, family carers, Interpretative Phenomenological Analysis (IPA)

Declaration

I declare that this thesis is my own work. It is submitted in fulfilment of the requirements of Edinburgh Napier University, for the award of Masters by Research.

Signature: Gillian Thompson

Date: 01/07/2017

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Chapter 1 – Introduction

The aim of the current project was to explore the experiences of mutual care for adults with intellectual disability (ID), and family carers. The project also explored health and social care professionals' perceptions and understanding of mutual care in adults with intellectual disabilities and their family carers.

This thesis presents some of the findings from a wider project. The wider research project sought to answer the following five main research questions. Firstly, what language is used by people with ID, family carers, and social work/social care staff to describe mutual care? Secondly, what types of care do people with ID provide to their family carers, and how did they come to take on this role? Thirdly, what are the views and experiences of adults with an ID and family carers on their mutually caring relationship? Fourthly, what supports do people with an ID and their family carers use to help them with their caring role and are there any barriers to seeking support? Finally, what are the perceptions and understanding of health and social care professionals in intellectual disability services, of mutual care between adults with an ID and family carers, and what impact does this have on their practice? This thesis focuses and reports only on research questions 1-4.

This thesis will firstly introduce the topic of mutual care in intellectual disability. The second chapter will describe the narrative literature review carried out which helped inform the research questions and aims of the current project. Subsequent chapters will describe the methodology and analysis used, and the findings. The final chapter will discuss the results, their possible implications, and directions for future research.

This introductory chapter will first consider definitions of intellectual disability and mutual care, the impact of ID, and its prevalence in Scotland. The background to mutual care and the issues it raises will be considered, including the impact on both the adult with an ID and family carers. The role of support services will also be considered. Finally, the rationale and need for research on the topic of mutual care in intellectual disability will be considered.

1.1 Definitions

Defining Intellectual Disability and the impact of having an ID

There are 3 required criteria that have to be met before someone can be diagnosed with an intellectual (learning) disability (BPS, 2015a). These are as follows:

1. significant impairment of intellectual functioning
2. significant impairment of adaptive behaviour
3. onset before adulthood (i.e. before the age of 18 years)

Research has shown that people with an ID face a number of disadvantages compared to the general population. For example, the life expectancy for a woman with an ID is 18 years less than for a woman without an ID, whilst for men it is 14 years less (NHS Digital, 2017). The Confidential Inquiry into the premature deaths of people with learning disabilities report in England (Heslop et al., 2013) found that over a third of deaths were premature and could have been avoided.

The health needs of people with an ID differ from the general population (Emerson & Baines, 2010). For example, those with Down Syndrome are more likely to have cardiac problems, whilst epilepsy is more common in people with an ID (Emerson & Baines, 2010). A review by Emerson & Baines (2010) on the health status of people with ID in England found they faced significant health inequalities and barriers to accessing services, in part because of the impact of communication difficulties. Additionally, people with an ID are at an increased risk of sensory issues with the prevalence of visual and hearing impairment being 10 times and 40-100 times higher than in the general population (Carvill, 2001). Having an ID is also associated with social disadvantage. For example, only 6 to 6.7% of adults with an ID are in paid employment in England and Scotland (Mencap, 2018b).

Prevalence of Intellectual Disability

Estimates of the prevalence of ID vary, depending on how this is measured, and which geographical area is covered. One estimate suggests there are 1.4 million people in the UK who have an intellectual disability (ID), of whom roughly 1.1 million are adults, giving a rate of 2.16%

of adults in the UK having an ID (Mencap, 2018a). Another estimate suggests there are 26,000 adults with an ID in Scotland that are known to services and that additionally there are 3 times as many adults who had an ID when they were at school but do not either identify, or are not identified by others, as having a disability and are not currently using statutory ID services (Scottish Government, 2013).

Numbers of adults with an Intellectual Disability living with family carer.

Estimates of the number or proportion of adults with an ID living with a family carer(s) also varies. For example, one estimate suggests just over half of UK adults with an ID are living in the family home, with 29,000 living with a parent carer aged 70 and over (Foundation for People with Learning Disabilities, 2018). In 2017, the number of adults with an ID known to local authorities was 23,186, of which 7,271 adults (31.4%) were living with a family carer, which for the majority was a parent (Scottish Commission for Learning Disability, 2017). It was also found that the older the adult with an ID was, the less likely they were to live with a family carer. For example, 60.3% of those aged 16-34 lived with a family carer, compared to 28.4% for those aged 36-54 (Scottish Commission for Learning Disability, 2017). However, these figures may underestimate the true figure, as they only includes those known to local authorities, and not all local authorities provided this information. Although the numbers and proportions vary depending on sources used, it seems clear that a significant proportion of adults with an ID are living with family carers.

Defining mutual care

Taggart et al. (in press) define mutual care as a relationship where both the family carer and person with ID are looking after each other. This care can take the form of practical support such as help with cooking and cleaning, dispensing medication, as well as keeping their family carer company, as they are less able to go out. In most cases of mutual support the person with an ID and their family carer would not be able to live independently without this mutual support. In situations where mutual support is present, both the person with the ID and the family carer have taken on a caring role and are interdependent on each other. The type of care provided by people with ID can vary, ranging from emotional support in terms of 'being there' and providing companionship, to physical household tasks such as cleaning, as well as personal care tasks and assistance with medication if required (Bowey and McGlaughlin, 2005; Gant, 2010; Grant, 1986; Hubert, 2006;

Knox & Bigby, 2007; Prosser, 1997; Taggart, in press; Walmsley, 1993; Williams and Robinson, 2001).

The impact of ageing

As noted above, adults with an ID have increased health needs and risk of sensory impairment compared to the general population. These are likely to increase as they age. In addition, adults with an ID are at an increased risk of developing dementia earlier in life, particularly adults with Down Syndrome who can develop dementia 30 to 40 years earlier than adults without an ID (BPS, 2015b). For those living with ageing family carers, it is likely that their carer is less able to do things they previously did, and this may result in changes in roles, or that certain tasks are no longer done.

The support available to adults with an ID is limited. As they get older, they can experience losses which affect this. For example, they can be “retired” from day services, which is a concept that adults with an ID can struggle to fully understand, and is not always in keeping with what older adults with an ID want (Judge, Walley, Anderson, & Young, 2010). In theory, adults with an ID can access Local Area Co-ordination services, as well as advocacy services. However, whether they access this support will depend on their awareness that it exists, and if they are accessible. There will likely be many barriers to accessing support, which services need to be aware of.

As family carers get older, their own health needs are also likely to increase, along with increased risk of physical comorbidity, and their dementia risk increases from age 65 onwards (Alzheimer’s Society, 2014). Parent carers or older sibling carers who care for an adult with an ID also have to cope with their own changing abilities as they age themselves which could trigger a sense of loss of their own independence, and affect how they see themselves.

Family carers, however, can access formal support from healthcare and social work services, such including from the community ID team, or social work services. However, there may be waiting times to get support, and they may have to meet certain threshold criteria to qualify for social work involvement. In their role as a carer, they can also access support from third sector carers’ organisations, although this can vary depending on region. In England, the Care Act (2014) means

that carers have a statutory entitlement to an assessment that is separate to the person they are caring for (Foundation for People with Learning Disabilities, 2015). The equivalent legislation in Scotland is the Carers (Scotland) Act, (2016), which places a duty on local authorities to provide support to meet carers' needs, although the eligibility criteria are set by each local authority, which means that support can vary across regions.

1.2 Background to mutual care

Why mutual care is important

The majority of adults with an ID live with family carers, usually their parents. As these carers become older their own needs increase. This can cause the dynamics of the caring relationship to change with the "cared for" person having to take on a caregiving role to maintain the family situation. As people are living longer mutual care will increase and become more common (Walker & Ward, 2013). While efforts have been made to develop materials and raise awareness of the issue of mutual care (Foundation for People with Learning Disabilities, 2010), what little research has been done in this area has shown that mutual caring continues to go by unrecognised and often under-valued.

Issues with the terms "carer" and the implied "cared for"

Research on "mutual care" between people with an ID (intellectual disability) and family carers has involved discussion of the appropriateness of the term "carer". It has been argued that 'carer' and 'cared for' have often been seen as dichotomous terms which can be unhelpful, as in reality relationships are based on reciprocity between two people, and it has been acknowledged that a person can both be a 'carer' and 'cared for' at the same time (Bowey and McGlaughlin, 2005; Grant, 1986; Walmsley, 1993; Williams and Robinson, 2001). Traditionally people with ID have been seen as passive recipients of care who take support from their carers, giving little if anything in return. There has often been a focus solely on the negative impact, such as the burden of the caring role and relationship on the carer.

There is a small but growing body of research challenging this by demonstrating that there can be some benefits in addition to the challenges of caring, and also looking at the reciprocal nature of the relationship between people with an ID and their family carers. People with ID are not always

passive recipients of care. Rather, they often empathise with their carer's point of view and show concern for their carer's welfare (Bowey and McGlaughlin, 2005; Gant, 2010; Williams and Robinson, 2001).

Mutual care, reciprocity, interdependence or?

As the concept of "mutual care" is fairly novel there is not yet a single definition. The current terms used vary both in the research literature and also in the language people with an ID and their families' use. What is clear is that the term "care" is not used by families or adults with ID. Instead various terms that have been used by adults with ID and/or family carers include 'interdependency' (Grant, 1986), "mutual support" (Taggart, submitted), "reciprocity" (Gant, 2010), "help" and "looking after" (Walmsley, 1996), "support" (Williams & Robinson, 2001), or "family business" (Knox & Bigby, 2007). Family carers rarely see the support offered by the person with the ID as "care" (Foundation for People with Learning Disabilities, 2010; Gant, 2010; Williams and Robinson, 2001). Due to the lack of a single, clear, definitive term for mutual care that is used by people with ID, family carers, and professionals, research on this topic is difficult to identify. In addition, the point at which someone with an ID takes on a caregiving role is not always clear, because others do not always perceive it as "care".

Research on reciprocity indicating some family carers not only give support but also receive support from people with an ID

A recent Scottish study interviewing older parent carers of adult children with ID found that for some of these parents their relationship was reciprocal and they reported benefits of caring (Cairns, Tolson, Darbyshire, & Brown, 2012). Research has found mothers with an ID have tangible and emotionally reciprocal relationships with others (Llewellyn, McConnell, Cant, & Westbrook, 1999). This has also been found in relationships adults with an ID have with their siblings (Kramer, Hall, & Heller, 2013). Weeks, Bryanton, Kozma, & Nilsson (2008) interviewed older mothers of children with ID and found they received and valued the tangible assistance and emotional support they received from their children. Perkins & Haley (2013) interviewed middle- and old-aged family carers (all parents) about the emotional and tangible reciprocity in their relationship with the adult child with an ID. For emotional reciprocity 25% reported that they received than they gave their child with ID. For tangible reciprocity, 22% of carers reported receiving more than they gave. Reciprocal relationships have also been found in family carers from BME groups who spoke

of the company and practical support they received from the person with an ID that they cared for (Hubert, 2006).

Mutual care emerging as an issue in wider research on future planning, and being under-recognised

Research on the wider topic of future planning, for example planning where the adult child with ID will live when their family carer is no longer able to or around to look after them, has indicated that mutual care does occur, and can effect the ability to plan for the future. A study which looked at the future care plans of older family carers for the adult with an ID, found evidence of mutual care in 4 out of 32 family carers, all of whom were elderly parents (Prosser, 1997). Bowey & McGlaughlin (2005) interviewed adults with an ID living with an elderly family carer about their views, concerns and aspirations for the future, and found that 34 of the 41 adults they interviewed helped out in some way at home providing support to their family carer. Nearly all (40 out of 41) were able to name someone they would go to for help with a problem. When the older family carers of these adults with ID were interviewed (Bowey & McGlaughlin, 2007), it was found that mutual care was a barrier to future planning.

Gant (2010) interviewed older family carers and adults with an ID and found mutual care took on a more significant role as carers become older, and that forms of mutual care included practical tasks, as well as emotional support and companionship. Yet, when these carers had been initially asked if they had received support, from the adult with ID, they said no. It was only later on during interviews that these carers discussed the tasks the adult with ID carried out to help them. Gant (2010) found that adults with an ID spoke with pride about the support they provided to their older family carer. This research provides evidence that mutual care is not often recognised by others, even by family carers and adults with ID who are directly experiencing it.

Research focusing more specifically on experiences of mutual care (also sometimes referred to as giving and receiving care) is limited, as shown below.

Experiences of mutual care from family carers

The first research to look at mutual care was conducted by Grant in the 1980s in Wales. Grant (1986) used health services, voluntary agencies and social services to recruit family carers of adults

with an ID (n = 103). Grant interviewed these carers about the informal care they provided. Some spoke about the help they received from their relative with ID, which indicated that mutual care (which Grant referred to as interdependence) was occurring in some of these families. Mutual care tasks reported by family carers included practical tasks, finances, as well as emotional and social support. In every case, the family carer was a lone carer who was either separated or widowed, with the majority also being female and elderly. Grant also asked these family carers about the contribution of professionals, and found that when families were visited by professionals at home, they were most commonly general practitioners and social workers.

Grant (1990) re-interviewed some of these family carers (n = 78) two years later. Grant randomly selected some cases and wrote about these in detail (Grant, 1990). This included a case of “enforced interdependence” between an older mother caring for her adult son with an ID where “her own survival was very much dependent on keeping him (her son) at home” (Grant, 1990, page 365).

A sensitive issue and an unwelcome demand

Walmsley (1996) recruited adults with ID through local ID services and organisations in the Midlands, England. Men and women with an ID (n = 22) were interviewed about their views of their relationship with their parents. Not all participants were currently living with their parents. They found 4 of 22 participants reported having a mutually supportive relationship and were carrying out care tasks for parents. This was often following the death of one parent, with the person with an ID being left to care for the remaining parent or when a parent had become frail. Two participants reported their parents were dependent on them, and both found the demands of their caring role were unwelcome, felt unable to negotiate their caring role, and restricted their freedom - leading to feelings of resentment. It is worth noting that this study initially planned to include interviews with family members and key staff, but this was “abandoned because of the sensitivity some interviewees had about approaches to families” (Walmsley, 1996, page 328).

Based on some of the participants she had interviewed previously (Walmsley, 1996), Walmsley (1993) wrote about interviews with women with ID (n=7) about their experiences of giving and receiving care to others (five participants were caring for parents, one had cared for their child,

and the other had cared for another person with ID). It was found that for some of these women caring was perceived as a valued opportunity, but for others it was exploitative and at the cost of their own wishes for how they wanted to live their lives.

More recently Taggart et al (submitted) interviewed adults with ID (n = 9) about their lived experiences of caring for family carers aged 60 and over. In eight cases adults with ID were providing care to elderly parents and in one case to an older sibling. Participants were recruited through community ID teams in Northern Ireland. Themes that were identified included the health needs of the ageing family carer, and that the onset of the caregiving role was often due to illness or unforeseen circumstances. Interestingly interviewees stated that whilst they had not been asked to take on the care-giving role, it was their decision to take it on. Adults with ID carried out tangible tasks such as cleaning, preparing meals, and assisting with medication. This study also looked at the supports that enabled them to care for their carer at home, which included formal paid carers, support from other family members, and respite/day services. For four of the nine adults with ID in this study it emerged that caring impacted on their physical and emotional wellbeing with common reported feelings being worry/anxiety, frustration and depression.

