

**Tolerating Uncertainty: Experiences of Caregiving and  
Perceptions of the Future for Adults with Intellectual  
Disabilities and Older Parent-Carers.**

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## **Thesis abstract**

Increased life expectancy for people with intellectual disabilities (ID) has meant that more adults with ID are living with ageing parent-carers. Incapacity or death of the parent can lead to crisis-care management, compounding the trauma of loss for the person with ID. Existing literature has tended to focus on experiences of younger families and is limited in relation to older families with ID. The aim of this thesis was firstly, to review the literature regarding the psychological impact of life-long parental caregiving and secondly, to develop a grounded theory of the experiences and perceptions of the future for older families with ID. A literature review regarding the psychological impact of life-long caregiving included 14 studies being identified and critically reviewed. Findings revealed that parents experience satisfaction as well as stress in their caregiving roles. Despite profound fears and anxieties regarding the future care of their son/daughter, the review highlighted that most parents do not make future plans. However, there is still scope for further research investigating the perceptions of the future and barriers to planning for older families with ID. A grounded theory was co-constructed with nine older parents and three individuals with ID. 'Tolerating uncertainty' was found to be the core process in participants' attempts to manage anxieties about the future. This research study provides a unique contribution to knowledge because it includes the perspective of both the older-parent and the person with ID, often an omission in the literature. It further adds to the growing evidence base of exploring the needs of older families with ID in order for interventions to be tailored accordingly. In the final chapter the process and findings of both the literature review and research study are reflected upon. The reflexivity of the researcher is also examined. The personal experience of conducting the research was both challenging and rewarding. It is important that the voices of these often marginalised groups are heard so that services can support these families in planning for the future and thus avoiding crisis-care management and increased trauma for the person with ID when their parent is no longer able to care.

Word count of thesis: 19,214

### **Note on terminology:**

- I. The term 'intellectual disability' will be used throughout this thesis and often abbreviated to ID. This is preferred to the UK-specific term 'learning disability' in recognition of its international usage.

The definition of intellectual disability (ID) is taken from the World Health Organisation (WHO, n.d) as meaning 'significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.'

- II. The terms 'carer' and 'caregiver' are used interchangeably throughout the thesis to refer to the person who provides care to another person who is dependent on him/her for help. This thesis concerns parent-carers who have, since birth, provided and continue to provide full time care to their son or daughter with an ID. The term 'older parent' refers to parents who are 65 years and over, in accordance with the WHO definition of an 'older person' (WHO, n.d).

## Journal Submission Details

The papers in chapter one and chapter two have been written in accordance with the guidelines for the *Journal of Applied Research in Intellectual Disabilities*; an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Both quantitative and qualitative methodologies are welcomed. Articles should not exceed 7000 words (excluding references, tables and figures).

All papers should be divided into a structured abstract (150 words) and the main text with appropriate sub headings. A structured abstract should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should then proceed through sections of Introduction, Materials and Methods, Results and Discussion, and finally Tables.

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977).

## **Chapter one: Literature Review**

### **Exploring the psychological impact of life-long parental caregiving of adults with intellectual disabilities**

#### **Abstract**

**Background:** The purpose of this review is to synthesise and critically review literature regarding the psychological impact of life-long parental caregiving of adults with intellectual disabilities (ID). This is in recognition of an increased longevity for people with ID resulting in more people now living with ageing parents.

**Materials and Methods:** A thorough literature search resulted in 14 studies being selected for inclusion in this review. They were each quality reviewed using a variety of critical appraisal tools.

**Results:** Four key themes were identified: 'factors associated with caregiver depression, stress and anxiety', 'satisfaction and reciprocity within the caregiving relationship', 'anxieties about the future' and 'interventions'.

**Conclusions:** A number of factors (including level of support, additional caregiving roles, challenging behaviour of the adult-child with ID, and how parents appraise their caregiving role) can affect the psychological well-being of the parent-carer. The findings may inform service providers about how best to support ageing parents in their caregiving roles. However, methodological issues and lack of longitudinal research present limitations to this review.



## Introduction

In recent decades, life expectancy for the general population has dramatically increased. Similarly, life expectancy for adults with ID has also significantly increased (Emerson & Baines, 2010). Therefore, people with ID are now more likely to be living with an ageing parent who themselves will have additional support needs. These parent-carers are unusual in that their caregiving roles can span several decades from childhood to adulthood and, in some cases, end only with their death. Whilst there has been a considerable amount of research regarding carers in general, this becomes more limited in relation to parent-carers of adults with ID, and the literature is even more sparse in relation to older parent-carers.

Over the past 20 years, a growing body of research into the psychological impact of caregiving has led to improved understanding. Family caregiving has long been informed by an understanding of stress as a central part of the caregiver experience (Grant & Ramcharan, 2001). Heller *et al.* (1992) investigated 489 family caregivers of adults with ID over the age of 30 and found that caregivers reported fewer burdens compared with caregivers of younger children with ID, although the reported burden was still significant. In a later study, Heller *et al.* (1997) sampled 112 families; half of whom the person with ID continued to live at home, half who had residential placements. The latter group reported less parental caregiving burden.

In a qualitative study, Shearn and Todd (1997) interviewed 33 mothers of adults with ID. The findings revealed that as mothers (and their children) grow older, they find it difficult to meet the demands of parenting, experiencing a reduction in physical resources and enthusiasm. These parents also reported feeling that they were prevented from achieving their personal goals, owing to heavy caregiving responsibilities (Ramachran & Grant, 2002; Todd & Shearn, 1996).

The increasing prevalence of aging family caregivers has been highlighted as an international issue. Eley, Boyes, Young and Hegney (2009)

found that out of 146 primary carers of adults with ID in Australia, the majority were female, over the age of 50 years and continued to provide medium to high levels of support within the family home. A similarity between the levels of support needs of persons with ID living at home and those living in supported accommodation was found. It is often assumed that those living at home require lower levels of service support, but such findings highlight and identify further the growing burden and concern for ageing parents caring at home.

Similarly, in a study conducted in Switzerland, Jecker-Parvex & Breitenbach (2012) found that 27% of adults with ID aged 35-64 reside with family carers, 80% of the latter being elderly parents among whom 16% are aged 77 or older. They identified that continuity of care depends on the absence of serious health issues in any member of the family, whilst sustainability also appears to depend on adequate finances and space within the family home. Notably, the majority of adults with ID who resided at their family home were living in rural and semi-rural areas where relatively spacious dwellings are more readily available than in cities. In addition, they identified that some form of daytime occupation outside of the home for the adult with ID is also a key factor in long term family care, in that it reduces the real risk of social isolation not only for the adult but for family members as well.

More recently there has been an increasing awareness that family caregiving can also provide much satisfaction and reward. Studies have observed that, even when faced with multiple demands from a variety of roles, most caregivers continue to derive satisfaction from their caregiving role, which is instrumental in the continuity of care provided to their family member (Grant *et al.*, 2007). Researchers attribute these satisfactions to three sources; the carer and the care-recipient relationship; the carer's self-esteem and meeting the needs of the person cared for (Grant *et al.*, 2007). In addition, some studies have acknowledged the existence of mutually supportive relationships, where the adult with ID may also take on the role of

a caregiver to their ageing parent(s) (Bowey & McGlaughlin, 2007). This highlights the changing nature of relationships as families increase in age.

### *Recent government policies*

Issues concerning family carers have been recognised in recent UK government papers, which aim to improve the lives of older families of adults with ID:

*Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century* (Department of Health; DOH, 2001) and *Valuing People Now* (DOH, 2009) highlighted the need for services to involve carers and adults with ID in service planning and for services to be more person-centred. A key message in these policies is that family carers should have the same rights to choices as other families. National priorities set out to include implementing the *Carers Strategy* (DOH, 2008) for families with ID, mainstreaming support for carers and strengthening networks between agencies. Other priorities included meeting the needs of family carers aged over 70 and addressing the issue of people with ID providing care for their older parents.

*The Carers Strategy* (DOH, 2008) identified the importance for carers to be afforded short breaks for respite and to have a life alongside their caring role. Carers should be supported to stay mentally and physically well, to be treated with dignity, and to have access to the integrated and personalised services they need to support them in their caring role.

### *Rationale and aims for this review*

Although recent government papers raise expectations of positive developments for people with ID and their parent-carers as they age, questions still remain about the impact of life-long caregiving on their psychological well-being and the support these parent-carers require from services. This literature review includes papers from 2009 onwards in light of potential service developments since the publication of these national

government policies. Although this review focuses on UK policy it is possible that international policy changes are similar and therefore international literature has also been included within this review. The aim of the review is to critically examine the most recent literature (2009-2013) regarding the psychological impact of life-long parental caregiving of adults with ID. It is anticipated that a deeper understanding of this issue will allow for services to target interventions that aim to reduce psychological distress and enhance well-being for parent-carers who continue to provide a caregiving role well into their old age.

## **Materials and Methods**

### *Search strategy*

Cochrane Library, Web of Science, EBSCO and NHS evidence provided access to multiple social sciences, medical and humanities databases, including Embase, CINAHL, Psych Info, Embase Academic Search Complete and Medline (January 2009- October 2013). The search terms used were: ("learning disab\*" OR "intellectual disab\*" OR "mental retardation" OR "learning disorder" OR "intellectual impairment") AND adult AND (carer OR caregiver OR parent OR family OR mother OR father) AND (psychol\* OR well-being OR "quality of life" OR stress OR anxiety OR "mental health") AND (ageing OR aging OR old\*). All abstracts were screened for relevance to the research question. A set of inclusion and exclusion criteria were chosen to ensure the correct studies were identified.