Experiences of mutual care from both perspectives

Research that has focused both solely and explicitly on the topic of mutual care, as well as sought the views and experiences of both the person with an ID *and* the family carer is scarce. Williams & Robinson (2001) interviewed both family carers and people with ID (n = 51 family carers, and n = 45 people with ID) in England. From interviews with family carers they found that 9 people with ID (5 men and 4 women) were providing care in the form of emotional or physical support to their family carer. Of the few family carers who recognised mutual care was occurring in their family, they were proud of the skills the person with ID had developed. People with ID spoke of the support they provided as part of ongoing learning of independence skills, and were very supportive of their parents' position. Williams & Robinson (2001) raised the issue of the difficulty in defining 'care' and that gender stereotypes could mask the true extent of mutual care, as some "care" could be seen as "skills building".

Knox and Bigby's (2007) Australian study involved interviewed families (n = 7) including the person with ID, parents and siblings about care within the family. This study found that mutual care was seen as an important means of keeping the family together, as families saw formal services as "topping up" what the family provided. This study also found that the roles and tasks changed of family members changed over the family life cycle, such as when family members got older, moved away or died.

It is worth noting that often the information that mutual care is happening comes from family carers themselves and not the person with an ID (Gant, 2010; Prosser, 1997; Williams and Robinson, 2001). It is not clear if this is due to people with ID not understanding or perceiving the support they provide as "care", a lack of recognition from others that the person with an ID is providing care, or both these factors.

Role of support services and staff in supporting families where mutual care is occurring

Research on the type of contact and support carers receive from professionals has mainly focused on social workers (for example see Hubert, 2006). This is likely due to the social worker's role as gatekeeper to support services. Literature reviews as well as individual studies have stressed the importance of professionals identifying families where mutual care is occurring very early, so that appropriate support can be offered to prevent crisis situations arising such as the relationship breaking down (Bowey and McGlaughlin, 2005, 2007; Foundation for People with Learning Disabilities, 2010; Ryan et. al, 2013). However in practice this rarely happens. Bibby (2013) found one of the main obstacles to this was a lack of trust carers had towards professionals. It was also found carers felt there was a lack of adequate support from professionals (Hubert, 2006).

In order for professionals to be able to identify families where mutual care is occurring there is a need to find out the type of language used by families when discussing their circumstances to allow mutual care to be recognised and any support needs identified. From the research it appears that "opinions on professionals" is a topic where the views of carers have been sought, but not the views of people with ID.

1.3 Rationale for the current study

Although research has found some evidence of mutual care, very few studies have looked at this topic in its own right. Little research has explored what mutual care means to adults with ID and family carers. In addition, health and social care professionals' perceptions and understanding of mutual care between people with ID and their family carers appears to be a neglected area. The evidence base appears on the surface to be relatively patchy, yet it is clear that mutual care has occurred and is occurring for a number of adults with ID and their family carers. However, there are many unanswered questions about mutual care. It is unclear what terms people use, what kind of care is provided, what support is sought, and what barriers there are to this.

Given the variable quality of the research mentioned, a systematic literature review was carried out to identify all relevant research, along with the use of inclusion and exclusion criteria to help establish what good quality research on this topic had found. Narrative synthesis was used to interpret the findings (Popay, et al., 2006). A qualitative study was then conducted, using Interpretative Phenomenological Analysis (IPA) to explore mutual care in adults with ID and family carers.

Conclusion

In summary, this chapter has considered definitions of intellectual disability and its prevalence in Scotland, and has reviewed definitions and usage of the term 'mutual care'. The background to mutual care and the issues it raises have been briefly described, including the impact on both the adult with an ID and family carers. The role of support services has also been considered. Finally, the rationale and need for research on the topic of mutual care in intellectual disability, has been outlined. The next chapter will describe in detail a systematic literature review on the topic of mutual care in intellectual disability, and the findings of the narrative synthesis of the evidence it found.

Chapter 2 - Systematic Review and Narrative Synthesis of Existing Research on Mutual Care and Intellectual Disability

This chapter presents a systematic review and narrative synthesis of existing research on mutual care and people with intellectual disabilities. It outlines the aims of the review, and the methods used to systematically identify all relevant research, including study inclusion and exclusion criteria. The results are then discussed and their implications considered. The gaps in the existing literature are highlighted and the current project, which seeks to address some of these gaps, will then be introduced.

2.1 Introduction

For the purpose of this review, the term ‘mutual care’ has been defined as when both the family carer and person with intellectual disabilities (ID) are caring/supporting each other (Taggart et al., in press), and includes an element of practical and tangible support e.g. help with cooking and cleaning, dispensing medication, as well as potential emotional support, for example, keeping their family carer company, and ‘being there’. In situations where mutual care is occurring, both the person with the ID and the family carer have taken on a caring and supportive role, and are often interdependent on each other.

Recent literature reviews and research on the wider issues of care-giving for family carers and future planning have found that mutual care is a barrier to future care planning for the person with ID (Bibby, 2013; Bowey and McGlaughlin, 2005, 2007; Cairns, Tolson, Darbyshire, & Brown, 2012; Gant; 2010; Prosser, 1997; Ryan, Taggart, Truesdale-Kennedy, & Slevin; 2013). However, it is less clear if research has specifically explored mutual care between adults with an ID and family carers.

Questions that informed the literature review:

The purpose of this literature review is to establish the extent and quality of the published research literature in relation to mutual care and people with intellectual disabilities:

1. What does the existing literature tell us about the experiences of mutual care for adults with intellectual disabilities and their family carers? Specifically:
 - a. What language do they use to describe mutual care?
 - b. What types of care do people with ID provide, and how did they come to take on this role?
 - c. What are the views and experiences of adults with an ID and family carers of their mutually caring relationship?
 - d. What support do adults with an ID and their family carers use to help them in their mutually caring role, and are any barriers to accessing these?
2. What does the existing literature tell us about the perception and understanding of mutual care between adults with an ID and their family carers, from the perspective of health and social care professionals in ID services, and does this have an impact on their practice?

2.2 Review Methodology

Search Strategy

The literature search was carried out in July 2016. A comprehensive search of the literature was carried out using 4 online databases: AMED, CINAHL, Medline, and PsycINFO. A search strategy was developed using terms for mutual care, intellectual disabilities, and the 3 populations in the research questions. These terms were then combined using the Boolean operators of 'AND' and 'OR'. See Figure 1 for a diagram of the search terms used. Some terms which may have been used historically, but are now considered offensive, were included in the search strategy, to ensure that older research papers would not be inadvertently overlooked. Truncation of search terms was used to identify any variations (e.g. care* would identify carer, cared). A wide range of search terms were included to ensure a thorough search of the literature.

Several other smaller databases were also searched. The Campbell collaboration is a small database of qualitative research, and the titles of all records were hand searched to check for relevance to the topic of this review. The Cochrane database contains systematic literature review articles. A general search on title, abstract, and keywords' using each of the following ID terms (learning disabilities, intellectual disabilities, learning difficulties, developmental disability, mental retardation, mental handicap) was conducted to identify if previous reviews had been carried out in the area.

Figure 1 - Literature Search Strategy for Mutual Care in ID Research

<p>Mutual Care Search Terms</p> <p>mutual care* mutual caring mutual support reciprocal care* reciprocal caring reciprocity reciprocal support co-dependent care* co-dependent caring co-dependent support co-dependen* interdependen* interdependent support co-caring co-care* family business shared care* shared caring shared support</p> <p>Combined these using OR search (A)</p>	<p>Intellectual Disability Search Terms</p> <p>learning disabilit* learning difficult* developmental disabilit* intellectual disabilit* mental retard* mental handicap*</p> <p>Combined these using OR search (B)</p>	<p>People with ID, Caregivers and Health/Social care staffs views</p> <p>older family care* elderly parent* adult child* sibling* family care* care receiver* parent* caregiver* social work* social care work* health care work* health care profession* general practitioner care recipient staff paid care* carer* agenc* care provider* family</p> <p>Combined these using OR search (C)</p>
<p>Combined A and B using AND search (D)</p>		<p>Combined B and C using AND search (E)</p>
<p>Combined D and E using AND search (F)</p>		

General searches on Google and Google scholar using key search terms were also carried out to supplement the search process.

Inclusion criteria for review

Each paper was assessed for relevance using the following inclusion criteria:

1. Type of paper: Primary research published in English in peer-reviewed journals.
2. Study Design: Qualitative data including interviews and focus groups. Studies with a mixed-methods design were included if sufficient qualitative data were reported to allow any mixed group findings to be disaggregated to identify specific findings for each of the population groups e.g. adults with ID and/or family carers.
3. Population: Adults with an ID and/or their family carers. Social care professionals working in ID services, and health professionals in community ID teams.
4. Focus of research: Narrative experiences of mutual care that include giving and receiving care between adults with intellectual disabilities and family carers. Studies that have looked at the views and experiences of mutual care from the perspective of adults with intellectual disabilities and/or family carers of adults with ID. Studies that have looked at perceptions of professionals working in ID services, specifically in social care/work, and in community ID teams.

2.3. Results

2.3.1. Study Selection

Search results for AMED, CINAHL, Medline & PsycINFO

The combined search strategies yielded 318 citations (see Figure 2, flow diagram of data retrieved at each stage). Following removal of non-journal articles (book chapters, thesis/dissertations, and

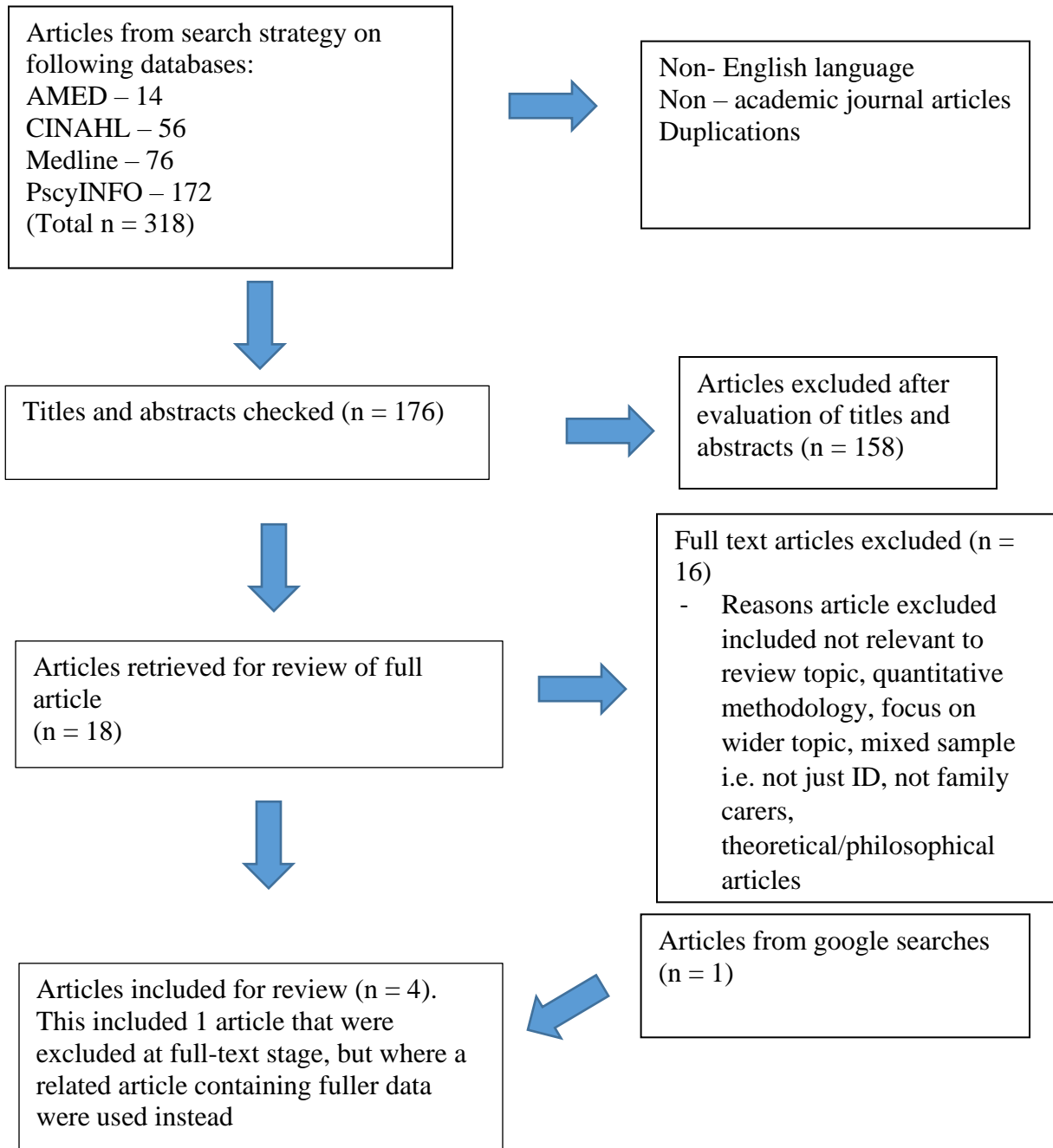
book reviews), articles in languages other than English, as well as any duplications, 176 remained. Of these 158 were excluded following evaluation of titles and abstracts, leaving 18 articles for which full-texts were read for relevance to the review topic. Of these 18 articles, 16 were excluded. Reasons for exclusion included: not relevant to review topic, quantitative methodology, focus on wider topic, mixed sample, that is not restricted to only people with ID, aggregated data from numerous populations, not family carers, and theoretical and philosophical articles. This left two articles that met the inclusion criteria.

During the literature search, 1 paper was identified during the review of the citations when reviewing the full-texts articles, that reported partial data (Walmsley, 1993), of some cases from a sample with ID. However, as the focus was specifically on carer roles and feminism in society, a later article incorporating the complete sample size was reviewed (Walmsley, 1996), and included as it met inclusion criteria and contained relevant qualitative data and findings. The Walmsley (1993) study was excluded to ensure that the same data was not reviewed and counted twice.

Search results for Campbell Collaboration, Cochrane Reviews, and other searches

There were 283 records in the Campbell collaboration, and the title of each was checked for relevance. For the Cochrane collaboration, the titles from each of the six searches (total = 131 articles) were checked. No relevant results were found in either of these two databases. From the searches on Google and Google Scholar websites, one relevant article was found (Gant, 2010).

Figure 2 – Flow diagram of data retrieved at each stage



2.3.1 Overview of included studies

From the 4 research studies included in this review (refer to Table 1), three looked at the experiences of both adults with ID and family carers (Gant, 2010; Knox & Bigby, 2007; Williams and Robinson, 2001), whilst one looked at the experiences of adults with ID only (Walmsley, 1996). All studies were conducted in England, with the exception of Knox & Bigby's (2007) study which was carried out in Australia. Family carers in these studies were usually parents (Gant, 2010), though sometimes siblings and other family members were included (Knox & Bigby, 2007).

With regard to the review questions, the evidence from the 4 articles will be looked at addressing each part of the review questions.

a) The language adults with intellectual disabilities and family carers use to describe mutual care

The language adults with ID and family carers used varied. What was evident following review of the papers is that adults with an ID do not use, and appear not to recognise and understand, the terms 'care' and 'carer' (Knox & Bigby, 2007; Walmsley, 1996; Williams & Robinson, 2001). In terms of language they did use, Walmsley (1996) found adults with ID used the term "help" and "looking after".

In common with adults with ID, family carers were found to rarely view the support offered by the adult with an ID as "care" (Gant, 2010; Knox & Bigby, 2007; Williams and Robinson, 2001). Knox & Bigby (2007) found from their sample of participants that both adults with ID and their family carers used the term "family business". The language the study authors use themselves also differed, with Williams & Robinson (2001) using the term mutual care, whilst Gant (2010) used the term 'reciprocal care'.

Table 1 - Papers included in review (ID – intellectual disability, PWID – person with ID)

Author	Participant Characteristics	Aims	Method	Results	Limitations
Gant (2010)	Older family carers aged over 60 who lived with a person with a ID (n=24) People with ID aged (n=14) Location: England	Older family carers perceptions of stress and experiences of longevity of care giving Views of people with ID about their relationship and life with their elderly parents	Recruitment - used staff members from a day centre run by local authority, to help identify people with ID and carers Data Collection - interviews with family carers ➤ focus groups for people with ID	From family carers: ➤ Mutual care emerged as one of the 5 themes (others were stress, impact of caring, and reluctance to use services) ➤ Re: mutual care, family carers spoke of both practical (e.g. household tasks), as well as emotional support (e.g. companionship) they received, and this was valued by family carers. ➤ Used language of war to describe accessing support/help from services ➤ When carers were asked if received support from person with ID, several said no. Only came out later on in interview when they mentioned certain tasks the person with ID did to help them. ➤ Through use of quotes, parents showed valued support from adult with ID. From adults with ID: ➤ Mutual care took on a more significant role as the carer becomes older. ➤ Concern re: welfare of family carer, as well as mutual care (practical and emotional) given to family carer. Also financial interdependence. ➤ Restrictions from parents or their self on own life, so parents not left on own ➤ Lack of knowledge and understanding around available options generally.	Only included people with an ID and verbal communication (excluded anyone non-verbal). Used focus groups for people with ID, individual interviews likely would have gathered richer data. Age restrictions on family carers, had to be aged over 60.
Knox & Bigby (2007)	Families of people aged 33-55 years with an ID, including person with ID, parents and sibling. Family size interviewed was 1-3, and 7 families in total)	Explore the perceptions of middle-aged person with an ID and their family members, about their understanding and negotiations of their family care arrangements.	Recruitment using purposive sampling, assisted by community-based organisations that supported adults with ID in Australia. Data Collection - separate interviews with person with ID, their family carer, and	➤ All participants saw care as 'family business' rather than 'care'. ➤ Each member of the family, including person with ID had a role (e.g. companion for older parent, household tasks, carer and adult with ID doing household tasks together). ➤ Important to families of family business as a means of keeping family independent of services, led to interdependence amongst family members (adult with ID, parents, and siblings). ➤ Tasks divided up taking account of who does what, depending on other demands for family members e.g. when father died,	- did not interview people with ID who had no verbal communication - interviewed people with ID and carers in presence of each other

Knox & Bigby (2007) continued	Of 7 families, 6 were widowed mothers. Location: Australia		family members i.e. Looked beyond carer/care recipient dyad. (participants with ID requested presence of their family member)	who took over tasks he did. Roles changed e.g. if sibling got new job, tasks would be adjusted if family structure or circumstances changed. ➤ Adults with ID took part in day-to-day decision making, however, had no direct role in planning for future. ➤ Day services not viewed as 'services' but as activities that were part of lifestyle for adult with ID. More formal services seen as a "top-up" to complement family business.	- only interviewed those already known to community services.
Walmsley (1996)	22 people aged between 30 and 70 with an ID. 14 women and 8 men, from a variety of living situations (included families, independent, group homes, hostels, hospitals). Location: England	Views of people with an ID on their relationship with their parent(s) and the care they gave and received from their parent.	Recruitment - through local ID services and organisations. Data Collection - at least 2 individual semi-structured interviews were done with each participant.	Subset of 6 Adults (5 women, 1 man) with ID who had experienced mutual care: ➤ they did not use the terms "care" or "caring" to describe what they gave. Did not use term "cared for" for support they received. They used the terms "help" and "looking after". ➤ only found in situations where PWID had lived with parents into their 40s, where one parent had died, and where surviving parent was becoming physically frail. ➤ Four adults (3 women, 1 man) described tasks they did as housework, shopping, cleaning and washing. No one mentioned performing personal services (e.g. washing/dressing). ➤ Two women spoke of demands on parents for companionship and household duties as unwelcome, and appeared they had <u>no</u> scope for renegotiating their roles with change in responsibilities ➤ Some restrictions on freedom for PWID as parent maintained ultimate control over finances and making decisions.	Only included PWID who had verbal communication. Only PWID who had been known to specialist ID services. It was mentioned by author that the original plan had been to also interview family members and key staff, but this was abandoned due to the sensitivity among participants with ID about approaches to families and staff.
Williams & Robinson (2001) Williams & Robinson (2001) continued	Family carers and people with ID (n = 51 families). Family carers, age between 20s – 70s, with majority being female People with ID aged 14-47, some with verbal communication, and some without. Location: England	Views on family care from people with ID and their family carers	Recruitment - Contacted families who had received a carer's assessment or service review for the PWID as part of wider research study. Data Collection - People with ID were interviewed using accessible info including large print, photos, and pictures. - People with ID who had no verbal	➤ All participants with ID empathized with their carer's point of view, supportive of carer's position For subset of 9 adults with ID: ➤ They were helping their carer in emotional and/or physical ways. Tasks included physical tasks, lifting carer, domestic chores, company, emotional support, and emergency help. ➤ Mix of genders, 5 men, and 4 women. Emotional support usually provided by women. Range of abilities, including adult with verbal impairment, as well as non-verbal adult. ➤ did not understand/use term "carer" or "care". Household tasks seen as part of programme for learning independent skills. ➤ Information of mutual care occurring came from family carers, not adults with ID. ➤ Appears no conscious choice to take on (or not) this role, just how it was it appeared.	Only recruited those known to specific services Age restrictions in recruiting people with ID under 50, and family carers under 80. 1 of the 9 adults with ID in subset was between age 15 – 20, unclear of exact age

			<p>communication had more informal interview, reactions and observations were noted down by researcher.</p>	<p>➤ Authors suggest gender stereotypes may be masking wider picture, as some “care” could be seen as “skills building</p> <p>Family carers:</p> <ul style="list-style-type: none"> ➤ none described the adult with ID as being a “carer”. ➤ strong identity of being a carer, felt responsible for PWID, meaning can be hard to talk about mutual care/dependency ➤ Lack of insight/recognition of mutual care. The few family carers who recognised mutual caring were proud of skills the adult with ID showed. ➤ 1 carer with disabilities, was living with 2 adults with ID, who provided hands-on care to her get out the bath. ➤ 1 carer had requested a carers assessment for adult with ID who was caring for another adult with a severe ID. 	<p>Ethnic minorities were represented in small number of families (n = 3), however, unclear if any in subset</p>
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b.) The types of care people with ID provide and how they came to take on this role

The types of care family carers report that the adult with ID provides can be split into practical support and emotional support. Practical tasks include household chores such as gardening (Gant, 2010, Williams & Robinson, 2001), housework and shopping (Walmsley, 1996), as well as the adult with ID and family carer doing tasks jointly such as washing the dishes (Knox & Bigby, 2007). Emotional support included ‘being there’ as well as providing companionship to their family carer, and this support was valued by family carers (Gant, 2010; Knox & Bigby, 2007; Williams & Robinson, 2001).

Walmsley (1996) found no adults with ID reported providing support to their family carer with personal care tasks. However, from family carers, there was evidence that some adults with ID were providing hands-on personal care-type tasks to their family carer, for example, assisting them with getting out the bath, or having responsibility to summon emergency help if their carer fell ill (Williams & Robinson, 2001). Another example was an adult with ID assisting their family carer to the bathroom when they were unwell (Gant, 2010).

Often the information that mutual care is happening came from family carers themselves and not the person with an ID (Gant, 2010; Williams and Robinson, 2001). It may be that this is due to people with ID not understanding or perceiving the support they provide as “care” and/or a lack of recognition from others that the person with an ID is providing care/support.

There was some evidence that when adults with ID are living with an older carer and where one parent has died (Walmsley, 1996), these carers are more likely to be female (Knox & Bigby, 2007). However, it must be noted that several studies specified age restrictions, and specifically recruited older parent carers (Gant, 2010).

The issue of financial interdependence, where the benefits the person with ID receives becomes part of the household budget, and is used by the family, and can be main/only source of income, was also found to be present in a number of families (Gant, 2010)

c.) The views and experiences of adults with an ID and family carers of their mutually caring relationship

For adults with ID, Gant (2010) found that they spoke with pride about the support they provided to their older family carer, and viewed it as helping make life easier for their older parent. It was also found that adults with ID did have awareness, and showed concern regarding the welfare of their older family carer (Gant, 2010; Williams & Robinson, 2001). The mutual care could also cause some restrictions for the adult with ID in terms of choice and autonomy e.g. the adult with ID not going to certain activities to avoid their carer being left on their own.

Gant (2010) interviewed older family carers and adults with an ID and found mutual care took on a more significant role as carers become older, yet when family carers had been initially asked if they had received support from the adult with ID, they had said no; it emerged during interviews the tasks the adult with ID carried out to help the family carer.

It is worth noting that in for some adults with ID, the mutual care was an unwelcome demand. In Walmsley's (1996) study, two adult women with ID spoke of the impact this had, with feelings of unhappiness and frustration at the demands that were made of them, and that they did not feel they had a choice in taking on these tasks.

Regarding decision-making, despite there being a mutual dependency between the adult with ID and the family carer when it came to making important decisions, that affected the longer-term life of the adult with ID and their family carer, often the family carer retained all the 'power' and 'control' in making these decisions (Knox & Bigby, 2007; Walmsley, 1996).

d.) The support adults with ID and family carers use to help them in their mutually caring role, and barriers to accessing this

Family carers were found to sometimes use the 'language of war' such as "fighting" to get help, to describe difficulties accessing support and services, whilst adults with ID lacked knowledge of

what was available, and options for support (Gant, 2010). In the Williams & Robinson (2001) study, one family carer had requested a carers assessment for her adult daughter with ID, who often cared for her more severely disabled sibling, and this was denied. This carer was quoted as “They (professionals/services) just cannot conceive of a disabled person being a carer or a young carer” (pg. 61).

In Knox & Bigby’s (2007) study, families saw services as “topping up” what family members did, and they were keen to keep things within “the family” where possible. However, it is noted that in this study, they interviewed not just the adult with ID and the parent, but also other family members who were involved. It is not clear if families where other family members are less involved, would share the same or different views on accessing supports.

2.) The perceptions and understanding of health and social care professionals in intellectual disability services, of mutual care between adults with an ID and their family carers, and the potential impact on their practice

Despite an extensive literature search, no research looking at the perceptions and understanding of health and social care professional in ID services was found. This is despite the fact that for all 4 studies included, the method of recruiting and identifying adults with ID and/or family carers was through those known to health and/or social care services.

2.4 Discussion and Gaps in the Research Literature

This review had a number of features of a systematic review including formal searching of multiple databases, clear questions, specific inclusion and exclusion criteria, and structured description of the included studies. However, a narrative synthesis of the included studies was performed as the primary aim of the review was to identify whether there was any evidence on this topic and if there were any gaps in the research literature. When it became apparent there were very few studies, systematic analysis did not feel feasible or appropriate.

Mutual care is about care and support being both given and received between 2 people. However, only three studies on mutual care have looked both at the experiences of the person with an ID and the family carer in a single study (Gant, 2010; Knox & Bigby, 2007; Williams & Robinson, 2001).

Lack of a definitive term or language used to describe mutual care, makes it hard to identify and describe mutual care clearly. There are discrepancies between the terms used in research and those used by people with ID and their families. This can have implications on services these adults with ID and their families receive, as well as the practice of professionals. The Foundation for People with Learning Disabilities (201) has stressed the importance of professionals identifying families where mutual care is occurring early and appropriate support can be offered to prevent crisis situations arising such as the relationship breaking down. However, in order for professionals to be able to identify families where mutual care is occurring there is a need to find out the type of language used by families when discussing their circumstances to allow mutual care to be recognised and any support needs identified.

The types of support varied in the research, however, it could be split into tangible (e.g. physical tasks) and/or emotional, and that family carers do value this support. However, it appears that recognition of this support from the point of view of the adult with ID and the family carer is limited, and that for the majority it appears to go unrecognised and unacknowledged. It was also found that often adults with ID were not aware of what supports were available and how to access these, and that they had little say in decisions about their own life. Some adults spoke positively of the support they provided, whilst for a small but significant minority, the experience of mutual care was unwelcome and unwanted.

In all 4 studies in this review, the authors spoke of the difficulties of policy dichotomising ‘care’ as either someone being a ‘carer’ or ‘cared for’. In reality relationships are often not uni-directional. It was suggested that service providers and professionals need to change this way of thinking, to enable better support for adults with ID and their family carers (Williams & Robinson, 2001). It was also noted that relationships do not stay static, and roles can change over time (Knox & Bigby, 2007; Walmsley, 1996).

Grant (1986) looked at the views of older family carers caring for an adult, and in a small subset of these cases found evidence of mutual care, which he termed ‘interdependence’. When Grant published this paper in 1986, he highlighted the need for future research to include and listen to the views and needs of the person with an ID on this specific matter. Yet in the 30 years since, only a handful of researchers have actually focused on the topic of mutual care and sought the views of people with ID on their experiences of mutual care (Gant, 2010; Knox & Bigby, 2007; Walmsley, 1996; Williams and Robinson, 2001).

Nearly all the studies on mutual care recruited people with ID and family carers using staff from day services, social care, and health care. Staff appear to be well-placed to identify mutual care, yet despite extensive literature searching there does not appear to be any published research that has looked at their perceptions and understanding of mutual care in adults with ID and their family carers.

Very little attention has been given to find out the views of people with an ID who have no verbal communication (Williams & Robinson, 2001), or carers from black and ethnic minorities. It is also noted that only adults with ID and families known to formal or specialist services were recruited for these studies. A significant number of adults with ID and their families are not known to specialist services, and little is known about their experiences. Aims for future research should be to try to include adults with a wider range of ID, as well as families from ethnic minorities, as most in these studies were Caucasian families, or data on ethnicity and cultural background was not reported. There have also been no studies that have explored the experiences of mutual care for people with ID and family carers in Scotland.

2.5 What the current project will aim to contribute to the literature

The current thesis aims to look at the experiences of mutual care for adults with ID, and family carers. The proposed research will address some of these gaps and make an original contribution to the research base for mutual care in ID. The project will look at the following aims and questions:

Research Aims

1. Identify the language people with ID and family carers use to describe mutual care.
2. Explore the types of care people with ID provide to their family carers, and how people with ID end up taking on this caring role.
3. Explore the views and experiences of people with ID and family carers on their mutually caring relationship.
4. Identify what supports people with ID and family carers use to help them in their caring role. Identify the barriers to seeking support.

Research Questions

This led to the following research questions being formed:

1. What language is used by people with ID and family carers use to describe mutual care?
2. What types of care do people with ID provide to their family carers? How did they come to take on this role?
3. What are the views and experiences of adults with an ID and family carers of their mutually caring relationship?
4. What supports do people with ID and family carers use to help them in their caring role. What are the barriers to seeking support?

Conclusion

In summary, this chapter has presented a systematic review and narrative synthesis of the evidence on mutual care in people with ID and their carers. The review process and methods, including the inclusion and exclusion criteria used to select studies, has been described in detail. The results of

the research included in this review have been discussed and considered in relation to the research questions the literature review sought to answer. The gaps in the existing literature have been identified, and the aim of the current research project has been introduced.

The next chapter will describe the rationale and study design used for the current project. This will include describing the methodology, including how data was collected and analysed, as well as considering potential ethical issues.

Chapter 3 - Methods

In this chapter, the rationale for the chosen study design will be presented. How data was collected will then be described in detail, along with the reasons why Interpretative Phenomenological Analysis (IPA) was chosen to analyse the data. In addition, methodological considerations with regard to recruitment approach used, ethical issues, sample size, and materials used will be described and explained. Once these general methodology issues have been explored, the specific characteristics of participants in this study will be detailed. Finally, the data subset chosen for analysis will be considered.

3.1 Rationale for study design and qualitative approach

There is very little existing research on the topic of mutual care in intellectual disabilities. No previous research has explored the experiences of mutual care for adults with ID and family carers in Scotland. The aim of this research is to address the gaps in the literature by exploring the experiences and perspectives on mutual care between adults with ID and their family carers.