### *Inclusion criteria:*

- Publication date 2009 onwards
- Peer reviewed articles
- Original article published in an English language journal
- Samples parent-carers of adults (18 years or older) with an ID
- Relates directly to family caregiving

- Measures or explores the psychological impact/experience of lifelong parental caregiving to adults with an ID

*Exclusion criteria:*

- Not related specifically to parental family caregiving of an adult-child with ID
- Main emphasis of paper not being on the psychological impact of caregiving (e.g. focuses on prevalence of carers, housing accommodation available etc.)
- Samples carers of adults with ID that are not parents (e.g. siblings, professional carers, paid carers etc.)
- Samples parent-caregivers of children or adolescents aged below 18 years
- Condition-specific papers such as Prader Willi Syndrome, autism and Down syndrome. (The inclusion of condition specific papers may distort the findings due to known health issues for adults with specific forms of ID, such as dementia in people with Down Syndrome, sleep disorder in Prader Willi Syndrome etc.)
- Grey literature
- Literature reviews

The search terms generated 2,322 records from the host databases (Web of Science, EBSCO and NHS evidence). Cochrane Library did not return any results. Limiters were applied on the host databases, which resulted in records excluded due to being published before 2009, not peer reviewed and not published in English language. This resulted in 567 records identified for screening. All abstracts were screened and records were excluded due to being identified as a duplicate (n = 121), not sampling parent-carers of adults (over 18 years) with an ID (n =385), not directly related to family caregiving (n = 5) and being identified as a literature review or book chapter (n = 8).

Full texts of the remaining 48 records were then assessed for eligibility. Further exclusions were made on the grounds of the record sampling adults

with specific ID and/or conditions (n=27), and due to the main emphasis of the paper not being on the psychological impact of caregiving (n=11). Ten papers met the eligibility criteria. A further four eligible papers were identified through a reference hand search. This resulted in fourteen papers being eligible for the purpose of this literature review. The search strategy process is illustrated in a flow diagram in appendix 1 along with the list of papers (n = 11) excluded at the final analysis and the reasons given for this exclusion.

### *Data extraction and critical appraisal*

Data extracted for each study included: full publication details, country of origin, study design, background and aims, sample characteristics, recruitment methods, procedure, findings, strengths and limitations (appendix 2). Each paper that met the inclusion criteria was read a number of times and analysed for content. The first reading was deliberately free of analysis and note taking and was designed to obtain an overall sense of the paper through un-interrupted reading beginning to end. Additional reading involved a degree of critical consideration of the research approach, methods and findings. Final analysis involved the completion of a Critical Appraisal Skills Programme (CASP; Public Health Resource Unit, 2006) tool, considering the quality of the research in greater detail.

In addition to the CASP, studies reporting quantitative data were also assessed for quality using questions derived from the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE; Elm *et al.*, 2007) and Young and Solomon (2009) (appendix 3). Qualitative studies were assessed using the CASP tool for Qualitative Research (Public Health Resource Unit, 2006), which assess rigor, credibility and relevance of the study.

Overall, the appraisal tools applied within this review addressed the following domains for both quantitative and qualitative studies:

- Clear statement of aims

- Appropriate methodology
- Recruitment strategy
- Data collection methods
- Reflexivity of the researcher
- Ethical considerations
- Rigour of data analysis
- Clear findings
- Value of research to understanding/clinical implications

## **Results**

### *Research aims and designs*

Four studies focused exclusively on the psychological experiences of family caregiving for adults with ID and ageing family carers' perceptions of the future (Cairns *et al.*, 2012; Dillenburger & McKerr, 2011; Yoong & Koritsas, 2012; Taggart *et al.*, 2012).

The remaining ten studies varied widely in their aims but included focusing specifically on female carers in terms of measuring depression (Chou *et al.*, 2010) and examining demands and coping resources (Rowbotham *et al.*, 2011a). Four studies made comparisons between carer sub-groups; one study aimed to examine the frequency and psychological impact of providing care to more than one care recipient, termed 'compound caregiving' and to make comparisons with non-compound caregivers (Perkins & Hayley, 2010). Two studies aimed to make comparisons between perceived stressors, coping strategies and quality of life between younger and older caregivers (Llewellyn *et al.*, 2010; Chou *et al.*, 2009) and one study aimed to make comparisons between mothers and fathers in terms of their perceptions of caregiver burden and satisfaction (Rowbotham *et al.*, 2011c). One study sought to apply a model of parenting stress (Hill & Rose, 2009) and one examined the associations between aggressive behaviour of the adult with ID and perceived carer burden and uplift (Unwin & Deb, 2011).

One study examined the course of coping and the relationships between caregiving stressors and satisfaction over a period of time (Rowbotham *et al.*, 2011b) and one study focused on exploring the reciprocal benefits that may exist in relationships between carers and their adult sons/daughters with ID (Perkins & Hayley, 2013).

Eight studies used a cross-sectional design, comprising semi-structured or structured interviews and administering validated questionnaires to a sample population (Chou *et al.*, 2009; 2010; Hill & Rose, 2009; Llewellyn *et al.*, 2010; Perkins & Hayley, 2010; Rowbotham *et al.*, 2011a, 2011b; Unwin & Deb, 2011). Three studies used qualitative techniques (Cairns *et al.*, 2012; Dillenburg & McKerr, 2011; Yoong & Koritsas, 2012). One study employed a mixed-method design (Taggart *et al.*, 2012) and one was a longitudinal study (Rowbotham *et al.*, 2011c).

### *Study characteristics*

The table in appendix 4 provides details for each study. Sample size ranged from four (Rowbotham *et al.*, 2011c) to 787 (Chou *et al.*, 2009). All studies, except one (Unwin & Deb, 2011) reported participant age, which ranged from 45 to 94 years. Only one study reported a younger age range of 16 to 54 years; however the mean age of this younger caregiver group was 43 years (Chou *et al.*, 2009). Four studies included only female caregivers, mainly mothers (Chou *et al.*, 2010; Hill & Rose, 2009; Rowbotham *et al.*, 2011a, 2011b, 2011c). The remaining ten studies sampled both male and female family caregivers, although the majority of participants were female in all cases. Five studies were conducted in Australia (Llewellyn *et al.*, 2010; Rowbotham *et al.*, 2011a, 2011b, 2011c; Yoong & Koritsas, 2012), five in the UK (Cairns *et al.*, 2012; Dillenburg & McKerr, 2010; Hill & Rose, 2009; Taggart *et al.*, 2012; Unwin & Deb, 2011), two in Taiwan (Chou *et al.*, 2009, 2010) and two in the USA (Perkins & Hayley, 2010, 2013).



### *Quality assessment*

The reviewed literature was first assessed for quality taking into consideration the hierarchy of evidence (NHS, 2005). The highest quality study was one which used a cohort longitudinal design, followed by cross sectional designs and studies using qualitative methodologies. The studies included in this literature review do not rank highly based on this framework due to there being no Randomised Controlled Trial (RCT) studies. It is possible that RCT studies were published prior to 2009.

### *Study aims and methodology*

All studies identified specific and clearly focused issues for further exploration. All recognised a growing trend for adults with ID to remain living in the family home and to have continued care from older parents, due to the improved life expectancy of people with an ID. Many studies identified that while there is a body of evidence concerning parental stress, caregiver burden and satisfaction in relation to parents of children, there is a paucity of evidence about the experiences of parents of adult children with ID. These studies aimed to contribute to a new body of evidence in this area.

Three qualitative studies explained the relevance of their research and the need to explore subjective experiences in greater detail due to the limited amount of evidence already available, especially in Northern Ireland (Dillenburger & McKerr, 2010; Taggart *et al.*, 2012) and in Australia (Yoong & Koritsas, 2012). Some international studies explained the rationale for exploring differences between age groups and gender among non-western families who care for an individual with ID, as few studies have explored these (Chou *et al.*, 2009, 2010). Four studies justified specific issues related to family caregiving that had not yet being explored; specifically with fathers (Rowbotham *et al.*, 2011c), multiple caregiving roles (Perkins & Hayley, 2010), the reciprocity of the relationship between carer and care-recipient (Perkins & Hayley, 2013), and the relationship between levels of aggression in adults with ID with caregiver burden and satisfaction (Unwin & Deb, 2011).

The longitudinal study justified the need to explore how caregiving demands, satisfactions and coping strategies impact upon caregiver well-being over time (Rowbotham *et al.*, 2011b).

### *Recruitment and selection*

The majority of studies gave details of their recruitment methods and selection processes. Some studies detailed an inclusion criteria (Chou *et al.*, 2009; Hill & Rose, 2009; Perkins & Hayley, 2013; Taggart *et al.*, 2012; Yoong & Koritsas, 2013), described a thorough process of recruitment (Cairns *et al.*, 2012; Unwin & Deb, 2011) and used a variety of recruitment methods in order to minimise potential bias (Llewellyn *et al.*, 2010; Perkins & Hayley, 2010). Furthermore, some studies demonstrated how the area from where the sample was recruited is comparable with the UK on a range of indicators (Hill & Rose, 2009). The strongest studies indicated how they overcame initial recruitment difficulties (Chou *et al.*, 2010) and reported the response rate (Hill & Rose, 2009; Taggart *et al.*, 2012). For three studies conducted by the same researchers (Rowbotham *et al.*, 2011a, 2011b, 2011c), the recruitment method remained the same although it was unclear as to whether this was within the same time frame. The longitudinal study (Rowbotham *et al.*, 2011b) stated that it was a follow-up study to a previous cross-sectional study (Rowbotham *et al.*, 2011a) and so the sample was selected from participants who had already taken part in the preliminary study. Studies that failed to provide sufficient details about their recruitment process raised questions about the appropriateness of their selection criteria.

For the majority of quantitative studies, power and effect calculations were not provided which made it difficult to determine whether the sample size was sufficient. However, the majority of sample sizes appeared small and participants were mainly recruited via purposive sampling. This raised questions about the representativeness of the sample and generalisability of findings. The majority of the studies focused exclusively on female caregivers, mainly mothers. One study was strengthened by providing the

perspective of fathers and examining gender differences (Rowbotham *et al.*, 2011b).

#### *Data collection methods*

All quantitative studies employed a cross-sectional design, using structured or semi-structured interviews which comprised of a series of questionnaires/surveys. Most studies collected socio-demographic details of the caregiver as well as the adult child with an ID. One study (Unwin & Deb, 2011) however, failed to provide demographics on the caregiver and instead just focused on demographic factors that related to the adult child with ID. Two qualitative studies demonstrated higher levels of credibility by providing details of their interview schedule, the interview setting and the background of the researcher who conducted the interviews. They also enhanced validity of their findings by comparing codes and themes with other members of the research team (Cairns *et al.*, 2010; Yoong & Koritsas, 2012). One qualitative study described nine interviews where audio-recordings had not been acceptable and so full accounts were written up immediately afterwards (Dillenburger & McKerr, 2010). Using just field notes in the analysis stage may have impacted on the accuracy and validity of the data collected. Qualitative studies, which used multiple means of data collection and analysis such as transcribing, recorded interviews, writing memos and keeping a reflective diary enhanced the richness and credibility of the findings (Cairns *et al.*, 2010; Dillenburger & McKerr, 2010). One study was strengthened using triangulation of quantitative and qualitative methods (Taggart *et al.*, 2012). Providing detailed descriptions of the data collection stages enables replication of this study.

#### *Reflexivity of the researcher*

One study provided details about the researchers' professional backgrounds and their roles in the data collection and analysis (Dillenburger & McKerr, 2010) but along with the other qualitative studies, failed to discuss their potential bias and influence on the research. This raised questions about the rigor of the findings. A strength of one qualitative study was the

researchers' reported use of reflexive journals and memo-writing throughout the data collection and analysis stages which enabled key insights and decisions to be recorded (Cairns *et al.*, 2012).

### *Ethical considerations*

All of the studies reported that they had gained ethical approval from appropriate bodies. Studies were strengthened by reporting detailed accounts of the ethical considerations they had taken throughout the research, such as using participant information sheets, gaining informed consent, informing participants of confidentiality guidelines, anonymity of data and providing participants with a summary of the findings (Hill & Rose, 2009; Llewellyn *et al.*, 2010; Rowbotham *et al.*, 2011c; Taggart *et al.*, 2012).

### *Rigor of data analysis/ outcome measures*

The range of psychological outcome measures was extremely varied. Many findings were based on self-report but many used validated self-report questionnaires. Not all studies provided details of the psychometric properties of these measures (appendix 5). Among the commonly used measures was the Centre for Epidemiologic Studies Depression Scale (CES-D). Perkins and Hayley (2010, 2013) report good inter-rater reliability of this measure at a correlation of 0.89. Chou *et al.* (2010) reports using the short – form, 10 item scale, of this measure and state that it “shows good predictive accuracy” when compared with the 20 item version. They report good inter-rater reliability (0.85) and good test-retest reliability (0.71), suggesting that it is a stable and reliable measure.

The Carer's Assessment of Difficulties Index (CADI) and The Carer's Assessment of Satisfaction Index (CASI) were also both commonly used measures. The CADI was reported to have high internal inter-rater reliability ranging from 0.72 to 0.96 (Taggart *et al.*, 2012; Llewellyn *et al.*, 2010; Rowbotham *et al.*, 2011a, 2011b, 2011c). Similarly the CASI was reported to have good inter-rater reliability at a correlation of 0.96 (Rowbotham *et al.*,

2011a, 2011b, 2011c). However, the test-retest reliability and validity was not reported for these measures. Other internally reliable measures included the General Health Questionnaire -28 (GHQ-28), with an inter-rater reliability of 0.88 (Rowbotham *et al.*, 2011a, 2011b, 2011c).

In terms of qualitative research, one study was strengthened by demonstrating rigour in the form of a table outlining the 'trustworthiness and authenticity criteria' (adapted from Guba & Lincoln, 1989) and detailing the steps taken to ensure that these had been met (Cairns *et al.*, 2012). All qualitative studies gave examples of using relevant, multiple quotes that were grounded in the data and some studies detailed the use of reflective diaries and memos to ensure that the researchers influence on the data was considered during data analysis (Cairns *et al.*, 2012).

### *Findings*

Analysis of the papers revealed four broad themes; (1) factors associated with caregiver depression, anxiety and stress; (2) satisfaction and reciprocity within the caregiving relationship; (3) anxieties about the future and, (4) interventions. These themes were derived through a process of open coding and categorising codes into broader themes. A synthesis matrix was then created in order to develop a thorough understanding of the state of knowledge derived from all of the studies and to make comparisons between the findings (appendix 6). These key themes will now be discussed in detail:

#### *1) Factors associated with caregiver depression, anxiety and stress*

All articles reported major impacts on caregivers' psychological well-being in terms of depression, anxiety and stress levels. Some studies reported finding elevated scores on measures of depression for their sample population across different cultures (Chou *et al.*, 2010; Rowbotham *et al.*, 2011a; Taggart *et al.*, 2012). Out of a sample of 350 female caregivers in Taiwan, Chou *et al.* (2010) found that 64-72% had high depressive symptoms.

Similarly, Rowbotham *et al.* (2011a) found that out of a sample of 27 Australian female carers, 26% scored within the clinical range on a measure of severe depression. In a UK study, 31% carers reported suffering from depression (Taggart *et al.*, 2012). In addition, several studies reported that carers located their experiences of depression as being a direct result of caregiving demands (Taggart *et al.*, 2012; Rowbotham *et al.*, 2011a) and overall reported caring as having a negative impact on their quality of life (Yoong & Koritsas, 2012). Perkins & Hayley (2013) found that when there is negative imbalance in the caregiving relationship (i.e. indicating the carer gives more than they receive in terms of duties), there is a significant correlation with depressive symptomology.

In contrast to the above finding, Rowbotham *et al.* (2011c) found that levels of depression for both mothers and fathers were relatively low on measures of severe depression. They provided several possible reasons for this anomaly between parental reports of psychological symptoms and reports on depression measures. They hypothesised that parents may have felt a need to project the impression that they were managing and so minimised their report of these experiences.

The majority of studies reported high levels of stress among parent-carers (Dillenburger & McKerr, 2010; Hill & Rose, 2009; Llewellyn *et al.*, 2010; Rowbotham *et al.*, 2011a). Some studies highlighted that the common sources of stress were feeling helpless or not in control, poor professional support and concerns about the future (Cairns *et al.*, 2012; Dillenburger & McKerr, 2010; Llewellyn *et al.*, 2010). Hill and Rose (2009) found that parental cognitions appeared to play an important role in parenting stress. In particular they found that mothers with a higher internal locus of control and greater levels of social support reported lower levels of parental stress. Furthermore, they did not find maladaptive behaviour to be a significant predictor of parental stress. This finding is inconsistent with other studies in this review reporting strong positive associations between caregiver burden and the severity of aggressive behaviour displayed by the adult with ID

(Unwin & Deb, 2011). However, given the small sample sizes of these studies it is difficult to draw conclusions from these findings.

Some of the studies also found that caregivers reported high levels of anxiety (Chou *et al.*, 2009; Taggart *et al.*, 2012). In particular, anxieties were found to be centred on concerns for the future should they become unable to provide care to their adult-child with an ID. This is particularly significant for older caregivers for whom self-reliance as a coping strategy appears to be the norm (Chou *et al.*, 2009).

The literature further highlighted differences in relation to psychological well-being among different sub-groups of parent-carers. Chou *et al.* (2009) found that compared with younger ones, older caregivers reported a lower quality of life, less family support, a more negative perception of having a family member with ID and greater worries about the future. Perkins and Hayley (2010) found many carers reported being a 'compound caregiver'; caring for an additional care-recipient (e.g. a spouse with dementia) in addition to caring for their adult-child with ID. However, they found no apparent differences between compound caregivers and non-compound caregivers in terms of their psychological well-being. They suggest that once caregivers have gone past a threshold of caregiving duties, additional hours of caring may not be associated with greater distress.

## 2) *Satisfaction and reciprocity within the caregiving relationship*

Despite the high levels of depression, anxiety and stress reported by carers, seven of the studies in this review also reported that carers gained tremendous satisfaction from their caregiving roles (Dillenburger & McKerr, 2010; Hill & Rose, 2009; Llewellyn *et al.*, 2010; Perkins & Hayley, 2013; Rowbotham *et al.*, 2011a, 2011b, 2011c; Yoong & Koritsas, 2012). Rowbotham *et al.* (2011c) found that mothers reported significantly both more caregiving difficulties and satisfactions than fathers.

Hill and Rose (2009) found that parenting satisfaction mediated the relationship between adaptive behaviour and parenting stress and between family support and parenting stress. Similarly, Yoong & Koritsas (2012) identified that caring for an adult with ID provided some parents with a sense of accomplishment and contentment. The carer role was valued, giving a sense of meaning, focus and purpose in life and in old age, which ultimately enhanced their quality of life. In addition, Perkins and Hayley (2013) found that some carers (22%) actually perceived receiving greater tangible support (i.e. help with physical tasks) than what they themselves provided to the adult with ID. This suggests that mutual support is significant for some older carers and can be beneficial to a caregiving situation that is often a lifelong endeavour.

These findings suggest that both stress and satisfaction can be associated with caring, which runs counter to the common perception that being a carer is overwhelmingly burdensome.

### 3) *Anxieties about the future*

Six of the studies reviewed highlighted parent-carers' anxieties and concerns about the future should they become unable to provide care for their offspring with an intellectual disability (Cairns *et al.*, 2012; Chou *et al.*, 2009; Dillenburger & McKerr, 2010; Perkins & Hayley, 2010, 2013; Rowbotham *et al.*, 2011; Taggart *et al.*, 2012; Yoong & Koritsas, 2012) and that these anxieties impacted negatively on parent's quality of life. Not surprisingly, this was more of a concern for older parent-carers (Chou *et al.*, 2009). In the vast majority of cases long term future plans had not been made (Cairns *et al.*, 2009, Chou *et al.*, 2009, 2010; Dillenburger & McKerr, 2010). Lack of information, support, advice, practical resources and lack of trust in services were cited as obstacles to future planning (Cairns *et al.*, 2012; Taggart *et al.*, 2012). Most parents felt that there were no suitable alternatives for care arrangements should they become unable to continue caring for their offspring (Cairns *et al.*, 2012; Dillenburger & McKerr, 2010). In instances when some carers had discussed future provision with services,



they had not found it to be helpful (Cairns *et al.*, 2012; Dillenburg & McKerr, 2010).