There were a variety of potential methodologies that could have been employed in this project. For example a quantitative approaches such as a survey could have been useful. However, this would have been difficult for adults with an ID to complete as they are more likely to have difficulties with literacy or be unable to read. Survey questions also tend to be quite closed which can limit the breadth of the data gathered. Other quantitative approaches such as questionnaires did not feel appropriate, as so little is known about mutual care, and peoples' experiences may vary so much, that questionnaires do not capture their experiences fully.

Qualitative methods include interviews. A structured interview was not felt appropriate as the research aim was to find out peoples' unique and personal experiences, and closed questions would potentially limit the richness of data gathered. With an unstructured interview, however, participants may struggle to stay focused on the topic, making it harder to get relevant information about their experiences. A semi-structured interview was felt to be most appropriate, providing some structure to the interviews to ensure they followed similar questions, whilst still allowing participants to expand on the range of experiences they could share. In summary:

1. A quantitative method would be too restrictive, as not enough is known on this topic to set rigid questions. Therefore a qualitative approach is more appropriate.
2. Little is known on this topic. It is likely that participants' experiences and feelings on this topic will vary. The use of a qualitative approach using semi-structured interviews will help ensure most of the same questions on this topic are asked to each population giving some consistency, whilst at the same time having the flexibility to adapt and respond as participants share their unique experiences.

A number of different qualitative analytic methods were considered. Thematic analysis was not felt appropriate as the research focused on exploring participants' unique personal experiences of mutual care. Grounded theory is an approach that is commonly used to explain a process or action through a theory (Padgett, 2016), and therefore would not have been an appropriate method to answer the research questions in this project. Discourse Analysis looks at how people use language to create and enact identities (Starks & Trinidad, 2007) however, this also was not felt to be a suitable approach, particularly as people with ID often tend to have significant difficulties with both receptive and expressive language. As this project was looking at the subjective lived experience from the perspective of research participants themselves, a phenomenological approach was deemed most appropriate (Harper, 2011; Starks & Trinidad, 2007). In summary, it was felt that the most appropriate methodology was to use a qualitative approach using semi-structured interviews that were analysed using interpretative phenomenological analysis (IPA). IPA was felt to be an appropriate research method as it is focused on understanding the unique experience of each participant (Padgett, 2016; Smith, Flowers, & Larkin, 2009; Starks & Trinidad, 2007). There are several reasons why this method was the most appropriate. These are discussed further below in section 3.3.

This study recruited participants from across two different populations. The reason for interviewing participants from these specific populations is this research is looking for the experiences and perspectives of these different populations on the topic of mutual care. The

researcher had experience of working with both adults with intellectual disabilities, and family carers.

3.2.1 Data Collection

All interviews were recorded and transcribed. Before the interview started, informed written consent was explicitly sought from all participants. Bryman (2008, page 451) outlines some of the advantages of recording and transcribing interviews which include:

- It acts as an objective record of what participants and interviewers said during interview, rather than relying on subjective memory recall.
- It allows more thorough analysis as it is a record not just of what was said, but *how* it was said.
- It allows repeated examinations of participants' answers.

All identifiable information was removed from transcripts, and these were stored securely. All participants were given the choice to have a copy of their transcript to read and amend as they wished. Five of the six participants chose to receive a copy, the other chose not to. It should also be noted that a verbatim record of what participants say is required for the particular analytic approach that this study used (Smith, Flowers, & Larkin, 2009). Reasons for this approach are given below.

3.2.2 Additional data gathered

Data was gathered during the wider project across three participant groups; adults with ID, family carers, and health and social care professionals working with adults with ID and their family carers (total N = 21). However, including all the participants is far beyond the scope of this MRes study. For the purposes of this dissertation, the data analysis focuses on a subset of the data collected from 3 adults with ID and 3 family carers. The demands of a verbal interview with adults with ID meant there was some variation in depth and richness of the data gathered across participants. Participants with richer data (as demonstrated by transcripts with more detailed responses) were selected for the analysis reported in this dissertation. This decision to analyse data from only 3

adults with ID and 3 family carers is supported by strategies to improve rigour as recommended by Noble & Smith (2015). For example, they recommend including rich and detailed verbatim description of participants accounts, as well as seeking similar and differing accounts to ensure different perspectives are represented, hence the decision to analyse fewer participants data but more in depth, as well as to include both adults with ID and family carers, so both perspectives were represented. It is considered sufficient for IPA to have three to six participants (Smith, Flowers, & Larkin, 2009; page 51). Therefore, the data used and reported in this thesis for each participant group was within these constraints. The additional data gathered will not be analysed in this dissertation. However, the data will be analysed at a later date by the project supervisors, and will form the basis for further publications.

3.3 Data Analysis

Interpretative Phenomenological Analysis (IPA) was used to analyse the interview data. IPA has foundations in phenomenology, hermeneutics and idiography, which mean the approach is grounded in the study and interpretation of particular people's particular experiences (Smith, Flowers, & Larkin, 2009). IPA is not concerned with making sweeping generalisations; instead its focus is on a homogenous sample's experiences and understanding of a specific topic.

Why is IPA appropriate for this study?

There are several reasons why IPA was felt to be appropriate:

1. IPA is a qualitative approach that examines how people make sense of their experiences and requires rich, descriptive data ideally from interviews with participants (Smith, Flowers, & Larkin, 2009).
2. Little is known about this topic, and it is likely that people's experiences will vary; therefore the focus of this research is on getting a greater understanding of participants' unique experiences.

How will IPA be used to analyse the data?

Each group's data were analysed separately using IPA. There were therefore two IPA analyses, one for adults with ID, and one for family carers.

The researcher followed the guidelines of Smith, Flowers, & Larkin (2009) when conducting IPA:

1. Transcripts were read and re-read by the researcher so they were familiar with, and immersed in the data.
2. Initial notes were be made. Anything of interest in the transcript was noted. Comments were made by the researcher on the transcripts, focusing on describing the content, the language used, as well as conceptual comments.
3. The researcher then used the transcripts and notes to develop emergent themes. This involved the researcher trying to interpret what was important in the transcripts and pulling the important bits out so themes start to emerge.
4. The researcher then searched for connections across the emerging themes. Due to the size of each group and the likelihood of their being a considerable amount of data, emergent themes were typed up, printed out, and cut up so there was one theme on each piece of paper. All themes were then spread over a large space. The researcher then grouped similar themes together and looked for patterns across cases within each group.
5. These themes were then be interpreted further by the researcher.

Once themes had been identified and defined in each group, the researcher explored whether there were any similarities and differences between the two groups.

3.4 Recruitment approach and ethical considerations

Recruitment for this study took place between 2015 and 2016. Initially, the researcher and their supervisors sought to recruit through social care organisations only, and ethical approval for this research study was sought and granted from Edinburgh Napier University's Ethics Committee, prior to study commencement. However, there were initial difficulties with recruiting sufficient numbers of participants through social care organisations. To aid recruitment, the researcher (with

support from their supervisors), applied for NHS ethical approval to recruit participants through staff in community ID teams in the region's health board. NHS ethical approval for this was granted by the Northern Ireland Regional Ethics Committee B (study reference number 16/NI/0019).

Adults with ID and family carers were recruited indirectly. The researcher approached local councils, local area co-ordinators, support providers, advocacy and carer organisations, and community ID teams. The researcher arranged to come along to meet with staff and briefly tell them about the research study. At this meeting, the researcher asked staff if they could pass on written information about the study (refer to Appendices for copies of study information sheets) to any adults with ID and/or family carers that they knew of, who would potentially be suitable for this research study. At every meeting with staff, the researcher advised that participation would be voluntary, confidential, and anonymous. Following this meeting, the researcher sent an email to each organisation, with a written summary of the research project, electronic copies of the 2 different participant information sheets, and the researcher's contact details in case there were any questions/queries.

The decision to recruit adults with ID and family carers indirectly was deliberate. There were several reasons for this. It was acknowledged by the researcher and their supervisors, that if the researcher had made the first approach directly, some adults, particularly those with ID, may have felt obliged to participate, or done so to "please" the researcher, or had difficulty articulating "no" to the researcher. Therefore, it was felt that indirect recruitment, with an initial approach made by someone known to the potential participants, but unconnected to the study, was a more ethical recruitment method. Due to ethical concerns regarding the vulnerability of adults with ID, as well as the need to obtain informed consent, the decision was made to only include adults with ID who had the capacity to consent voluntarily, and had the verbal abilities to take part in an interview. This meant that the adults with ID who participated were likely to have an ID in the mild to moderate range, and that those with an ID in the severe range would likely be excluded.

For all participants, there were procedures in place for the research student to follow if a disclosure of abusive treatment was made. The procedure was for the student to discuss it with their supervisor and refer on to other services if appropriate (for example social work). As adults with an ID are more vulnerable to abuse, it was detailed in the participant information sheet that should they tell the research student that someone was harming them, then the researcher would have to tell their supervisor. On a few occasions, disclosures were made which resulted in the research student discussing with their supervisor and following advice. When disclosures were made, the research student again explained to the participant that they needed to discuss this with their supervisor. A procedure was also in place for withdrawal. All participant information sheets stated that participants had the right to withdraw at any time, and without having to give a reason.

For participants with an ID, there was a need to be aware of ethical considerations around accessibility of participant information sheets and consent forms. The research student spoke to an experienced speech and language therapist (SALT) working in an adult intellectual disability service for advice on how to present the patient information letter and consent forms (e.g., pictures first, then text). Visual information was also used along with simplified language to make documents more accessible to people with an ID. All names reported in this thesis are pseudonyms to protect the confidentiality of participants.

3.5 Materials and Procedure

Materials

Prior to commencement of the study, study information sheets and consent forms were compiled for each of the two participant groups, adults with ID, and family carers. This included an easy read version with visuals for adults with ID. Semi-structured interview schedules for each of the two participant groups were also prepared. Copies of the participant information sheets, consent forms, and interview schedules for each of the adults with ID and the family carers are provided in the Appendix.

As part of a condition for ethical approval for recruiting through the NHS, the researcher notified the GP of any adult with ID who expressed an interest in participating. A distress protocol was put in place for adults with ID and family carers, in case they became distressed, and a list of organisations they could contact for support was given at the end of the interview. For a copy of these documents please refer to the Appendix.

Adults with ID

Participants

Adults with intellectual disabilities (N = 3) were recruited from a region of Scotland, and were invited to participate in a one-off interview. See Table 3.1 for details on the demographics of participants with ID. There were 3 women, and the ages of participants ranged from mid 30s to early 60s.

Inclusion and exclusion criteria

People were eligible if they willing to participate voluntarily and to give written consent, having an intellectual disability, aged over 18 years, experience of providing support/help to their family carer, and being able to cope with the demands of interviews. Those unable to give consent or unable to cope with the demands of the interview because of disability, were unable to take part.

Table 3.1: Demographic details for adults with ID

Adult with ID	Gender	Age	Family member they cared for
Helen	Female	Early 60s	Historical, cared for parents
Rebecca	Female	Mid 40s	Mother
Claire	Female	Mid 30s	Mother

Prior to recruitment commencing, it had been assumed (perhaps naively) that all adults with ID would be living with their family member, and that mutual care would be occurring at the present time, however this was not the case for all participants. For one participant (Helen) there was a strong history of mutual care with her parents, however, they were now deceased.

Procedure and interview

All potential participants with an ID were given a copy of the easy read study information sheet. Due to the potential vulnerability of this population, and as some adults with ID had difficulties with reading, the researcher offered to meet with potential participants informally first, to go over the information sheet and answer any questions they had, before deciding whether they wished to participate. If an adult with ID decided to participate, written informed consent was obtained prior to interview.

All participants were given the choice of having someone they knew present during the interview. The researcher carried out all interviews, using the semi-structured interview schedule. The location of the interview was chosen by the participant, and was usually their home or another familiar setting. During the interview demographics (e.g. age, gender) and information regarding current family situation (e.g. relationship to their family carer, how long they lived with family carer), and how they heard about this research, were collected from participants. Interviews usually took between 30 – 60 minutes. For participants who were recruited through NHS organisations, their GP was notified of their interest to participate, and following interview, a list of contact details for support organisations was given, as part of the conditions for ethical approval.

Family Carers of adults with ID

Participants

Family carers of adults with ID ($n = 3$) were recruited from a region of Scotland, and were invited to participate in a one-off interview. See Table 3.2 for details on the demographics of family carers. All family carers in this sample were parents. Alexandra and Mary cared for their adult daughters with an ID, whilst Patricia cared for her adult son with an ID. There were 3 women and the ages

of participants ranged from late 50s to early 60s. Family carers were interviewed individually. All parents currently lived with their adult child with ID.

Table 3.2: Demographic details for family carers

Family Carer	Gender	Age	Family carer role
Patricia	Female	Late 50s	Mum
Alexandra	Female	Late 50s	Mum
Mary	Female	Early 60s	Mum

Inclusion and exclusion criteria

Family carers were able to participate if they were willing to participate voluntarily and gave written consent, and caring for an adult with an ID, aged over 18 years, experience of receiving support/help from their relative with ID, and being able to cope with the demands of interviews. Those unable to give consent or unable to cope with the demands of the interview because of disability, were unable to take part.

Procedure and interview

All participants were given a copy of the study information sheet, and if they decided to participate, written informed consent was obtained. The researcher carried out all interviews, using the semi-structured interview schedule. All family carers in this sample chose to be interviewed at home. During interview, demographics (e.g. age, gender) and information regarding current family situation (e.g. relationship to adult with ID that they care and live with, how long they have done this for), and how they heard about this research, were collected from participants. Interviews usually took between 45 – 70 minutes. For participants who were recruited through NHS organisations, a list of contact details for support organisations was given after interview, as part of the conditions for ethical approval.

Rigour and Researcher Reflexivity

A potential criticism of qualitative research is that it lacks scientific rigour. Mays & Pope (1995) outlined some ways to try to improve this. Rigour was promoted in this research by having a varied sampling strategy, with participants recruited from local councils, local area co-ordinators, support providers, advocacy and carer organisations, and community ID teams. This also meant that geographically, within the health board that the research took place, it included urban, suburban, and rural areas. In addition, the sampling strategy has been clearly described, as well as how the fieldwork was undertaken, as recommended by Mays & Pope (1995). Noble & Smith (2015) compiled a list of 9 strategies for qualitative researchers to adopt that can help enhance rigour, and in this study several of these strategies were adopted, including the use of rich verbatim descriptions of participants' accounts to support findings; inviting participants to comment on the interview transcript; and acknowledging biases in sampling. One of the strategies suggested by Noble & Smith (2015) is data triangulation, and there was an element of this in the current analysis, as both the perspectives of adults with ID and family carers were reported. However, due to limited resources, not all the strategies recommended by Noble & Smith (2015) were used, for example, engaging with other researchers to reduce research bias. However, it is acknowledged that it is important not to follow any strategies or criteria prescriptively, as within the qualitative research community, there is no generic framework for assessing quality, and Rolfe (2006) argues that instead of prescriptively following generic criteria for qualitative research, each study should be judged on its own merits.

Reflexivity in qualitative research is also important to consider, as it can be affected by the researcher's characteristics and experiences (Berger, 2015). In terms of reflexivity, the researcher is female, and had worked in a community ID team for a number of years, working mainly with older adults with ID, and family carers. Whilst this was not something the researcher disclosed to participants (mainly as they did not want to colour/ assert potential power as a "healthcare professional"), it has to be acknowledged that the researcher's experiences will have had an impact on how data was collected. Some benefits of this are that having worked with this population, the researcher was sensitive and mindful of the language and approach used when interviewing participants, as well as taking steps to make materials more accessible to those with an ID.