Parents who had made plans were less likely to describe feelings about the future so negatively (Cairns *et al.*, 2012). For the few parent-carers that had considered future plans there was a preference for siblings to take over the care of the adult with an ID, yet in many cases this had not been discussed openly (Chou *et al.*, 2009; Dillenburg & McKerr, 2010; Taggart *et al.*, 2012). Furthermore, as birth rates in the UK decrease there are now fewer children to support ageing parents. This informal support network which has traditionally supported ageing parents previously may need to be replaced with alternative options in the future.

In contrast, compound caregivers, when compared with non-compound caregivers, were found to have an increased desire to place their son/daughter into residential care (Perkins & Hayley, 2010). The act of being a compound caregiver may produce an increased sense of urgency about addressing the future. Perkins and Hayley (2013) also found that the relative disadvantage in tangible reciprocity (i.e. the carer giving more than they receive) was associated with a decreased desire for residential placement. In particular, parents of sons/daughters with greater needs were less likely to want to place their adult-child into alternative residential care. The researchers suggest that this may indicate a perceived sense of role captivity as a lifelong carer may be more salient to those parents whose sons/daughters require more extensive support (i.e. have a severe or profound ID). Several of these carers felt that they were most qualified to look after their care recipient, despite receiving support from formal services.

#### 4) *Interventions*

Some researchers recommended that interventions should focus specifically on the physical and emotional health of the carers and argue that these should be assessed at regular time intervals across the lifespan (Taggart *et al.*, 2012). Dillenburg and McKerr (2010) highlight the

importance of support networks for parent-carers and argue for these to be set up and maintained well in advance of a crisis situation. Several studies suggest tailored intervention programmes which may be of benefit to parent-carers, such as structured cognitive behavioural therapy (CBT) to help target unhelpful cognitions associated with how parents view themselves and their caring role (Hill & Rose, 2009). Some researchers argued that services should focus on rebuilding levels of trust with families as the basis for targeting specific interventions (Cairns *et al.*, 2012) and raise professionals awareness of the needs of compound carers (Perkins & Hayley, 2010) and parents whose son/daughter present challenging behaviours. Dillenburger and McKerr (2010) recommend that early intensive behavioural intervention is offered routinely once a child is diagnosed with an ID in order to support parents and avoid crisis situations. Perkins and Hayley (2013) recommend that carer interventions that seek to enhance real and perceived reciprocity may be of value to enhance coping mechanisms of carers.

Most studies agreed that services should help older families to plan for the future and that this should be reviewed at different life stages. Of note was the finding that carers who provide more tangible assistance were less likely to consider an alternative residential situation for their care recipient (Perkins & Hayley, 2013). This suggests the importance of future planning, and the encouragement of early preparation for the eventual transference of care to another family carer or an alternative residential situation remains a priority.

Some stated that a holistic approach to future planning would be beneficial (Hill & Rose, 2009), taking into account the perspective of the adult with ID (Rowbotham *et al.*, 2011a). Taggart *et al.* (2012) identified a number of educational programmes that have been successfully developed to assist ageing families with ID to develop future plans (Heller & Caldwell, 2006; PLAN, 2008). They recommend that these be implemented in more services across the UK.

## Discussion

### *Summary of findings*

The papers reviewed highlighted some important issues with regards to increased levels of depression, anxiety and stress among this population. Factors affecting psychological well-being include parental cognitions, support networks, taking on additional care-recipients and the maladaptive behaviour of the adult with an ID. In addition, parental satisfaction and perceived reciprocity within the caregiving relationship was found to be a mediator to psychological well-being. The majority of parent-carers reported tremendous satisfaction with their caregiving roles, which is contrary to previous research on caring focusing on the caregiving burden. One particular anxiety for parents was concerns regarding the future of their son or daughter. A couple of studies explored barriers to future planning in more detail (Cairns *et al.*, 2012; Taggart *et al.*, 2012), but on the whole parent-carers perceptions of the future appeared to be a gap in the literature.

Implications for health and social care practice include raising awareness and providing training for professionals around the issues faced by older-parent carers, tailoring appropriate psychological interventions to meet their needs and providing older-parent families with helpful and timely information, resources and strategies to help them to plan more effectively for the future. Future planning is a painful and sensitive topic that many ageing carers do not want to face. However, with an increasing ageing population of people with ID, it is not something that service providers can ignore. The consequences of not supporting these family carers will lead to crisis management, increase in anxiety and caregiving burden. Since the vast majority of parents in the studies reviewed expressed a desire to continue caring for their adult son/daughter well into their old age, despite their own deteriorating health issues, it is important that services respond to

the needs of these older families in order to reduce psychological distress and enhance well-being of the caregiver and the adult with ID.

### *Theories of caregiver stress and coping*

Taking into account the findings from this review, the impact of life-long caregiving may be understood by models of stress and coping. Pearlin *et al.* (1990) presented a conceptual model of caregiving stress, specific to Alzheimer's caregivers but generally applicable to all caregiving situations, which depicts four domains of the stress process: background and contextual factors (including carers' social economic status, services used and family network); stressors (primary and secondary); mediators of stress; and outcomes. Primary stressors result from the needs and demand of the cared for person such as their cognitive status and behavioural difficulties. Secondary stressors include role strains (activities outside of caregiving) and intrapsychic strains (impact of caring on psychological state). The outcomes of this process include negative mental health consequences such as increased distress, depression and anxiety. The model highlights that the stress process is cyclical and interactional and that a person's coping resources will act as a mediator.

Pearlin *et al.* (1997) described how the stress proliferation process develops when carers experience stressors associated with their caregiving role (e.g. sleep deprivation) which then negatively impacts on their capacity to perform other roles (e.g. reduced performance at work), creating secondary stressors (e.g. low self-esteem). Thus, people experiencing stressors across several roles will have reduced psychological well-being when compared to those who are not exposed to the same stressors. They reasoned that the long-term impact of caregiving can lead to a depletion in the caregivers' coping resources and reduce their perceptions of control, which can have significant health consequences, such as depression.

Pearlin (1999) later hypothesised that as caregiving demands accumulate it is possible that coping resources would also increase. For

example, if a mother experiences satisfactions in her role as a carer and feels a sense of competency due to her ability to deal with caregiving demands then this may overflow into other aspects of her life where she is also required to deal with demanding situations.

Schulz and Salthouse (1999) described a sequential, cyclical model in which the caregiver's appraisal of the situation will determine their ability to cope. For example, they claim that a positive appraisal leads to positive emotional responses and a sense of well-being. Alternatively, an appraisal of the situation as stressful could lead to negative emotional reactions. They suggest that these reactions may interact with the care recipient behaviours to create an escalation of negative outcomes, ultimately increasing the risk of physical and mental health problems.

The findings from this review can be considered in conjunction with these models. For example, Hill and Rose (2009) found a strong association between parental cognitions and parental stress. Parents who had more negative appraisals of their caregiving demands were seen to have a lower internal locus of control. Similarly, Perkins & Hayley (2013) found that there was a strong association between relative disadvantage (i.e. giving more than received) in tangible reciprocity within the caregiving relationship and poorer mental health of parent-carers. Unwin and Deb's (2011) findings connect with Pearlin's (1999) stress proliferation model, suggesting that caregiver burden was significantly higher in caregivers whose offspring displayed aggressive behaviours. Similarly, Rowbotham *et al.* (2011c) support cognitive-based theories, suggesting that parents who are satisfied with their caregiving role were more likely to experience satisfaction in other roles.

The finding that compound carers do not have a reduced psychological well-being compared with non-compound caregivers, demonstrates increased resilience in their caregiving roles, supporting Pearlin's (1999) hypothesis. However, further longitudinal research is needed to determine whether accumulated satisfaction can lead to positive psychological states in the same way proliferation of demands can lead to

depression.

Despite limitations, these models provide a useful way for making sense of the impact of caregiving and provide a basis on which interventions can be tailored to suit the needs of older families of adults with ID.

### *Limitations*

There are a number of limitations that need to be considered when interpreting the findings from this literature review. Despite using multiple databases and search terms when exploring this topic, it is possible that alternative search terms may have produced more literature. Although it was not the aim of this review, the inclusion of more specific intellectual disabilities and conditions in the search criteria may have yielded more results and allowed for more comparisons between sub-groups.

The majority of the papers reviewed used purposive sampling of families known to ID services. This approach limits the involvement of families who have never accessed services and so the findings reported here may have missed the perspectives of these parent-carers. It is possible that their views may be very different. Furthermore, most studies used self-report measures, which although practically useful they are potentially less valid and therefore only limited conclusions can be drawn. The majority of the studies had small sample sizes, which limits the extent to which these findings can be generalised to the wider population. Although the studies reported here have been carried out in a variety of countries, there is also a noticeable absence of diversity amongst the samples in the studies. The majority of the studies sampled mothers and therefore fathers are relatively neglected in the literature. Moreover, not all studies supplied information on the ethnicity of parent-carers but where they did, there tended to be an under representation of minority ethnic groups, which limits the strength and generalisability of the findings to the wider population.

In one respect reporting on studies from a variety of countries was considered a strength of this review. On the other hand, the small sample of UK studies (n=5) made it difficult to draw conclusions in light of the recent UK government policies upon which the rationale for this review was developed. Including international literature in this review is justified on the basis that the psychological impact of life-long caregiving to an adult with ID is a relevant issue across all cultures.