However, it is also acknowledged that the researcher's own biases could have influenced how questions were asked, as they were coming from a background where they had experienced mutual care in their clinical role within a healthcare team. It is also acknowledged that the researcher has personal experience of having a family member with an ID, and that this could have influenced the level of empathy, and sensitivity, given to participants during the interviews. It is acknowledged that the researcher's professional, and to a lesser extent personal, experiences, did play a role in influencing the choice of topic. In addition, two members of the supervisory team had extensive experience working in ID services. Steps to address this potential bias included giving participants the option to review their transcript, to check from the participant's point of view that they felt it was an accurate reflection/account of the interview.

Conclusion

In summary, this chapter has explained the rationale for the study design chosen, how the data were collected and why Interpretative Phenomenological Analysis (IPA) was chosen to analyse the data. Methodological considerations were discussed with regard to recruitment approach used, ethical issues, sample size, and materials used with participants. The specific characteristics of participants in this study were described. The data subset chosen, of adults with ID, and family carers, that were used for analysis were detailed. Finally, the issue of rigour and reflexivity was discussed.

The next chapter will describe the results from the analysis of the subset data used in this study, using Interpretative Phenomenological Analysis (IPA). This will consider the results from firstly adults with ID, and then family carers, before summarising the themes in both groups.

Chapter 4 - Results

This chapter describes the results from the analysis of the subset data used in this study, using Interpretative Phenomenological Analysis (IPA). Firstly, the resulting themes from the adults with ID will be considered, with the master themes and subordinate themes being outlined and detailed, with quotes used from participants to demonstrate each theme. The master themes and subordinate themes from family carers will also be detailed, with quotes to support each theme. Themes common to both adults with ID and family carers will be considered. Finally, the findings of the study are discussed in relation to the research aims. See Tables 4.1 and 4.2 for details of the master and subordinate themes that emerged in each of these groups.

Table 4.1: Summary of master and subordinate themes from IPA analysis of adults with ID (N=3)

Master Theme	Subordinate themes
Experiences of living with my ageing family carer	Changes in my role
	Helping each other
	Decision-making
	Changes in my parent's abilities and health
Support, and the difficulties with accessing this	Supports and things that help
	Barriers and Difficulties
	The Future

Table 4.2: Summary of master and subordinate themes from IPA analysis of family carers (N=3)

Master Theme	Subordinate theme
Our roles living together over time	Changes in my role and my adult child's role
	Static roles
	Shared tasks
Support, barriers and difficulties	Informal supports

	Formal supports
	Barriers to getting help
	The impact of having a child with an ID
	An uncertain future

4.1 Results from Participants with Intellectual Disabilities

Two master themes emerged from the analysis; the first was ‘Experiences of living with my ageing family carer’, whilst the second was ‘Support, and the difficulties with accessing this’.

4.1.1 Experiences of living with my ageing family carer

This master theme was comprised of a number of subordinate themes, which are discussed in detail below. For Helen she had previously lived through the experience of living with both her parents as they got older until they died, whilst for both Rebecca and Claire, their experiences of living with their parent were current and ongoing.

Changes in my role

As the adults with ID had become older, their roles had changed. They spoke of having specific tasks that they did, usually as a result of their family carer not being able to, or of wanting to do tasks to help their family carer. All three adults with ID who participated, spoke of the things they did as “helping” their family carer.

For Claire, she spoke of doing the dishes as a surprise for when her mum returned home, and that one of her household tasks was taking the bins out herself. Some changes in their role was welcome, as Claire described liking the tasks she did around the house such as doing the bins and recycling, and seeing these as a chance to get out and get some exercise.

“I do it myself”, (Claire, referring to helping with household tasks)

For Rebecca, her feelings were more mixed, with some tasks enjoyed, whilst others were not enjoyed but described as needing to be done.

There was a change in role with growing independence for Claire and Rebecca. Claire talked of doing her own laundry, going out to her day service, and meeting up with friends in town, as well as being responsible for her pet cat and dog. Whilst for Rebecca, she was also a mother to her young child, and spoke of spending time with her child to give her own mother a break from caring for her grandchild.

For Helen whose parents had been her family carers, her role changed when her parent's health had begun to deteriorate. She had taken on more responsibilities, particularly around the house, such as cleaning, laundry, and helping with food shopping. She lived with her parents till their death, and had also provided hands-on personal care to them, as she described having to help her mum in and out of the bath, and with other daily tasks.

Helping each other, and being part of a team

There were also tasks that were shared and done “together” with their family carer. Helping each other, was often the result of complimenting theirs and their family carers abilities. Often, the help from the adult with ID would take the form of physical or practical support, whilst the help from the family carer would often be for cognitive tasks. Both Rebecca and Claire spoke of helping their family carers with physically demanding tasks such as gardening and shopping, and that these were shared:

“my mum takes the (empty) trolley down with her, I take it (full trolley) back up”, (Claire)

Claire spoke of her mum helping remind her of things, whilst both Rebecca and Claire spoke of finding reading difficult, and their family carers helping them by reading letters out to them.

“sometimes if I forget my mum remembers me”, (Claire)

The lives of the adults with ID were intertwined with their family carer, with not just time spent doing tasks together, but also shared responsibilities and time spent together. Rebecca described herself and her mother cooking and eating meals together as a family with her child. Whilst this sharing sometimes extended to finances, as Claire described sharing the cost of household cleaning supplies with her mother.

There was a value and comfort in being part of a team, and doing things together. For Helen she spoke of the loss of her parents, of missing them, and reminisced about things she did with them using the term “the three of us”.

Decision making

Whilst the adults with ID were all providing help to their family carer, their family carer had cared for them since they were young. As adults, they spoke warmly and lovingly of their family carers, and were supportive of their position. However, even though they were adults, and taking on more responsibilities, decision making responsibilities continued to be retained by their family carers. Particularly for Helen, she spoke of the demands, and decisions made by her mum, even when her mum was confined to her bed most of her time:

“she’s (mum) thumping down the stair, she’s wanting something”, (Helen)

For all three women with ID, they did not explicitly mention decision making responsibilities in their relationship with their family carer. It appeared that they accepted and did not question that their family carer would continue to hold decision making responsibilities whilst they lived together. In order to make choices, there has to be an awareness and insight that choices are available. For adults with ID who have always lived with their family carers, it is likely they may never have been given this knowledge or experience.

Changes in my family carer’s health and abilities

All 3 participants, spoke of changes in their family carer's abilities, due to changes in their family carers health as they got older and frailer. For Helen who had cared for her mum, she spoke of things her mother was no longer able to do physically, such as bending. There was some distinction between participants in the language they used in terms of 'having' to help:

"I have to help my mum...she is getting older", (Rebecca)

Whilst for others there was a sense of obligation, but they also 'wanted' and 'liked' to help:

"I like to do that because my mum just had her two knee replacements...she had a lot of operations before...if she gets landed in hospital I would go in and visit her all the time, that's only me I'm visiting her", (Claire)

There was an acknowledgement and insight from the adults with an ID that their role had changed as a direct result of the changes in their family carer's health and abilities. For example, for Claire, what her mum was able to do, depended on how her mother was feeling that day,

"it depends if she (mum) is in the mood for that (referring to her mum cooking/baking)", (Claire)

For Helen, the change in her parents health and abilities was most pronounced, having seen both significant changes in her parents, with noticing that her father was no longer able to drive, had become more confused, and would wander off due to dementia. Whilst as her mother got older, she became physically impaired:

"I had to help her fix her bra and stuff... she (mother) couldn't bend to put her socks and shoes on so I had to help her", (Helen)

For Helen there was also a sense of achievement and recognition of the help she gave her parents, as they had looked after her, but as they had gotten older:

“(I) looked after the 2 of them”, (Helen referring to both her parents)

4.1.2 Support, and difficulties accessing this

This was the second master theme. When asked who they had or would go to for help, informal sources, as well as more formal sources were mentioned. However, there were also barriers and difficulties to getting support, as well as thinking about what could happen in the future.

Informal Support

For all participants informal support was thought of first, with these often being only one person or a few key people that were known and trusted. This was usually immediate family members and/or neighbours.

“maybe my big sister, or maybe a couple of neighbours”, (Rebecca)

For Helen, knowing she could get support from her next door neighbour was important to her, even though she had only asked for this if things were particularly difficult:

“(neighbour) was the only one I could get...only person I could get to, only person, nobody else but (neighbour)”, (Helen)

There was a theme throughout that as the participants lived with their family carer as a unit of 2, that any issues were possible were solved within that unit, and that support was only asked for from these informal sources as a last resort.

Formal Support

Formal support was often limited and not mentioned as easily or quickly as informal support. Often when participants were asked who they could go to for support, they struggled to identify and name formal sources they could access if they needed help:

“maybe the social worker, or, the, maybe the doctor... erm, I could call the doctor’s surgery”, (Rebecca)

For Helen, formal support for her father helped reduce the demands that were being placed on her, as care staff visited to help her father with her personal care. She also spoke of support from her key worker, such as when her father was in hospital, her key worker at her day service took her to visit him, and the recognition from this worker about what Helen had coped with. For Helen, it was clear that this support took different forms including practical help, and recognition and emotional support.

Barriers and Difficulties

All participants described issues that could be classed as barriers and difficulties, despite their family carer’s support. The barriers and difficulties below are based on those raised during the interview from the perspective of the adult with ID, and demonstrate that even with support from their family carer, they still experienced a range of difficulties from wider systems. One of the main difficulties and barriers adults with ID encountered was knowing what help and support was available, and who they could go to for this. Often, this lack of knowledge about what, if any support was available, led to a sense that there was no option but to just get on with things:

“well I didnae mind helping them, cos it’s my dad and my mum, and I said there’s no one here but me to help them but me, so I helped them....nobody else to do it”, (Helen)

Sometimes, this also lead to difficulties about knowing what and who to go to for help. Helen described a situation where she went to a neighbour and they helped her physically assist her mum to her room. There was a recognition for Helen of the impact of her experience helping her parents, and she described her key worker at her day service acknowledging this by telling her:

“nobody knows what (I) went through”, (Helen, reflecting on helping her parents)

Further, there could be tension with other family members, and a sense of having to keep things ‘within’ the family circle. Helen recalled witnessing an argument between her mother and aunt, over the tasks her mother was expecting her to do, which her aunt felt were too much for Helen. The role of Helen was passive in this, with the word and decision of her mum being final and absolute.

There was also an insight of when financial difficulties were present in the home, and Claire was very aware of these difficulties:

“she (mum) doesn’t get much, she doesn’t get much money looking after me”, (Claire)

Worries about what to do when their family carer’s health is poor or they are ill emerged during the interviews. For Claire, she had tried to contact the GP as she was worried about her mum, but felt conflicted as her mum did not want her to do this:

“If she is not well, if she has a funny turn...I’ve tried to phone the doctor, but she didn’t want me to phone it”, (Claire)

Barriers could also be in terms of written communication as several participants spoke of difficulties with being able to read written communication they received. This did not appear limited to these adults with ID:

“she (mum) reads the letters but she doesn’t ken (know) what that means... they just make the writing so small, mum told them to make it a wee bit bigger for her, but they still don’t do it”, (Claire)

The Future

There were worries and hopes about the future. The general feeling amongst all participants was for things to continue as they were at present, though there was an acknowledgement of hopes and fears for the future.

“maybe a little bit more help in the future....if my mum died”, (Rebecca)

For Claire, she alluded to worries about what would happen if her family carer became ill or died, and that she had thought about living on her own, but that she would want to be near family:

“It’s hard because if anything happens to mum....I don’t want to stay in (current town)...I want to stay in (neighbouring town) with some other family there”, (Claire)

For Helen, she was presently living her future as her family carers had died. She spoke of living on her own in positive terms, of making her own decisions and asserting her independence:

“it’s my house, I can do what I want”, (Helen)

4.2 Results from Participants who were Family Carers

There were two master themes that emerged from the analysis, the first was ‘Our roles living together over time’ and the second was ‘Support: difficulties, and barriers.’

4.2.1 Our roles living together over time

This master theme was comprised of a number of subordinate themes, which are discussed in detail below. All 3 family carers were mothers caring and living with their adult child with an ID. Patricia lived with her son, whilst Alexandra and Mary lived with their daughters.

Changes in my role and my adult child’s role

This was a theme throughout for all 3 family carers who explicitly acknowledged that there were things they found harder to do as they had gotten older. For Patricia she had experienced a sensory impairment that had resulted in a change in both her and her son’s roles:

“That’s (sensory impairment) just been in the last few years... I say (to son) you’ll need to help me”, (Patricia)

Whilst for Mary she was conscious that she was getting older and her health was impacting on what she was able to do around the home:

“I cannae, I struggle (to change the bed)” and “all the illnesses I’ve had”, (Mary)

At the same time, she was able to acknowledge her daughter was doing more such as helping around the house without being asked, and starting to manage her own money,

“she (daughter) just looks after herself....and make sure I’m alright”, (Mary)

Mary elaborated on this further about what her daughter making sure she was alright involved;

“If you’re not well and that she’ll (daughter) come in and visit you (in hospital) and make sure you’re okay and everything”, (Mary)

For Alexandra there was an awareness that it was harder to do things she could do before due to chronic health problems and the impact of this for her, though this was somewhat contradictory at times:

“I’ve slowed down a wee bit...if I take my time I’m fine...I’ve not been that bad” and “I need a hand now”, (Alexandra)

In addition there was an appreciation of the things her daughter did to help her, though this did require some encouragement and instruction from Alexandra, as well as a sense that her daughter valued and wanted to be helpful and caring:

“She’s (daughter) very obliging and she’s helpful”, (Alexandra)

“I think she does enough for me, and she looks after me in her own wee way. She’ll say to me I just want to look after you”, (Alexandra)

The changes in their adult child’s role was usually an increase in practical support. This included reading things out to their carer when asked, and help when going out and about such as tasks like going shopping and on the bus. Within the home environment, household tasks mothers spoke of their adult child with ID doing included tasks such as taking out the bins.

Static roles

Whilst there was an acknowledgement that things had changed, there was also very much a strong sense that these mothers still saw themselves as carers, protectors, and defenders of their adult child. They were keen to stress they were still capable despite there being some difficulties in the things they could do due to changes in sensory abilities and health. These parents were keen to stress that these issues were not having a detrimental impact on what they could do, and that they were still capable carers:

“I’ve obviously looked after him (son)I still do that for him”, (Patricia)

“Things are just the same...nothing has really changed...I’ll always look after (son) you know what I mean, so nothing has really changed”, (Patricia)

“Nine times out of ten I do a lot on my own...I’m still able enough to do things”, (Alexandra)

“It’s me being her mother more than anything” and “I do a lot of things off my own back for her”, (Alexandra)

For Mary, she spoke during the interview of her daughter becoming more independent, but that she felt she had to always be there to check she was okay and ensure her daughter was safe and managing, even when Mary’s had her own health issues to deal with:

“Before I go into hospital I’m going to get food in for her (daughter, to the home)”, (Mary)

“She’s (daughter) a good bit more independent, as long as I keep an eye on her”, (Mary)

Shared tasks

There was a sense from these mothers and family carers that they were part of a twosome with their adult children and they had some shared tasks, where their adult child’s abilities complimented their mother’s abilities;

“we try and work as a wee team”, (Alexandra)

Examples of tasks included laundry, with Mary’s daughter putting the washing out, and Mary bringing it back in. Another example given by Mary was that she brings the empty bins back in as due to her health issues she struggles to pull a heavy bin, whilst her daughter is able to manage this:

“I bring them (bins) in and she (daughter) puts them out”, (Mary)

For Patricia she would prompt her son to do things that she was no longer able to do when they went out shopping. Due to changes in her abilities, neither she nor her son were able to go out to the shops independently, but together they managed to go out and complete this task.

4.2.2 Support: barriers and difficulties

This was the second master theme that emerged.