One limitation is that some studies were conducted by the same researchers (Perkins & Hayley, 2010; 2013; Rowbotham *et al.*, 2011a, 2011b, 2011c). Some of their findings were drawn from the same data, which may have compromised the originality of their findings and may have produced biases within this review. An additional issue resulted from the fact that only peer-reviewed articles were included in this review. The omission of grey literature and non-peer reviewed articles may have failed to recognise up to date and important information regarding caregiving experiences.

#### *Implications for health and social care practice*

The research discussed here suggests that the demanding role faced by parent-carers is not fully recognised by health and social care professionals. It therefore highlights significant implications and recommendations for health and social care practice. The studies emphasise the need for health and social care professionals to rebuild levels of trust by signposting parent-carers to sources of advice and informing them of their rights and entitlements. Furthermore, the majority of the studies emphasise the need for raising professional's awareness through training concerning the issues faced by older parent-carers. These issues include how carers perceive their caregiving role, additional care recipients they may have, the links between aggression and caregiver burden and barriers to future planning. Moreover, they emphasise the need for access to flexible services, appropriate resources and strategies to help carers plan for the future and therefore alleviate their anxieties about this and avoid crisis situations. It is important that services listen to and respond to the needs of such older

families, developing interventions that aim to reduce psychological distress and enhance well-being amongst this group. The studies reviewed offer recommendations of possible intervention programs that can be tailored to the needs of older families with ID.

The review emphasised how most older parents do not make explicit plans for the future, despite having significant anxieties about future care of their son/daughter when they are no longer able to care. The studies reviewed make recommendations of a holistic approach to future planning that involves the person with the ID and that is reviewed across the lifespan. Evaluation programmes that have been successfully developed to target future planning would identify areas of good practice internationally for UK services to implement. The studies highlight how helping older families to plan for the future will be more cost-effective than the cost of providing crisis-care services and accommodation which is too often the norm following changing life events. Interventions that aim to reduce psychological distress and promote well-being amongst ageing carers and adults with ID will enable caregivers to continue within their role as they enter into old age should they so wish to.

Clinical psychologists may be well placed in their role to help provide support to these families. This could be through tailored psychological interventions, as previously mentioned such as CBT for the parent-carers or behavioural interventions when addressing the challenging behaviours of the adult with ID. Furthermore, systemic practice could be useful since this approach considers explanations for difficulties and coping that are not located within the individual but within the relationships, systems and contexts of people's lives and experiences. Systemic therapy could help the whole family system to explore options and plan more effectively for the future together, alleviating their anxieties and promoting psychological well-being amongst all members of the family system.



### *Areas for future research*

Whilst there is a considerable amount of research investigating the physical and mental health of different types of carers, this is limited with regards to older-parent carers of adult offspring with an ID. Therefore, further qualitative analysis is needed to understand these perspectives and the needs of older parent-carers.

The majority of the studies are cross-sectional designs and as a result they do not represent variations in experience over time and therefore additional longitudinal research is needed. Since the literature is limited with regards to the older parent-carer population of adults with ID, it may be helpful to further explore the sub-groups of these carers. For example, attention could be given to older fathers undertaking full-time care, carers who represent different cultural backgrounds, carers who are restricted to low incomes and compound carers.

Some of the studies made reference to individual psychosocial interventions aimed at improving carer well-being and whilst these sound promising, further research is needed to determine the effectiveness of these. In addition, there appeared to be a gap in the literature with regards to exploring issues around future planning, despite caregiver anxieties about the future being a main finding from this review. Whilst a couple of the studies in the current review explored barriers to future planning in some detail, this issue warrants further investigation in order for interventions to be tailored to meet the needs of these families. Future research should include the perspective of the care-recipient (the adult with ID), as this is limited in the current literature and would add value to the findings.

### **Conclusions**

This literature review highlights key findings regarding the psychological impact that life-long caregiving can have; both negatively in terms of depression, stress and anxiety and positively in terms of

satisfactions derived from the caregiving role. The studies offered a variety of interventions, from staff training to more specific tailored psychosocial interventions to support parents within their caregiving role. Whilst the existing literature is clearly valuable in informing clinical work with older parent-carers of adults with ID, the limited methodology and scope of the current research highlights several important areas for future research. The literature acknowledges that whilst most older parent-carers do not make explicit plans for the future, there is a gap in the research which focuses on the future perspectives of both the parent and the person with ID. This issue needs to be addressed in order to establish how services can best support older families in planning for the future, thus easing their anxieties, reducing psychological distress and avoiding crisis-care situations to changing life events. This in turn will lead to enhanced psychological well-being for the parent-carer and the adult with ID.

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## Chapter two: Research Study

### Tolerating uncertainty: experiences of caregiving and perceptions of the future for older families with intellectual disabilities

#### Abstract

*Background:* Improved life expectancy means that more adults with Intellectual disabilities (ID) are now living with ageing parents. Yet little is known about the experiences of older families with ID and their perceptions for the future. Existing research often focuses parent perspectives and neglects views of the person with ID.

*Materials and Methods:* Semi-structured interviews were conducted with nine older parents and three adults with ID. A constructivist approach to grounded theory was adopted.

*Results:* 'Tolerating uncertainty' was found to be the core process in participant's attempts to manage anxieties about the future, encompassing six key categories: 'accepting', 'facing challenges', 'being supported/isolated', 'meaning making', 're-evaluating' and 'confronting the future'.

*Conclusions:* The findings have implications for services that attempt to support older parents' abilities to continue to provide care, including the need for tailored interventions to help families plan for the future and thus avoid crisis-care or family break-down.

## Introduction

Improvements in health and social care over the past 20 years have led to improved longevity for the general population, including people with Intellectual Disabilities (ID) (Emerson *et al.*, 2012). Alongside this is the recognition that parent-carers are also ageing. It is estimated that approximately 29,000 people with an ID live with a family member over the age of 70 in the UK (Foundation for People with Learning Disabilities, 2012). This represents a significant challenge, as service providers must respond to the needs of these older families in order to reduce psychological distress and avoid crisis-care situations when the parent-carer becomes no longer able to provide care.

Research into family caregiving highlights that stress and burden is central to the caregiving experience. However, a preliminary literature, conducted by the author, revealed new insights into the caregiving experience. Older parents experiences of depression, stress and anxiety in their caregiving role can be mediated by the high levels of satisfaction associated with caring for an adult-child with ID (Dillenburger & McKerr, 2010; Hill & Rose, 2009; Rowbotham *et al.*, 2011b; Yoong & Koritsas, 2012). Other factors affecting the psychological well-being of older parents include availability of support networks, cognitive appraisals of their caregiving roles (Hill & Rose, 2009), taking on additional caregiving recipients (Perkins & Hayley, 2010), and the challenging behaviour of the person with ID (Unwin & Deb, 2011).

Despite having significant anxieties, research consistently demonstrates that most parents do not make explicit plans for the future (Taggart *et al.*, 2012). Failure to plan for the future may lead to a crisis situation, when a parent dies and the person with ID is moved to new accommodation (Bowey & McGlaughlin, 2007). Thompson and Wright's (2001) report highlights how crisis management can compound the trauma of bereavement through inappropriate placement, with long-term consequences on quality of life.

Research has begun to explore ageing parents' reluctance to relinquish their caregiving roles (Bibby, 2012; Gilbert *et al.*, 2008). Parents may ignore the inevitability of their own mortality in order to protect their children. They may have difficulties in letting go of their loved ones as it could increase loneliness and a reduced sense of purpose in later life. In addition, the existence of mutually supportive relationships may mean that neither the parent nor their son/daughter want to relinquish it (Bowey & McGlaughlin, 2007). Thus, future planning can become even more problematic as the older parent may rely on the person with ID for support.

Other obstacles to future planning include reduced confidence in existing service provision. In addition, lack of information, practical resources and support make it difficult for older families to consider future alternatives (Cairns *et al.*, 2012; Taggart *et al.*, 2012). This is despite government attempts in recent years to support older families and avoid the emotional impact of crisis care (Department of Health, 2001, 2008, 2009).

Parents who do make plans usually rely on non-disabled offspring for the future care of their son/daughter but they do not expect them to replicate the hands-on caregiving role that they provide (Heller & Arnold, 2005). Often future plans are not openly discussed within the family. Siblings may take on this assumed caregiving role unwillingly, potentially leading to family breakdown. Moreover, the person with ID is rarely consulted in future plans (Ward, 2012), militating their involvement about important decisions about their life.

Most research in this area has focused on the perspective of parents rather than adults with ID. However, the few studies that have explored the experiences of adults living with older parents found that they were aware of the likelihood of an end to family care and had significant anxieties about this. They also expressed preferences about future support (Bowey & McGlaughlin, 2005). In a study conducted in Switzerland, four adults with ID were interviewed about their future preferences (Jecker-Parvex &

Breitenbach, 2012). They expressed wishes for the opportunity to live more independently alone in their own apartment or sharing with a few peers. Nevertheless most did not want to leave their current lodgings, and many indicated clearly that they did not wish to live in congregate settings whether institutions for people with ID or homes for the elderly. Ward (2012) argues that services should allow people with an ID to have a meaningful involvement in plans for the future well before the need arises.

Internationally, there have been some educational programmes developed to proactively tackle the issue of future planning for older families with ID (Heller *et al.*, 2005). Thus far, positive claims about such programmes have been made but further evaluation of the long-term impact of these is needed.

### *Summary*

- Previous studies have focused on the physical and psychological needs of families with young children with ID. Less is known about transitions in the life cycle for adults with ID and their parents as they age.
- Researchers have acknowledged parental anxieties regarding the future care of their children yet there is a paucity of research exploring specifically older parents' experiences of caregiving and their perceptions on the future.
- Existing research focuses largely on parental perspectives and neglects the voices of individuals with ID.
- Further qualitative investigation is warranted to explore the experiences of older families and perceptions of the future, including perspectives of both the older parent and the person with ID.

### *Rationale and aims for current study*

This study aims to explore the experiences of older parents and adults with ID about being a life-long caregiver/care-recipient and their perceptions

of the future. It is hoped these findings will increase understanding of the experiences of older families with ID. This will guide professionals in meeting the needs of older families and helping them plan for the future, thus avoiding crisis care and family breakdown. In turn this will reduce psychological distress and enhance well-being for these family carers and adults with ID. Older carers and adults with ID represent vulnerable groups in society and will otherwise continue to be marginalised if these issues are not addressed.

### *Epistemological position*

Charmaz (2006) states that qualitative researchers should take a reflexive stance towards their research and 'become aware of their presuppositions and grapple with how they affect the research' (p.131). The researcher is a trainee clinical psychologist with an interest in systemic theory and experience working in a community ID context. Supervision was sought from a clinical psychologist, who practices systemic therapy in a community ID context and as well as an academic supervisor in a university context.

The researcher adopted a constructivist approach to data interpretation, which acknowledges the active role of the researcher in data collection. She maintained a reflexive journal to record experiences and observations and to assess how her interests, preconceptions and assumptions influenced the research inquiry. Supervision helped challenge these and limit potential influences on the analysis.

## **Materials and Methods**

### *Design and ethical approval*

This study adopted a constructivist Grounded Theory (GT) methodology due to its applicability to explore topics where there is little pre-



existing knowledge. GT was preferred to other qualitative methodologies such as Interpretive Phenomenological Analysis (IPA) due to the study employing a heterogeneous sample. GT allows for interpretations about group differences using the constant comparative method and identifies group processes, which this study aims to achieve.

The constructivist approach to GT 'sees both data and analysis as created from shared experiences and relationships with participants' (Charmaz, 2006, p.130.) It emphasises the interpretation of diverse social worlds and multiple realities (Cresswell, 2007). A constructivist approach fosters the researcher's reflexivity about their own interpretation, rather than aiming for a more objective reality, leading to a theory that 'is situated in time, place, culture and situation' (Charmaz, 2006, p.131).

The study was approved by University and NHS ethical committees. Copies of all documents can be found in appendix 7.

### *Participants and recruitment*

Participants were recruited from a Community Learning Disability Team (CLDT) within the West Midlands using purposive sampling. Families who met the eligibility criteria (table 1) were identified by clinicians. Potential participants with ID were screened to determine their cognitive ability to participate in a semi-structured interview. This was done using clinical judgement of clinicians who knew them well. Details of potential participants were passed on to the gatekeeper, a clinical psychologist within the CLDT.

Potential participants were sent an invitation letter (appendix 8) and information sheet about the study (appendix 9). These documents were also presented in an easy-read format, following Department of Health, (2010) guidelines to produce accessible information for people with literacy difficulties. Participants were asked to return the opt-in slip attached to their invitation letter or contact the gatekeeper directly. They were then contacted by the researcher to arrange a suitable time and location to meet.

*Table 1: Eligibility criteria*

<b>Adults with ID</b>	<ul style="list-style-type: none"> <li>• Aged 18 years or over</li> <li>• Diagnosis of an intellectual disability (as defined by the World Health Organisation, n.d., This information was accessed from clinical notes via the gatekeeper)</li> <li>• Currently living with an older parent-carer(s)</li> </ul>
<b>Older parent(s)</b>	<ul style="list-style-type: none"> <li>• Aged 65 years or over (according to the World Health Organisation, n.d., definition of an 'older person')</li> <li>• Has provided full-time care to their adult-child with an ID disability since birth</li> <li>• Currently living with their adult-child with an ID</li> </ul>

Recruitment took place from November 2013 to April 2014. 12 participants (nine older parents and three adults with ID) were recruited from six family units. All participants were interviewed separately. Older parents comprised six mothers and three fathers, aged between 65 and 85 years (mean age = 76 years). Step-fathers were not interviewed due to not meeting the inclusion criteria. Adult-children included two males and one female (mean age = 45 years, range = 38-57 years) and all had a mild ID. All older parents were married except one who was widowed. Eight owned their own homes. All identified themselves as White British.

In recognition of the constructivist approach, the vignettes in table 2 summarise the older families' experiences and situate the data in context of their lives. Pseudonyms are used to protect confidentiality.

*Table 2: Participant vignettes*

Family 1	Jack and Nancy are in their eighties and live with their son, Mark who is 57. Mark has additional physical health problems including epilepsy. Mark attends a day centre and requires support from his parents with regards to personal care and daily living tasks. Nancy has begun to experience memory difficulties, meaning that Jack assumed responsibility for the majority of the caregiving tasks. Mark was unable to be interviewed in his study due to his level of ID.
Family 2	Susan is in her late sixties. She lives with her husband, Robert, and her daughter, Kate who is 44. Robert is Kate's step-father. Susan has recently experienced some physical health difficulties, impacting on her caregiving role. Kate has an additional diagnosis of autism. She has recently expressed an interest in moving out of the family home. Kate and Susan have been exploring supported living environments for Kate.
Family 3	Mary and Michael are in their late 70's/early 80's. They live with their son, Ian who is 53. Michael has recently been undergoing treatment for bowel cancer. Mary cares for both Michael and Ian at home, despite her own health problems. Ian has an additional diagnosis of autism. Ian's parents provide help with daily living, financial and emotional support. Ian's views are included in this study.
Family 4	Barbara is in her mid-eighties and lives with her son, Anthony, who is 54. Barbara's husband died seven years ago. Until recently, Barbara provided full time care for Anthony but he now receives support from paid carers in the community three days per week. This was due to deterioration in Barbara's physical health. Anthony was not interviewed for this study due to his level of ID.
Family 5	Theresa is in her seventies and lives with her husband, Brian and daughter, Jessica, who is 52. Brian is Jessica's step-father. Jessica suffered a stroke at the age of six resulting in severe

	physical and intellectual disabilities. Jessica requires a high level care from her parents and support from paid carers. Jessica was not interviewed for this study due to her level of ID.
Family 6	Eileen and Liam are in their mid-sixties. They live with their son, Oliver. Oliver has a rare genetic syndrome which contributes to his experiences of depression and anxiety. Eileen and Liam support Oliver emotionally and provide help with daily living tasks. Oliver also receives support from paid carers in the community. Oliver's views are included in this study.

### *Procedure*

Prior to the interview taking place, participants were provided with written and verbal information about the study aims, what was involved and issues concerning confidentiality. Participants were made aware that responses were anonymous and that they could withdraw at any time. Each participant completed a consent form and demographic questionnaire (appendix 10 & 11).

Pseudonyms were assigned to all participants and identifying information was changed on all documents relating to the study.

### *Interviews*

All participants were interviewed in their own homes and the researcher adhered to Trust guidelines for lone working. Participants from the same families were interviewed separately.

Semi-structured interview schedules were used for both older parents and adults with ID (appendix 12), exploring experiences of caregiving and perceptions of the future. Interview questions were based on relevant literature relating to experiences of caregiving. They were developed following consultation with a clinical psychologist working clinically in an ID

context and an academic supervisor with experience of conducting GT research.

The interview schedule was used flexibly and participants were encouraged to talk about things they felt to be most important in their experiences of being a parent-carer/care-recipient and their perceptions of the future. The researcher asked mainly open questions with closed questions only to clarify information. Prompts were also prepared for each question in order to help participants elaborate on experiences. Further questions developed were added in subsequent interviews as theoretical codes and categories emerged.

Interviews lasted approximately one hour for older parents and approximately 20 minutes for adults with ID. Participants were debriefed at the end of the interview, offered information about support services and the opportunity to meet with a clinical psychologist for a follow-up session. No participants requested this.

### *Data analysis*

Interviews were audio-recorded and later transcribed verbatim. This process allowed the researcher to become immersed in the data and absorb content and meaning from the material.

The first stage of data analysis involved open coding where the data was dissected into shorter segments and assigned labels as the researcher asked 'what is happening here?' and 'what does this mean?' These labels, or 'active codes' (Charmaz, 2006) were used to identify processes within the data.

The second stage of data analysis involved focused coding in which larger sections of the data were coded using more abstract labels. The most relevant open codes were raised to focused codes. The researcher

continually compared new codes and categories with existing data to fully develop theoretical codes and overarching categories.

Memo writing was used to define each code's properties and identify gaps in the data (appendix 13). Theoretical sorting and diagramming aided the development of categories into concepts. An example of the data analysis process is shown in Table 3 and further illustrated in appendix 14.