Informal support

All family carers identified and named immediate family members they could go to for support. For Alexandra, she spoke of her parents previously helping by looking after her daughter when she was a child to give her a break. For current supports, this was usually their other adult children.

“I’ve got my daughters...they would help out”, (Patricia)

Though these mothers spoke of being aware that their other children had their own lives, jobs and families, and so this was a support they used for certain things. For Alexandra she spoke of being conscious of the type and level of demands she felt she could put on her adult son:

“he’s (son) got his own life to lead too...I’m proud of him but...say I was to become ill he wouldn’t be able to take her (her daughter with ID) three days. It would be too much for him”, (Alexandra)

Friends were also mentioned as a source of support. However, regardless of whether it was family or friends, trust in the person they were confiding in is essential,

“I usually try and talk to friends, somebody I can confide in and trust...there’s not a lot of people that I do trust”, (Alexandra)

Formal support

For Patricia when she had encountered difficulties with her son, she had described going to see her GP for support and explicitly asking for help:

“I asked the doctor you need to refer me to somebody, I need help here. (community ID nurse) has been really good with (son)... (social worker) has been really good...I feel I’ve got quite a good support there”, (Patricia)

For Patricia she spoke of having a positive relationship with these professionals supporting herself and her son. She spoke of trusting these professionals:

“I don’t hold anything back...it’s to help (son), everything is to help (son) and I feel I can’t hide it back”, (Patricia)

“I’ve had a lot of support from the team (Community ID Team)”, (Alexandra)

However, other generic services were accessed for support, particularly when it came to dealing with letters and forms:

“I have to go to Citizen’s Advice a lot...I’m hopeless with forms...they (referring to Citizen’s Advice) are quite helpful”, (Alexandra)

Barriers to getting support

For Alexandra one of the key barriers to accepting formal support was opposition from her family:

“I held back a lot before I decided to accept (formal) help...they (family) wouldn’t let me take the help”, (Alexandra)

Barriers or difficulties with getting help included waiting lists to access support from community ID teams:

“It’s like everything else, you’ve got to wait (referring to be on waiting list for a community ID nurse for her daughter)”, (Alexandra)

Experiences of social work input varied widely. Family carers spoke of the time it took for a social worker to be allocated to their adult child with ID. In addition the brevity of social services input when a social worker did finally become involved was mentioned as being an issue for several of these mothers, as well as the lack of written information and impact this had on relationships with social work:

“You’re lucky if you get the support (from social work) for about three month”, and “I just felt, well, I wasn’t getting the support from them (social work)”, (Alexandra)

“he (social worker) told us his first name so I can’t even remember that, because it was never written down or anything...I wasn’t getting a lot of information”, (Mary)

There were also barriers in terms of having the knowledge of what benefits and services were available to offer support. Mary had previously tried to get benefits due to financial difficulties. However, she spoke of being told she was eligible for this several times by other parents with children with an ID. It was clearly frustrating for Mary that information on support was not being easily available and having to depend/find out about benefits and services through chance discussions with other parents:

“I gave up (applying for carer’s allowance) because it was a waste of time really...annoys me when I can’t get help...nobody tells you (referring to what help is available)”, (Mary)

There was also a sense of feeling overwhelmed and unsure of who to turn to for support;

“I wouldn’t know what to do”, (Mary)

The impact of having a child with an ID

Alexandra spoke of learning when her daughter had an ID at an early age, and taking on board what this meant.

“she’s (daughter) easily distracted” and “She’s (daughter) very dependent on me”, (Alexandra)

“I’ve got to prepare her for things”, (Alexandra)

Patricia spoke of how due to her changing abilities, she had been encouraging her son to gradually develop his skills, and her pride in his achievements at him gaining new skills such as being able to have a shower himself and learning to make a cup of tea:

“I’m glad that he is able (to help)...I’m happy he is able to do that now...before everything was done for him”, (Patricia)

There was a sense of this role of carer being continuous, and that this responsibility of being a parent to a child with additional needs was a lifelong responsibility:

“I’m quite stubborn and headstrong...as long as I’m able to look after her (daughter), I will”, (Alexandra)

Alexandra described have some paid employment as a positive and seeing going to work as an escape. She spoke of wanting to be able to work more hours, but that due to welfare benefits, she would not be any better off;

“I’ve got to have a life of my own as well”, (Alexandra)

“When (daughter) is out I’m out...but usually it’s just at the weekends I’m socialising”, (Alexandra)

However, Alexandra also spoke of the positives in her relationship with her daughter in terms of the purpose and *raison d’être* that this relationship gave;

“she (daughter) keeps me going”, (Alexandra)

There was some insight into wanting to keep doing things for their child, but that they had to allow their adult child the opportunity to develop their skills and allow their independence to grow. This would likely be automatic for most children going into adulthood, but children with ID often do not have the same access to develop these skills;

“I think I had to realise what she was going to do when I’m not here”, (Mary)

But with her daughter having an ID, there was also an awareness that learning these skills would be harder for her daughter;

“She’s (daughter) not got the mind of her age. She’s younger than what she is mentally”, (Mary)

An uncertain future

There were worries about the future for all 3 participants. There was a sense that energy and coping was channelled into trying to cope and survive in the current time, resulting in little energy and resources to consider thinking about the future in any depth:

“I just take it day by day I think”, (Patricia)

“I’ve just got a lot on just now”, (Alexandra)

“I’m quite happy just struggling along”, (Mary)

There was some alluding to the future, though plans were often hazy and vague. The uncertainty of what exactly the future would hold, was difficult to face, both for the carer, and their adult child:

“Eventually, I know I probably have to think about respite...maybe as I get older”, (Patricia)

“It’s always coming up about independent living...I know one day it will happen but I can’t really speak to (daughter) about that because she gets upset about it”, (Alexandra)

“I’ve got a plan...an emergency care plan”, (Alexandra)

There were some hopes for the future, but these were fragile. Mary's daughter was waiting for a council flat, as she had planned for her daughter to eventually move into her own place, though with Mary living nearby, however, despite waiting for several years, no suitable properties had come up, and it was clear for Mary that she was conscious she was getting older, her health problems were ongoing, and that she felt things were stuck with her daughter not being able to be settled in case anything happened to Mary;

“Hopefully living near each other...knowing that she's okay would make me fine. I wouldn't need to worry...I'm not getting any younger”, (Mary)

Mary stated explicitly and clearly what she wanted for her adult child for the future, but that these hopes were dependent on systems out-with her control;

“I want her to be in a house settled, in case anything happens to me”, (Mary)

4.3 Summary of Themes in both adults with ID and family carers

Overall, from separate analyses of data from adults with ID and family carers, 2 master themes emerged for each group. See Tables 4.1 and 4.2 for details of the master and subordinate themes that emerged in each of these groups.

In both adults with ID and family carers there were common themes about changes in roles and helping each other, as well as around the broader theme of support, challenges, and difficulties. Both groups were aware of the changes in family carers' abilities as they get older and they have health or age-related sensory difficulties. For adults with ID they were very aware of the changes in their family carer and spoke of worries about what the future. Whilst family carers were aware of the changes in their health, they tended to downplay the impact this had on what they could do as a family carer.

4.4 Discussion of the findings

Now the project has finished, the researcher will send out a brief summary of the findings to all participants as previously planned. This will include an easy read version of the summary for adults with ID who took part.

There were several key messages from the findings of this project, and these are related back to the research aims. As these are based on the small subset analysis of 6 participants (n=3 adults with ID, and n=3 family carers), caution must be taken in terms of the recommendations that can be made and the conclusions drawn.

There are several conclusions arising from this thesis. The in-depth nature of the interviews in this study gave a richness and level of detail about the informal and formal support available, as well as the barriers and difficulties that both adults with ID and family carers face. It is argued that previous research has acknowledged this only briefly (Gant, 2010; Williams & Robinson, 2001).

Language used to describe mutual care

None of the adults with ID or the family carers used the term mutual care to describe the support they gave and received from their relative. The term “care” was not really used by this group and did not appear to be a term they identified with. The preferred term was “help”, with adults with ID in the current study seeing the things they did as “helping” their family carer, and this echoes the findings of research done by Walmsley (1996). Although this term is general and lacks specificity, it does encompass different forms of support, and is a common word that is easily understood by others.

Types of support provided

The types of support provided by adults with ID to their family carers tended to be practical support such as helping with household tasks, or those that involved carrying or pulling something weighty (e.g. food shopping or taking out the bins). It could also involve helping their family carer when out and about. For some adults with ID the support they provided involved hands-on care to their

family member. In all the support provided, there was an increase in the sense of responsibility the adult with ID was taking on, and the skills they had developed. Like Gant (2010, and Williams & Robinson (2001), this study found that adults with ID were providing support through practical tasks include household chores such as laundry and emptying the bins. In addition, there were also shared tasks that the adult with ID and family carer did jointly, supporting the findings of Knox & Bigby (2007).

Often this shift towards mutual care appeared to be triggered by a change in the health or abilities of the family carer. These changes in health and sensory abilities were usually due to the family carer ageing. Often, these mutually caring partnerships developed naturally and unconsciously, with a sense that if the family carer needed help, then their son or daughter would help them if they were able to.

Views and experiences of people with ID on mutual care

For most of the adults with ID, their experience of mutual care had often not been consciously chosen. They were often aware and had some insight into the changes in their family member's abilities and recognized their carer was getting older. This finding supports and adds to previous research which found adults with ID did have awareness and showed concern regarding the welfare of their older family carer (Gant, 2010; Williams & Robinson, 2001). The overwhelming sense from adults with ID is they were supportive of their family carer's position, with support being offered willingly, echoing Gant's (2010) finding that adults with ID spoke with pride about the support they provided to their older family carer. However, for some, support given for certain tasks the person with ID did not like was given more out of a sense of duty and obligation to their family carer. This latter finding partly supports Walmsley's (1996) study that found for some adults with ID, mutual care had led to feelings of unhappiness and frustration at the demands that were made of them, and that they did not feel they had a choice in taking on these tasks.

There was for some an acknowledgement that there could be difficulties though there was a sense of acceptance regarding their situation. Often, they did not see themselves as caring for their parent, which supports Gant's (2010) finding that adults with ID viewed it as helping make life

easier for their older parent. For some there was a sense of purpose and value, but for others there had been real difficulties that they had to endure and muddle through. Overall though, even where there had been challenges, the general feeling was a sense of a close and supportive relationship with their family carer.

Views and experiences of family carers on mutual care

In this project the analysis was based on mothers' experiences. Whilst they acknowledged the help their child provided them, they continued to see themselves as the "carer" and parent of their child, and there was a sense of perpetual responsibility towards their adult child in terms of protecting and keeping them safe. This may have been due to their perceptions of their adult child's vulnerability due to their ID, or possibly that their main role and *raison d'être* had been to care for their child, and so there was likely a lot of their value, identity and purpose attached to this role.

Often these family carers acknowledged changes in their health or abilities that tended to occur as they got older. However, they also appeared keen to stress that they were still capable to care for their child, and decision-making responsibilities remained with the family carer, despite their being some changes in roles. This latter finding echoes previous research which found that even when family carers abilities had changed, often family carers retained all the 'power' and 'control' when it came to decision-making (Knox & Bigby, 2007; Walmsley, 1996). Often this help from their adult child was viewed as helping their son or daughter learn new skills and gain some independence, rather than their child helping them with tasks they would either struggle or be unable to do.

Support for adults with ID and family carers

Support could be split into informal and formal sources of support. Adults with ID tended to struggle to identify and name sources of support. Often informal support were mentioned first, and these tended to be a select few individuals, being either immediate relatives such as adult siblings, or people they knew and trusted such as next door neighbours.

For formal sources of support, adults with ID mentioned people they already knew or had encountered, but in terms of identifying sources very few were mentioned. Often if there was someone involved or known to them in a professional capacity and if a formal source had helped them previously or had ongoing involvement, they sometimes mentioned them as a source.

For family carers, informal sources of support tended to be other adult children or friends, and trust was important in accessing these individuals as sources of informal support. There was also an acknowledgement that there other adult children had their own lives, and these family carers were keen not to overwhelm or overly depend on these sources.

For formal sources of support, family carers spoke of specialist ID services such as social work and community ID teams. Other more generic sources were also mentioned such as Citizens Advice for help with things like filling in forms.

Barriers to seeking/getting support

For both adults with ID and family carers, when it came to informal support, there was a sense that where possible these were only accessed if within their partnership they were not able to solve difficulties. It appeared that these sources of support were only sought as a last resort or when things became particularly difficult. It was acknowledged that these individuals who were named as informal support were often seen as having their own lives, and other responsibilities and demands.

For adults with ID there were numerous barriers to seeking and getting support. The first was around a lack of accessible information and knowledge on sources of support. In order to access support an individual needs to know there is support available, that they are eligible for this support, and what this support could look like. There was also a strong sense of a lack of recognition from others of their mutual caring role, and so if this is not recognized by others, support may not be offered when they are needed.

For family carers there were various barriers to support. For some, resistance from family put them off taking formal support that had been offered. In addition waiting lists for community ID team input were mentioned. Regarding social work input, some had also experienced waiting lists for this, and it was raised that social work input was often very brief and felt somewhat impersonal.

There were worries about the future, from both adults with ID and family carers. There was a sense from adults with ID that they were not aware what options of support were available. For family carers, there was a sense of their energy being spent on managing day to day, and that the future was something they were aware of but their resources were tied up in keeping their head above water. For those who had made explicit plans, there were barriers around available housing for their adult child to move into on their own, and this could be frustrating.

Conclusion

In summary, this chapter has described the results of the analysis of the subset of data used in this study. The data were analysed using Interpretative Phenomenological Analysis (IPA). The resulting master and subordinate themes for adults with ID and family carers have been described in detail separately, with quotes used to support each theme. Themes from both adults with ID and family carers were considered. Finally, the key findings of the study were discussed in relation to the research aims and in the context of the existing literature.

The next chapter will look at conclusions and recommendations based on this research. Reflections on the project will be discussed including some of the difficulties encountered by the researcher. The strengths and limitations of the research will be considered, before potential next steps for the study will be explored, as well as wider issues future research should aim to address. Finally, the clinical, social, and policy implications from this research will be discussed.

Chapter 5: Conclusions and Recommendations

This chapter will look at the conclusions and recommendations arising from this research. Some of the issues that arose during the process of undertaking this research project will also be discussed and reflected on. Limitations and strengths of this research will be discussed, including possible future steps and directions to be considered, as well as wider issues which future research should aim to address. Finally, the clinical, social and policy implications of the findings will be considered, with suggestions for ways of addressing these.

5.1 Conclusions from this thesis and Recommendations arising

There are several key conclusions from this project for both adults with ID and family carers. The first is that none of the adults with ID or the family carers used the term mutual care to describe the support they gave and received from their relative. The preferred term was “help”. Both groups also had worries about the future; for adults with ID they were not aware what options of support were available, whilst for family carers the future was something they were aware of but their resources were tied up in keeping their head above water day to day.

For adults with ID, the types of support provided by adults with ID to their family carers tended to be practical tasks they did on their own or jointly with their family carer. In all the support provided, there was an increase in the sense of responsibility the adult with ID was taking on, and the skills they had developed. Often the shift towards mutual care appeared to be triggered by a change in the health or abilities of the family carer, usually due to ageing, and for most of the adults with ID, their experience of mutual care had often not been consciously chosen. Adults with ID tended to struggle to identify and name sources of support, reasons for this included a lack of accessible information and knowledge on sources of support. There was also a lack of recognition from others of their mutual caring role, and this contributed to the lack of support.