*Table 3: Example of moving through the stages of data analysis*

<b>Stage of analysis</b>	<b>Example</b>
Open coding	<p>Jack reflected on his decision to not make any active decisions about the future care of his son:</p> <p><i>“You can turn your back on it, can’t you, when it’s something you don’t want to discuss.”</i></p> <p><b>This was coded as ‘not wanting to discuss the future’</b></p>
Focused coding	<p>The code ‘not wanting to talk about the future’ was linked with other codes from other participant transcripts, including ‘dealing with things as they arise’, ‘hoping and praying’ and ‘taking it in your stride’</p> <p><b>A new focused code was created labelled ‘avoiding future orientated thinking.’</b></p>
Theoretical coding and identifying a core category	<p>The focused code ‘avoiding future orientated thinking’ was combined with other focused codes, such as ‘anxieties about the future’ which developed a higher order overarching category: <b>‘confronting the future.’</b></p> <p>The category ‘confronting the future’ was linked with other categories such as ‘accepting’, ‘facing challenges’, ‘meaning making’, ‘being supported/isolated’ and ‘re-evaluating’, which developed a higher order overarching category of <b>‘tolerating uncertainty.’</b> On further analysis the category <b>‘tolerating uncertainty’</b> appeared to encompass all of the higher order categories. This therefore was raised to become the core category.</p>

### *Quality and reflexivity*

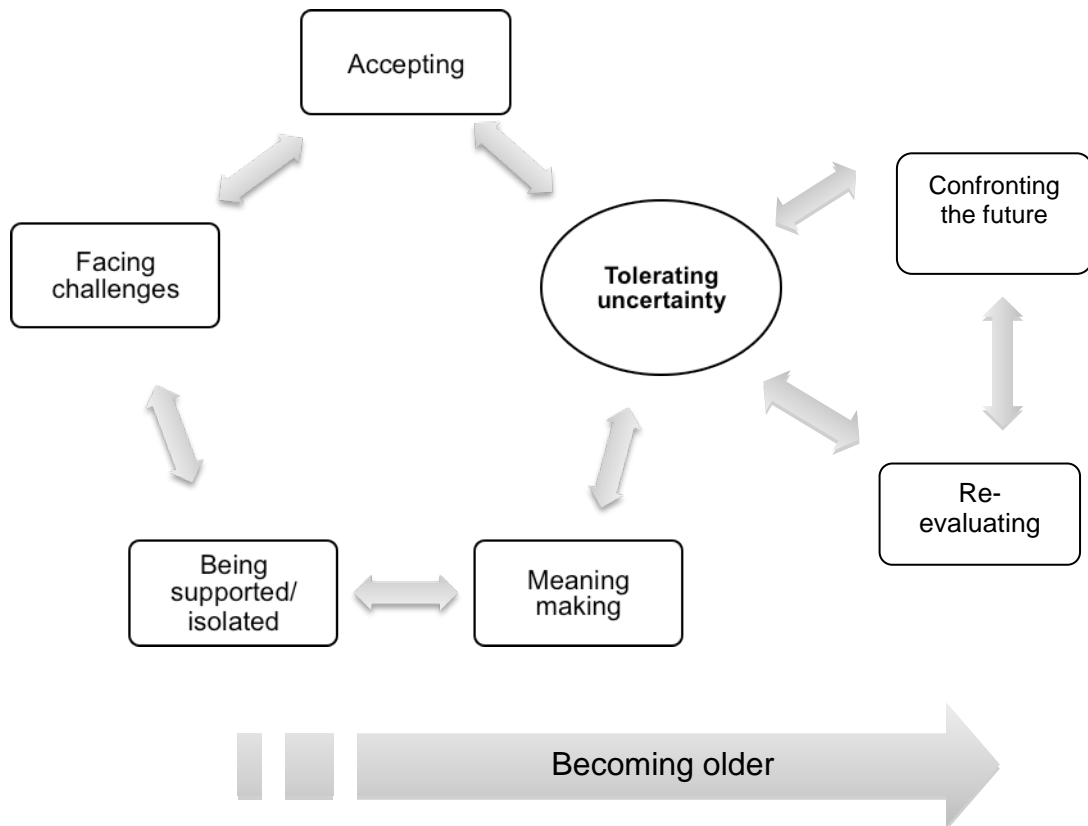
Charmaz (2006) offers four criteria in evaluating grounded theory research; credibility, originality, resonance and usefulness. The analysis was subject to stringent checks. Supervision was sought with the research team to discuss coding and theoretical interpretation. Regular memo-writing formed an audit trail for review of the inquiry process.

A constructivist approach to GT acknowledges the influence of the researcher's epistemological position and prior experiences. Keeping a reflexive diary and supervision helped the researcher to consider different perspectives and reduced the influence of pre-conceived ideas.

## **Results**

A core process of 'tolerating uncertainty' captured participants' attempts to manage their anxieties about the future. Key categories of 'accepting', 'facing challenges', 'being supported/isolated', 'meaning making', 're-evaluating' and 'confronting the future' all influenced one another (as indicated by the arrows in figure 1). 'Tolerating uncertainty' featured in all six categories. The ways in which parents handled uncertainty across the lifespan determined their ability to manage their caregiving role over time, and their children's ability to manage their anxieties about a future without their parent(s). The views of individuals with ID are captured within the majority of the categories. However, these are presented tentatively as fewer people with ID were involved in the study.

Figure 1: The grounded theory



The first category 'accepting' describes how parents came to accept their roles as caregivers for their children with ID and how they grieved for the loss of the child they had expected. They described 'facing challenges' throughout parenthood as they attempted to provide the best care for their child. 'Being supported/isolated' determined the parents and person with ID's ability to cope with challenges that arose. Despite these challenges, participants engaged in a process of 'meaning making' in which they were able to maintain positive perspectives and find fulfilment and satisfaction from their lives. As participants faced issues such as ill-health and death, they 're-evaluated' their role as a parent-carer/care-recipient. Here, some participants engaged in a process of 'confronting the future' by either making explicit proactive plans or using a strategy of avoidance to allay their fears. The key categories are described in detail in the following sections.



### *Tolerating uncertainty*

This core process represents how parents and individuals with ID attempted to manage their anxieties about the future from the early years to the present day. Most parents described *“living one day at a time”* (Nancy). This sentiment was echoed by Oliver, an individual with ID: *“I just take each day as it comes”*.

By focusing on the present, parents were able to manage the uncertainty of discovering their child had an ID and the continuing challenges this presented. Older parents avoided or minimised thinking about their own mortality, ill-health and what might happen when they were no longer able to care for their son/daughter. Similarly, most adult-children avoided contemplating a life without their parents.

‘Tolerating uncertainty’ was a passive process characterised by: *“waiting and seeing what happens”* (Mary) and *“taking things in your stride”* (Jack). Sometimes having a strong faith or religion meant participants did not feel it was necessary to plan for the future. This enhanced their capacity to cope with daily uncertainty. In contrast, Susan and her daughter Kate tolerated an uncertain future by actively preparing for it. This is further discussed in the category ‘confronting the future’.

### *Accepting*

This category relates to how parents accepted their role as caregivers for their children. All described a transition which involved loss, accepting their situation, and protecting their child. Many parents described shock and devastation when they discovered that their child had an ID, accompanied by a sense of loss for the child that they had expected to have. Theresa spoke of *“having no choice but to adapt”* to her daughter’s profound needs following a stroke.

Sometimes caring for a child with ID triggered memories of losses of earlier children: *"It was devastating really...I lost a child very early on and then we were so delighted when we were going to have Anthony and we thought things were going to be alright and unfortunately they weren't."* (Barbara). Nancy talked about how the experience of losing a child created a fear of losing her son with ID: *"Well the fact that I'd lost one son, I knew that sons could disappear."*

All of the parents fully accepted and embraced their role as caregivers for their children. Parents described this as *"a way of life"* and *"like a job"*. All experienced strong feelings of unconditional love towards their children. This helped them to integrate their roles of carer and parent: *"We've just got on with it being parents. You just say, well I'm her mother and that's it!"* (Susan).

Parents described caring as best as they could for their children, by protecting them from harm or the potential distress of unfamiliar environments. For example, many had declined respite support. In doing so, parents also protected themselves and their son/daughter from difficult feelings of loss and separation:

*"I've always thought about how would she react? How would she understand that she'd gone somewhere different and she might think that her family have thought we don't want her anymore."* (Theresa).

### *Facing challenges*

Participants' continued to experience pressures and challenges in their roles as care-givers/care-recipients. Three sub-categories included 'changing nature of child's condition', 'challenging behaviours' and 'being restricted'.

Oliver discussed how his experiences of anxiety had begun from when he had been bullied about his ID in the past. He talked about the physical relief of *"pulling [my] hair out"* as a way of managing emotional pain. His

parents commented on the impact that these behaviours have had on them: *“Over the last month he has been taking all the skin off his fingers, these are things that you don’t like to see, they’re very distressing.” (Eileen).*

Parents described how their son/daughter’s health problems added additional complexity and uncertainty. For example, parents whose son/daughter had epilepsy used words such as *“frightening”, “unpredictable” and “distressing”* when reflecting on their experience. The complexity of their son/daughter’s difficulties affected parents’ ability to cope and in many cases parents felt restricted in all aspects of their lives:

*“We’ve got two shadows, we’ve got ours and we’ve got Oliver’s... That’s one of the problems because where we go Oliver has to go because he doesn’t like to stay in the house by himself. We’re not missing out but it would be nice I suppose to do things on our own” (Liam).*

Theresa spoke of adjusting her employment to “centre around the needs” of her daughter. Mary spoke of *“being restricted by time constantly”*. Nancy felt *“stuck in a routine”* that had governed her life for many years. For these parents, their lives had been consumed by their caregiving role.

### *Being Supported/being isolated*

Participants’ experiences of informal and formal support were polarised, leading to two sub categories; ‘being supported’ and ‘being isolated’. How much families were supported determined their ability to cope with challenges. All parents described how support from wider family systems helped them to cope within their caregiving role. Individuals with ID also valued the support they received from family members. Kate’s parents helped her with *“cooking and cleaning”* and Ian valued his parents *“taking him out”* to places he enjoyed visiting. Oliver described the emotional support he received from his family: *“I go to my mum and dad if I’m worried about something and they help me...they look after me wonderful [sic].”*

Individuals with ID expressed how support from services was helpful: *"I have an anxiety problem, so I have carers to take me out and it sometimes helps."* (Oliver). Many parents also felt that formal support was crucial in allowing them to cope within their caregiving role: *"She goes to day services everyday like. I couldn't cope if she had to be at home, I'd have a nervous breakdown!"* (Susan).

Some individuals with ID were fearful that the limited formal support that they found valuable might not be available in the future. Ian spoke passionately about the potential closure of the day services: *"My centre is closing! [shakes head] no, no, not happy!"* (Ian). Parents also anticipated the loss of services that they found helpful: *"Having the day centres' has helped an awful lot. But that looks as though it's coming to an end unfortunately."* (Theresa).

Whilst some participants had found services helpful and feared losing them, others felt *"disappointed"* with the professional support offered to them. Some individuals with ID felt let down by the formal care they had received:

*"I have carers but the last few weeks they have let me down something rotten... they go off sick so I have different people. And I don't like change so I'd rather have the same people."* (Oliver).