Conclusions from family carers in this thesis were solely based on mothers’ experiences. Whilst they acknowledged the help their child provided them, they continued to see themselves as the “carer” and parent of their child, and there was a sense of perpetual responsibility towards their adult child in terms of protecting and keeping them safe. They often acknowledged changes in

their health or abilities as they aged but were keen to stress that they were still capable to care for their child, and they retained decision-making responsibilities. In terms of supports, informal sources were favoured (e.g. trusted other adult children or friends), but family carers were keen not to overwhelm or overly depend on these sources. For formal sources of support, family carers spoke of specialist ID services such as social work and community ID teams, as well as generic services (e.g. Citizens Advice). For family carers there were various barriers to support, including resistance from family to access formal supports, as well as waiting lists for both community ID team and social work input.

It is recommended that services for both adults with ID and family carers, as well as third sector and generic support services, are aware that mutual care may be occurring in the families they are working with, and that it likely will not be described or viewed as “care”, instead more likely as “help”. There is a need for professionals and services in this area to increase their awareness and openness to the possibility of mutual and reciprocal care, for example by actively asking families about this. This will help identify if mutual caring is occurring, so that it is recognised and acknowledged by services. This requires an openness to viewing adults with ID as being care-givers as well as care-recipients, (the latter will likely require not just a personal or professional shift in attitudes, but also societal in terms of how adults with ID are viewed). This recommendation could be delivered through staff or awareness training, as well as the use of case studies, or input from families with lived experience of mutual care.

The second recommendation is a need for recognition and appropriate supports, as there is no point of increasing awareness of mutual care, if there are no supports for identified needs e.g. respite care for either the adult with ID and/or family carer, or paid carers “topping up” mutual care if needed. It is also important that services are aware that both adults with ID and family carers may not know of what support is available and how they can access these.

It is recommended that future research explores mutual care amongst married people where one or both spouses have an ID. This was not included in this project, and it is felt this population deserves to be looked at and explored in its own right. It is also recommended that research should try and include those adults with ID and family carers not known to formal services. As they would not

be in receipt of any formal support or services, then it is possible their experiences may differ to those known to services. However, by the very nature of this population not being known to services, it is acknowledged that it can be very difficult to identify, target, and access this population for research.

5.2 Reflections on issues encountered during this project

Over the course of this project there were several developments and issues that emerged, some of which were anticipated and some that were not, and this has led to the following reflections.

Re-defining mutual care

Initially mutual care was defined as when both the family carer and person with intellectual disabilities (ID) are caring for and supporting each other, and includes an element of practical and tangible support (e.g. help with cooking and cleaning, dispensing medication), as well as potential emotional support (e.g. keeping their family carer company, and ‘being there’). In situations where mutual care is present, both the person with the ID and the family carer have taken on a caring and supportive role, and are often interdependent on each other. As there was a lack of research on this topic, this definition was seen as a working definition.

However, it soon became clear that this definition was lacking and inflexible as it assumed that the person with an ID was living with the family carer who was an immediate family member. During visits to services to let them know about the project, numerous staff spoke of families they knew where there was an interdependency and queried whether this would fit the definition of mutual care for this project, such as those living nearby to their family member, or mutual care occurring with an extended family member.

It is suggested that mutual care needs to be reconceptualised and redefined to allow it to encompass the variety of situations that adults with ID and their family members are experiencing. This would require broadening and increasing the flexibility of the term mutual care. It is felt this is required as if the term is too narrow it loses its utility and applicability and runs the risk of being meaningless.

In this project married couples (where either one or both had an ID) were not included. Yet, it is likely that there would be a mutually caring relationship in most marriages. This is something that should be potentially be included in definitions of mutual care.

Recruitment Issues

Initially, it was decided to recruit participants through non-NHS organisations. This approach was used as it was felt that if the researcher approached potential participants directly, they may feel coerced, particularly for adults with ID, where there can sometimes be a potential power imbalance or a desire to please others. Initial informal enquiries to local councils and third sector organisations indicated anecdotally that some staff had come across situations of mutual care between adults with ID and their family carers.

However, once University ethical approval was granted and recruitment through non-NHS sources began in earnest, it became clear that there were some unexpected recruitment difficulties. The response to the project and assisting with recruitment varied widely across different services. It was made clear that any potential participants had rights and participation would be voluntary, but that services were being asked to pass on information to potential participants so they could make the choice themselves about whether they wanted to participate or not.

It became apparent to the researcher that there appeared to be some suspicion about the motives of the project by a few services. This had not been anticipated by the researcher as being a potential issue. Unfortunately, despite meeting with some of these services to reassure them that the project had ethical approval, give them a chance to have any concerns answered, and reassure them that there was no ulterior motive (as this would be unethical), unfortunately, ultimately these services refused to support the project.

Amongst some services that did agree to support the project, there was evidence of some ‘gate-keeping’ by staff. This may have been due to staff concerns about passing on information about the project to either adults with ID or their family carers as they felt it was either not the appropriate

time or that it the person would not want to participate. Although well-intentioned, the outcome of this was that these potential participants were never told about the project and thus never had the chance to decide and choose for themselves whether or not to take part in the project.

As a result of difficulty recruiting participants from these organisations, the decision was made to recruit through NHS Community ID Teams. This required going through the IRAS ethics process which was a considerable undertaking. However, once a favourable ethical opinion was granted, a number of participants were recruited, and it was felt this was a worthwhile process. On reflection, it would have been preferable to have applied for NHS ethics at the same time as University ethics. The period of time where no participants were successfully recruited through non-NHS sources (despite the researcher's best attempts) meant the recruitment period had to be further extended once NHS ethics was granted. This lead to delays in the project as it took significantly longer to recruit sufficient numbers of participants than originally planned.

Breadth and Size of the Project

This project was ambitious in size and number of participant groups. Both the researcher and some of the supervisors have an interest in ID and had worked clinically in ID services, and thus there was a real passion to explore mutual care across various different groups that would have either experienced this or known families where it was occurring. The sample size was discussed by the researcher and their supervisors prior to the study commencing. There were some concerns about the proposed sample size, and as a result it was amended to include the words "up to" 10 in each group to allow some flexibility in reducing proposed sample sizes.

However, the total number of participants recruited lead to a huge amount of data being generated. For the researcher this was their first qualitative research project, and after seeking guidance from an experienced expert in qualitative research, it was acknowledged that this was too much data for an MRes project. This was why a subset of data was chosen for the purposes of this thesis. On reflection, a smaller sample size or fewer participant groups would have been appropriate, and it is noted that it would have taken less time to recruit fewer participants.

5.3 Strengths of this research

A strength of this project was that a thorough and systematic search was carried out to identify what the existing literature was on this topic. This led to clear gaps and inconsistencies in the literature being identified, which this research tried to address. Another strength of this research is that it tried to recruit adults with an ID and family carers across a broad variety of organisations including statutory and third sector organisations, to try to reach a wide range of potential participants, covering both urban, suburban, and rural areas. The researcher also took various steps to reduce potential barriers to participation in research. For example, participants with an ID were given the option to first meet the researcher informally to discuss any questions they had about taking part, and practical steps were taken to try to increase their comfort - such as the production of easy read and pictorial information sheets and consent forms, and having the option of having a friend or familiar person present during the interview if they wished. Processes to minimise any potential imbalance of power between participants and researcher were also introduced, for example, adults with an ID were initially told about the project by someone not directly involved with the project. This was a conscious part of the recruitment strategy, to minimise the risk of participants potentially feeling obligated or pressurised to take part. In terms of rigour, certain strategies were used in this study as recommended by Noble & Smith (2015), such as using rich verbatim descriptions from participants to support findings, as well as inviting participants to comment on the interview transcript, which also partly limits the potential for bias from the researcher in terms of reflexivity.

5.4 Limitations of this research

There are several limitations of this research. Firstly, only a proportion of the data gathered was analysed, meaning its credibility and trustworthiness is potentially compromised, which in turn means caution must be employed when drawing conclusions and limits the recommendations that can be made. It is also acknowledged that this research was very ambitious for an MRes, in its scope to try to recruit across multiple populations. Whilst not all data collected was analysed and reported in this dissertation, the rest of the data will be analysed for further publication by the student's supervisors. The data from interviews with health and social care professionals is felt to be particularly important, as this does not appear to have ever been researched before. Whilst there

was a justification for using interviews to gather data, this could have disadvantaged adults with an ID who had limited verbal abilities and/or a more severe level of ID, as well as potential participants who were not able to converse freely in English, for example, those for whom English was not their native language. It is also acknowledged that only participants known to services were recruited. Only a proportion of the population of adults with ID and family carers will be known to services, so a sizeable proportion of eligible people who experience mutual care may not have been aware or been able to take part in this study. It is also acknowledged that on reflection rigour could have potentially been improved, by having the analysis repeated to ensure reliability and allow potential for other perspectives to emerge (of those doing analysis); however, this would have been challenging to do in the context of an MRes, where resources were limited. This study did not employ all the 9 strategies recommended by Noble & Smith (2015), which was predominately due to the researcher doing the analysis themselves, and there being no option to have other(s) repeat the analysis to see what similarities and differences arose from having more than one person doing the analysis in terms of other perspectives which would have increased the richness of the data analysis, as well as helped improve reflexivity, as a limitation of this project is that only one researcher carried out the data analysis. It is also acknowledged that the researcher was new to qualitative research at the start of this project, and having now been through the process, on reflection, if they had completed a reflexive research diary, as recommended by Rolfe (2006), this would have enhanced both the rigour and reflexivity of this project and its findings.

5.5 Clinical and Social Implications

This project aimed to explore experiences of mutual care. It is hoped the findings and key messages from this project, from all the data collected can be disseminated widely.

Across services and organisations supporting adults with an ID and/or family carers, there needs to be improved awareness and recognition of mutual care, so that it can be identified and supported in a way that is helpful to both the adult with ID and the family carer. A way of addressing this could be through training or awareness raising for staff in health, social, and third sector organisations, as staff in these sectors are likely to be working with adults with an ID and/or family carers. Staff in these support services are likely to be in a good position to provide support or signpost these families on to support services they can access.

When situations change and there is no support from others, formal or informal, then there is potentially a high risk of a mutual care situation escalating into a crisis. It should also be noted that lack of knowledge/awareness of their rights for adults with ID could result in them not always willingly taking on a mutually caring role. If they are not given a choice about providing help, then there is a risk of exploitation or coercion. Where mutual care is present, there is a duty on statutory services to check that this is being done willingly, and not in an abusive way for the adult with an ID and/or the family carer. If one of the parties in the mutual care situation is being coerced, the person is not making an informed choice to provide the care. In these circumstances there may be a duty for statutory services to intervene under The Adult Support and Protection (Scotland) Act (2007).

More widely, there needs to be a recognition that the dichotomy of ‘carer’ and ‘cared for’ is not always accurate, as most relationships are intertwined and reciprocal, often involving mutual care. Part of what perpetuates this dichotomy are systemic factors such as social attitudes and prejudices towards people with an ID. For families where mutual care is present, there needs to be recognition of this by not just the family carer and the adult with an ID, but by those in the wider system such as family, friends, and services. Advocacy services may be particularly well-placed to raise awareness of this within the ID population.

There is also a need to acknowledge that there will be a change in the number and needs of people with ID for social care services. It may therefore be increasingly challenging for social care workers to deliver services to those in need. Emerson & Hatton (2008) estimated that there will be an increase in the number of older adults with ID, and young people with complex needs in England from 2009 to 2026.

5.6 Policy Implications

Most health and social care policy tends to see adults with an ID as being ‘cared for’ and family members they live with as ‘carers’, for example, when applying for welfare benefits such as Carer’s Allowance. This may perpetuate the view that adults with an ID are always receiving care,

and that their relationships are not reciprocal. Potentially, if adults with an ID were recognised as carers, it may have an impact on policy, in terms of their eligibility for benefits in respect to their caring role.

For mutual care to be properly recognised, adults with an ID engaged in mutual care need to be recognised as carers. From a policy perspective, this would increase the demands on local authorities to support them, as outlined by the Care Act (2014) in England, and the Carers (Scotland) Act (2016). In the current climate of austerity, this could be a challenge for local authorities, but it must be acknowledged that adults with an ID are one of the most vulnerable and marginalised groups in society.

In Scotland, the first strategy published by the Scottish Government for people with ID was ‘The Same as You’ (2000). This led to the closure of long-stay hospitals and a move to more person-centred and community-based care and support. Following this, the Scottish Government published a new strategy called ‘The Keys to Life’ (2013) which outlined the Scottish strategy for ID. Although ‘The Keys to Life (2013) made a number of recommendations (52), these have been predominately around health, as this has been an area where there have been significant inequalities (for example Emerson & Baines, 2010; Heslop et al., 2013), as well as making services more accessible for people with ID. However, there are no specific recommendations around mutual care, and this is something that future strategies and policies on ID should try to address.

5.7 Closing Remarks

In summary, this chapter has discussed the key findings from the results of this study, their implications, and recommendations arising from these. Some of the issues that arose during the process of undertaking this research have been discussed, and reflected on by the researcher. Strengths and limitations of the research have also been considered. The next steps for the study have been outlined, along with consideration of wider issues which future research should aim to address. Finally, potential clinical, social, and policy implications have been discussed, with reference to the need for increased awareness and recognition of mutual care from services for adults with an ID and their family carers, as well as possible ways to address these implications.

Hopefully future research will help raise awareness and recognition of this currently neglected area.

References

Alzheimer's Society (2014). *Dementia UK: Update*. Second Edition. Alzheimer's Society, UK.

Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15 (2), 219-234.

Bibby, R. (2013). 'I hope he goes first': Exploring the determinants of engagement in future planning for adults with a learning disability living with ageing parents. What are the issues? A literature review. *British Journal of Learning Disabilities*, 41, 94 – 105.

Bowey, L. & McGlaughlin, A. (2007). Older Carers of Adults with a Learning Disability Confront the Future: Issues and Preferences in Planning. *British Journal of Social Work*, 37, 39 – 54.

Bowey, L. & McGlaughlin, A. (2005). Adults with a Learning Disability Living with Elderly Carers Talk about Planning for the Future: Aspirations and Concerns. *British Journal of Social Work*, 35, 1377 – 1392.

British Psychological Society (2015a). *Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood*. Leicester, UK: The British Psychological Society

British Psychological Society (2015b). *Dementia and People with Intellectual Disabilities*. Leicester, UK: The British Psychological Society.

Bryman, A. (2008). *Social Research Methods*. Third Edition. Oxford University Press.

Cairns, D., Tolson, D., Darbyshire, C., & Brown, J. (2012). The need for future alternatives: an investigation of the experiences and future of older parents caring for offspring with learning disabilities over a prolonged period of time. *British Journal of Learning Disabilities*, 41, 73-82.

The Care Act (2014). Parliament, Westminster, London, UK.

Carers (Scotland) Act (2016). Scottish Government. Edinburgh, UK.

Carvill, S. (2001). Sensory impairments, intellectual disability, and psychiatry. *Journal of Intellectual Disability Research*, 45 (6), 467-483.

Emerson, E. & Baines, S. (2010). Health Inequalities & People with Learning Disabilities in the UK: 2010. Improving Health & Lives: Learning Disabilities Observatory, Durham.

Emerson, E. & Hatton, C. (2008). Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England. Centre for Disability Research, Lancaster University, UK.

Foundation for People with Learning Disabilities (2018). Learning Disability Statistics: Support. <https://www.mentalhealth.org.uk/learning-disabilities/help-information/statistics/learning-disability-statistics-/187696> Access online 16th September 2018.

Foundation for People with Learning Disabilities (2015). *Thinking ahead: a planning guide for families*. Mental Health Foundation, London, UK.

Gant, V. (2010). Older Carers and Adults with Learning Disabilities: Stress and Reciprocal Care. *Mental Health and Learning Disabilities Research and Practice*, 159-172.

Grant, G. (1986). Older Carers, Interdependence and the Care of Mentally Handicapped Adults. *Ageing and Society*, 6, 333 – 351.

Grant, G. (1990). Elderly Parents with Handicapped Children: Anticipating the Future. *Journal of Aging Studies*, 4 (4), 359 – 374.

Harper, D. (2011) 'Choosing a qualitative research method', in Harper, D. and Thompson, A. R. (eds.) *Qualitative research methods in mental health and psychotherapy*: Wiley-Blackwell.

Heslop, P, Blair, PS, Fleming, PJ, Hoghton, MA, Marriott, AM & Russ, LS, (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report. Norah Fry Research Centre, Bristol, UK.

Hubert, J. (2006). Family carers' views of services for people with learning disabilities from Black and minority ethnic groups: a qualitative study of 30 families in a south London borough. *Disability and Society*, 21 (3), 259 – 272.

Judge, J., Walley, R., Anderson, B., & Young, R. (2010). Activity, Aging, and Retirement: The Views of a Group of Scottish People with Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 7 (4), 295-301.

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 their lives together”. *International Journal of Disability, Development and Education*, 54 (3), 287-304.

Kramer, J., Hall, A., & Heller, T. (2013). Reciprocity and Social Capital in sibling relationships of people with disabilities. *Intellectual and Developmental Disabilities*, 51 (6), 482-495.

Mays, N. & Pope, C. (1995). Rigour and qualitative research. *British Medical Journal*, 311, 109-112.

Mencap (2018a). How common is learning disability? <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability> Accessed 16th September 2018

Mencap (2018b). Employment. <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/employment> Accessed 17th September 2018.

NHS Digital (2017). Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017. <https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017> Accessed 16th September 2018.

Need2Know: Mutual Caring (2010). *Foundation for People with Learning Disabilities*.

Noble, H. & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence Based Nursing*, 18 (2), 34-35.

Padgett, D.K. (2016). *Qualitative Methods in Social Work Research*, 3rd Edition. SAGE Publications.

Perkins, E.A. & Haley, W.E. (2013). Emotional and tangible reciprocity in middle- and older-aged carers of adults with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 10 (4), 334-344.

Popay, H., et al. (2006). Guidance on the conduct of narrative synthesis in systematic reviews; a product from the ESRC methods programme.

<http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.178.3100&rep=rep1&type=pdf>
Accessed 24th September 2018.

Prosser, H. (1997). The Future Care plans of older adults with intellectual disabilities living at home with family carers. *Journal of Applied Research in Intellectual Disabilities*, 10 (1), 15-32.

Rolfe, G. (2006). Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*, 53 (3), 304-310.

Ryan, A., Taggart, L., Truesdale-Kennedy, M., & Slevin, E. (2013). Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary. *International Journal of Older People Nursing*, 00, 000–000 [10.1111/opn.12021](https://doi.org/10.1111/opn.12021)

Scottish Commission for Learning Disability (2017). Learning Disability Statistics Scotland 2017. Published 5th December 2017. <https://www.scld.org.uk/wp-content/uploads/2017/12/2017-Learning-Disability-Statistics-Scotland.pdf> Accessed online 16th September 2018.

Scottish Government (2013). *The Keys to Life - Improving Quality of Life for People with Learning Disabilities*. Edinburgh, UK: Scottish Government

Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. SAGE Publications.

Starks, H. & Trinidad, S.B. (2007). Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory. *Qualitative Health Research*, 17 (10), 1372-1380.

Taggart et al. (submitted for publication). Mutual Support: an exploration of the role of adults with intellectual disabilities caring for their older family carers. *Disability & Society*.

The Adult Support and Protection (Scotland) Act (2007). Scottish Government, Edinburgh, UK.

The Same as You (2000). Scottish Government, Edinburgh, UK.

Walker, C. & Ward, C. (2013). Growing Older together: ageing and people with learning disabilities and their family carers. *Tizard Learning Disability Review*, 18 (3), 112-119.

Walmsley, J. (1993). Contradictions in Caring: reciprocity and interdependence. *Disability, Handicap & Society*, 8 (2), 129-141.

Walmsley, J. (1996). Doing what mum wants me to do: looking at family relationships from the point of view of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 9 (4), 324-341.

Weeks, L.E., Bryanton, O., Kozma, A., & Nilsson, T. (2008). Well-being of Mid- and Later-life mothers of children with developmental disabilities. *Journal of Women and Aging*, 20, 115-129.

Williams, V. & Robinson, C. (2001). 'He will finish caring up for me': people with learning disabilities and mutual care. *British Journal of Learning Disabilities*, 29, 56 – 62.

Appendix 1: Project Information Sheet and Consent form for Adults with ID

Information about the study

Photo of
Researcher

Hello my name is Gillian.
I am a researcher at Edinburgh Napier
University.
I work with people like you.



We are doing a study.

A study is a way of finding things out.

Do you want to be in the study?



This information sheet tells you about the study.

This is to help you decide if you want to be in
the study or not.



This is what we want to find out:

We want to find out about your experiences doing things to help your family member.

This includes what you do to help them.

We also want to find out how you feel about this.

Why do we want to find this out?



Listening to your experiences will help us understand what it is like for you to help your family member.

This will help staff and carers know what sort of supports help people who care for a family member.

What will you have to do?

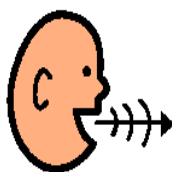


Photo of
Researcher

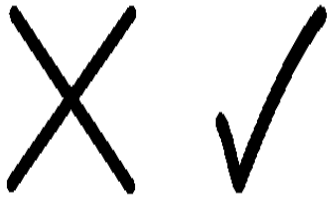
Gillian would like to meet you. Gillian will ask you some questions about the things you do to help your family member and how you feel about this.

Gillian can meet you at a time that is good for you. This could be at your work, day service or at home.

You can meet with Gillian on your own or with a family member, friend or staff member if you would prefer.

The meeting up to talk may take up to 1 hour to complete.

We may also ask your family member about the help you provide to them.



We will ask you to be in our study.

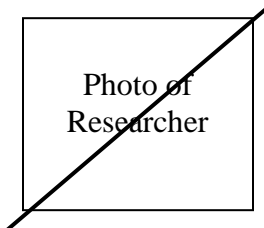
You can say yes or no.



If you decide you want to be in the study you must sign your name on the consent form at the end of the information sheet.

If you find it difficult to write, someone else can help you.

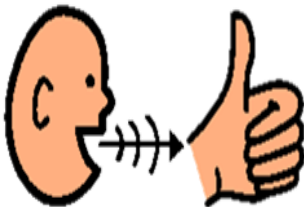
What happens if I say no?



If you do not want to be in the study that is okay. You can say no.

Gillian will NOT contact you again.

What happens to the information I tell Gillian?

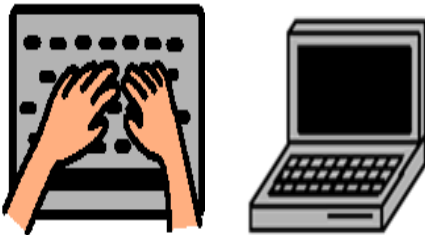


Everything you tell Gillian is private.

Gillian will not let anyone know who talked to her for this study.

If you tell us someone is hurting you or you are hurting somebody we will have to pass this information on. But we will tell you if we are going to do this.

What happens to the information after the interview?



Gillian will put your answers to the questions into the computer. Your name will not be put into the computer. No-one will know that the answers are you.

The only people who will be able to see your answers are Gillian and the other people in Gillian's team.

What we will do with the information



When the study is finished we will tell others about what we have found out.

We will write about this in a magazine or in a report.

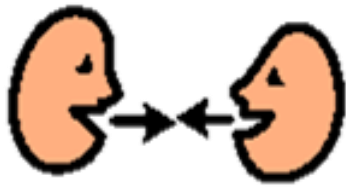
If you want, we can give you a copy of the report so you can read about what we found.

No one will know that what you said. We will use a pretend name. We will not tell anyone your name. No one will know that it was you that said it.

Can the study upset you?



Most people will not be upset by the study. But thinking about the help you provide, and how you feel might make you sad.



You can leave the meeting at anytime.

You must have someone (a family member, friend or carer) who you can talk to about this. You can also talk to Gillian and others after the meeting if you want to.

Contacting Gillian

Photo of
Researcher

You or your carer can contact Gillian if you want to know more about the study:



Gillian's phone number is [REDACTED]



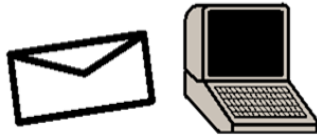
Or you can write to Gillian.

Her address is:



[REDACTED]
School of Nursing, Midwifery & Social Care
Edinburgh Napier University,
Sighthill Campus,
Sighthill Court.
Edinburgh
EH11 4BN

If you find it difficult to write, someone else can help you.



Or you can send Gillian an email:



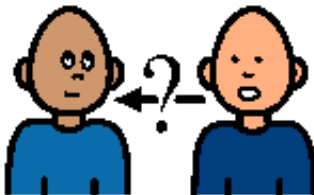
You can keep this information sheet but if you want to be in the study you need to complete the last 2 pages and send them back to me.

Consent Form



I say it is OK for Gillian from Edinburgh Napier University to meet me for this study.

I have seen the information sheet about the study. I understand what it says.



I had a chance to ask questions about it.

I agree to be in the study.



If I do not want to be in the study anymore, I do not have to.

I can tell Gillian I do not want to be in the study at anytime. I will still get good care from my carers and staff.

Gillian will not tell anyone I was in this study. She may write what I say and what I do but no one will know it was me.



Photo of
Researcher

I can phone Gillian if I want to know more about the study. Gillian's phone number is [REDACTED]

My signature

Date

Gillian's signature

Date

My address is: _____

My phone number is: _____

My family member's name is: _____

My date of birth is: ____/____/____

Who told me about this study: _____

Appendix 2: Project Information Sheet and Consent form for Family Carers

Exploring mutual care between people with intellectual disabilities and their family carers in Scotland.

I would like to invite you to take part in a research study we are undertaking. It is important that you understand the purpose of the research and what it will entail before you make your decision. Please take time to read the following information carefully.

What is the aim of this study?

The aim of this study is to explore family carers experiences and views of the help they receive from their family member with an intellectual disability.

Why have you been approached?

You have been approached because you are a family member caring for a person with an intellectual disability.

Do you have to take part?

No, it is up to you whether or not you wish to participate. If you do, you are still free to withdraw at any time.

What is involved for you?

You will be asked a number of questions during an interview about the help your relative with an intellectual disability provides, as well as your views and experience of this. This interview will take no longer than an hour. Interviews will be audiotaped. Audiotapes will be destroyed after the interview has been transcribed. Transcripts will be stored securely and all details will be anonymised so no one will know you were interviewed.

What are the possible disadvantages and risks of taking part?

It is hoped that by careful attention to the discussion process, carers will feel supported to contribute their thoughts and experiences without any ill effect.

What happens to the information?

We will give you a code which will be used instead of your name when inputting the data onto the computer. At no point will your name be identifiable on the instruments or in the final report. All data will be stored securely and subsequently destroyed after six years in accordance with Edinburgh Napier University's policy.

A summary report will be circulated to each carer and we will be willing to discuss the findings at future meetings you may consider appropriate. We will also inform participants should the study be published in the future.

How can you make a complaint?

We hope that through careful planning, participating in the individual interviews and the subsequent analysis and publication of the data gathered through the discussion, will not cause you any ill effect.

Complaints can be discussed in the first instance with me and I will try to resolve your complaint to your satisfaction. If I fail to resolve your concern or complaint, you can direct your complaint to Edinburgh Napier University. Your complaint will be addressed in accordance with Edinburgh Napier University's Complaint Process.

Who is organising the study?

This study is being organised as part of a research master's degree I am undertaking. This study is being supervised by Professors Michael Brown and Thanos Karatzias, and Dr Bob Walley. Indemnity for this study has been secured through the Edinburgh Napier University Research Governance Processes. A copy of the letter confirming indemnity is available from us on request.

What should you do now?

If you are willing to participate, please complete the attached consent form and send it to me at the address below. We will then be in contact to arrange a suitable time and date to complete the interview. Everyone who returns a consent form though will be contacted to either outline the next steps or to thank-you for your interest in this study.

Thank you for reading this information sheet and considering participating in this study. Please contact me on the details below should you have any queries.

Yours sincerely,

Gillian Thompson (Postgraduate Research Student)

Tel: [REDACTED]

E-mail: [REDACTED]

Address: [REDACTED]

Edinburgh Napier University,
Sighthill Campus,
Sighthill Court,
Edinburgh EH11 4BN



Exploring mutual care between people with intellectual disabilities and their family
carers in Scotland
Family Carers CONSENT FORM

Please initial each box

1. I confirm that I have read and understood the information leaflet
for the above study and have had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary and that I am free to
withdraw at any time, without giving any reason, and without my
rights being affected

☐

3. I agree to the interview being recorded on audiotape and transcribed.
I am aware that the audiotapes will be destroyed once transcribed.
Transcripts will be stored securely, and all data will be anonymised.

☐

4. I agree to take part in the above study

☐

Name of Family Carer:.....

Address: :.....

Signed:.....Date:.....

Name of research member taking consent:.....

Signed..... Date:.....

Contact telephone number or email address.....

Appendix 3: Interview Schedule for Adults with ID

1. Who do you live with? How long have you lived with your family member?
2. Tell me about a usual day at home. What sort of things do you do to help at home?
3. What would you call the things you do? If no answer give suggestions Care? Support? Help? Jobs? Housework? Or something else?
4. Have you always done this? When/why did you start doing this? How was it decided? Did you have a choice?
5. Is there anything you do that your family member used to do?
6. How do you feel about the things you do at home to help?
7. Do you want to keep helping at home? If yes, why? If no, why not?
8. What do you find hard/difficult about caring? What makes it easier? Is there anything you like about helping at home?
9. What things help you continue caring? Supports – formal, informal
10. Who would you speak to if you found it difficult to continue helping at home? Have you ever had to do this? Did it help? Is there anything that stops you or makes it hard to get help that you need? What help would you like to see for people like yourself that help family members at home?
11. What would you like in the future for you and your family member?
12. Do you have any questions for me?

Appendix 4: Interview Schedule for Family Carers

1. Who do you live with? How long have you lived and cared for your family member with an ID?
2. Tell me about a typical day at home. What sort of things does your family member do to help out at home?
3. What would you call the things they do? If no answer give suggestions Care? Support? Help? Jobs? Housework? Or something else?
4. Have they always done this? How did this role come about? When/why did they start doing this? How was this decided?
5. Was there a change in roles that you and your family member had? Thinking about the help you receive from your family member, has this had any impact or affected your perceptions of yourself as a carer?
6. How do you feel about your family member helping at home? Do you want this to continue? If so, why? If not, why not?
7. What are the key challenges facing you? What things would help you and your family member continue to manage at home?
8. Who would you speak to if you found it difficult to continue helping at home? Have you ever had to do this? Did it help? Is there anything that stops you or makes it hard to get help that you and your family member need?
9. What would you like in the future for you and your family member?
10. Do you have any questions for me?

Appendix 5: Distress Protocol for Adults with ID and Family Carers recruited through NHS sources

For all participants with an ID and family carers:

As standard, both participants from both these groups will be given a hardcopy list of support organisations they can contact should they wish to seek support following interview.

For participants who show any signs of distress:

In the unlikely event a participant shows any sign of distress during interview (e.g. becoming tearful, or getting upset), the interviewer will ask them if they want to take a break or stop the interview.

If a participant chooses to stop or take a break, the interviewer will respect their wishes.

In the highly unlikely event that a participant is reluctant to stop, but becomes more distressed, the interviewer will stop the interview to reassure them that that is okay to withdraw at any time and that they do not have to give any reason.

Support organisations that can be contacted for support will be discussed with participants.