Some parents felt services were *"inflexible"* to their needs and spoke of how managing challenges alone with limited support had made them feel isolated: *"He doesn't get much support really and I think this is unfortunate that we have tended to become a bit isolated, the family is it basically."* (Jack). Similarly, Eileen said: *"You just have to get on with it by yourself because there's not really anybody else to help and it's not fair to put onto others."*

The differences between supportive and isolating experiences of parents and individuals with ID were noticeable in the interviews. Kate and

Ian felt a greater connection with services and had not experienced the isolation described by their parents.

### *Meaning making*

Finding positive meanings allowed participants to cope with the daily challenges they faced. Three sub-categories were 'maintaining positive perspectives', 'feeling satisfied' and 'caring providing a purpose'. Individuals with ID described experiences of living with their parents in positive ways: *"My mum and dad take me to the garden centre. I like it there."* (Ian).

Despite the challenges of the caregiving role, parents found satisfaction and fulfilment in caring for their son/daughter:

*"There's nothing better when I take Oliver down to the sea and he has a smile on his face. That makes us happy. As long as he is happy, then we are satisfied."* (Liam).

Some parents described how caring had given them *"a purpose in life"* (Michael) and a motivation to look after themselves as they entered into old age:

*"Well for one thing, I know every day I've got to cook a meal at night don't I? And if I lived on my own I wouldn't bother (laughs) and so we always have a dinner at night which is good for me because it makes me do it"* (Barbara).

Many parents felt a sense of pride when they compared their ability to cope with others. This enabled them to develop a greater sense of control over the challenges they continued to face: *"When I sometimes think back I think how on earth did I cope?!...you know, things other people can't believe even you deal with."* (Nancy).

### *Re-evaluating*

This category represents participants' assessment of their positions as a carer/care-recipient at different points across the lifespan. All parents acknowledged they were unable to care forever: *"But there again we're not young are we? We don't last forever."* (Jack). Many parents discussed how their deteriorating physical health impacted on their ability to sustain the level of caregiving that they were accustomed to:

*"As I've got older I've had some health issues, my tolerance in support of Oliver is slightly not as good as it used to be because I can't do physical things as I used to and he can't seem to understand that."* (Liam).

Some parents had acquired additional caregiving roles, which added additional strain. For example, Jack and Mary also cared for their sons when their spouses became unwell. Similarly, individuals with ID had re-evaluated their position as care-recipients and had considered becoming more independent. Kate felt her plan to move into supported living accommodation was best for herself and her parents: *"I thought about it myself. I want to move out and they want to be on their own."*

### *Confronting the future*

As parents were faced with ill health, the future felt more uncertain. They all spoke of profound anxiety and fear about what might happen to their son/daughter when they become no longer able to care for them:

*"I do worry that he won't be happy and that he won't be looked after but I hope that he will, I hope that there are still people that will do that but you can't do anything can you?"* (Barbara).

Individuals with ID offered contrasting perspectives about the future. Ian and Oliver felt that an independent future without their parents to care for

them was “bad” and “scary”. However Kate expressed “feeling excited” about moving into her own flat.

#### *Avoiding thinking about the future*

Minimising or avoiding thinking about the future allowed participants to live in the present and allay their fears. Whilst many parents found this a helpful strategy, it prevented some of the adults with ID from exploring the possibility of a different future. Ian found it difficult to consider the prospect of not being cared for by his parents and spoke passionately about “wanting to stay at home forever.” His parents described the future being a background worry they hadn’t discussed with him: “It’s something that is in the background really, I think about it but we don’t talk about it I suppose.” (Michael).

Oliver described how talking about the future was difficult: “If you think about the future it’s scary so I just take each day as it comes...sometimes when people ask me about the future it can push my buttons and make me a bit cross.” (Oliver). His parents echoed this same view: “When we’ve tried to talk to Oliver he gets very defensive, saying ‘do you want me to move out?’ so we just avoid talking about it.” (Eileen).

#### *Letting go versus unconditional care*

Most parents believed that they would continue to care until they were no longer physically able: “As long as I am alive I will look after him.” (Mary). Barbara said: “I’ve made the decision to carry on caring for as long as I can. That’s my way. I mean, he is my son and he is my care isn’t he?” (Barbara).

Susan represented a “deviant case” in the analysis. She had decided to let go of her caregiving responsibilities after experiencing physical health difficulties. She described how this decision was made easier as her daughter expressed a desire to move into supported living accommodation. Susan spoke of her attempts to prepare Kate for this transition: “I’ve tried to

*teach her such a lot in the last few years to make her more independent.”* Kate described how she was looking forward to practicing these independent skills: *“When I have my own place I can do more like cooking, and ironing. Mum does all that now.”*

Susan described the difficulty of ‘letting go’ psychologically: *“I shall worry all the time but I’ve got to learn that Kate has got to start doing things without me.”* Kate did not share the same concerns, she said: *“[moving home] was an easy decision, I’d thought about it myself.”* Through open conversations about the future, Kate had been able to generate new possibilities and become more independent.

#### *Desires and plans for the future*

Most participants had not made any explicit plans for the future. However they had hopes and desires for their adult-children in the event that they were no longer able to care for them: *“I’d like him to be somewhere and happy doing his own thing, you know if he was in a flat not far away”.* (Eileen).

Oliver had had some ideas about where he would like to live in the future but decided that currently he would like to continue living with his parents:

*“It has gone through my mind before, sometimes when I just want to get away from problems I think ‘I want my own flat’. I would like my own space, be my own person. I wouldn’t be sharing with people. I’d like to live on my own, with help from carers I suppose. I’d like to live by the sea [laughs] but I’ll just leave things how they are at the moment.”* (Oliver)

Oliver’s parents spoke of how they would support his decision to move home if he initiated this in the future but that they would not force this decision for him: *“If Oliver wanted to move then we would support him in*



*every way...we wouldn't shut the door on him." (Liam). They spoke of how their caregiving responsibilities wouldn't cease if Oliver decides to move home: "It doesn't matter where he will be or what will happen, you can't get away from the care responsibility." (Eileen).*

Ian expressed a firm preference to remain living at home with his parents: *"I like living here, it's nice. They are not horrible...I want to stop at home." (Ian). Kate was excited about the prospect of moving out of home, she spoke of looking forward to "living with friends and decorating [her] new bedroom."*

Many parents described how on-going service changes had hindered future planning: *"It's difficult for services now with cuts, I understand that, but some of the care accommodation is appalling that I've seen." (Liam). Lack of information about alternative options meant they felt they had no choice but to continue caring into old age.*

#### *Having hope and feeling hopelessness*

Parents described having faith that their adult-children would be cared for in future, whilst expressing concern that 'outside' care would not be as responsive and loving as the care they provide: *"they wouldn't care for him like I do" (Barbara). Most parents did not expect their non-disabled offspring to take over future care: "It wouldn't be fair to them, they've got their own lives." (Jack).*

For Barbara, religious beliefs enabled her to hold hope for the future and tolerate uncertainty: *"All I can hope and pray for is that he is cared for when I'm no longer here." Nancy held hope that her son would die before her and her husband, in order to protect him from experiencing the pain of bereavement: "I hope that he will go before us so that he wouldn't have to be sad about it." (Nancy).*

Adults with ID did not appear to experience the same feeling of hopelessness about their potential future care as their parents did. Kate was looking forward to developing a greater sense of independence. Oliver described how seeing friends move out had given him a positive view of supported living: “[Friend] lives in a flat. The carers seem nice.” Previous conversations about the future helped individuals to generate new possibilities and ideas. Ian found it difficult to feel hopeful about a future without his parents in it. How parents tolerated their own anxieties influenced their children’s ability to envisage a different future. Adopting a position of “*living one day at a time*” (Nancy) allowed the majority of parents to maintain balance and protect their children from experiencing uncertainty.

## **Discussion**

This study presents a grounded theory, exploring the processes involved in being a caregiver and a care-recipient, and highlighted perceptions of the future. ‘Tolerating uncertainty’ was the central process, encompassing six key sub-processes: ‘accepting’, ‘facing challenges’, ‘being supported/isolated’, ‘meaning making’, ‘re-evaluating’ and ‘confronting the future’. How much participants felt supported and gave positive meanings to their role as a care-giver/care-recipient determined their ability to cope with day-to-day challenges and the uncertainty of the future.

Most parents were not seeking alternative future care arrangement whilst they could still manage to care. However, in some cases, this position was one of acceptance rather than choice. Many felt hopeless when they considered the care services might offer their children and looked towards the future with profound anxieties and fears. ‘Living one day at a time’ allowed parents to minimise or avoid thinking about the future, thus protecting their son/daughter from uncertainty. However as parents were ageing and facing ill-health this became a harder task.

Avoiding talking about the future prevented adults with ID from developing ideas about a different future. Despite this, some individuals expressed desires and preferences and did not experience the same feelings of hopelessness as their parents did about future care.

Within systemic literature, the 'family life cycle' illustrates how stressors can facilitate or hinder transitions including the birth of a child, leaving home and children setting up their own home (Dallos & Draper, 2010). Vetere (1993) claim that this sequence of life events differs in families where one member has a disability (Goldberg *et al.*, 1995). This was apparent in the narratives of the participants and the transitions they experienced, as they became older parents and adults with ID.

The core category of 'tolerating uncertainty' encompassed all of the key categories. Mason's (1993) concepts of 'certainty' may be helpful in explaining how participants were able to tolerate persistent uncertainty. It appears that parents adopted a position of 'safe uncertainty' during the early years of parenting. This position assumes that nothing is fixed and everything is in a state of flow, allowing parents to cope with the changing demands of the caregiving role. However as parents' age and face ill-health the uncertainty of the future may become intolerable. Many felt their options were now limited, leading them into a position of 'unsafe uncertainty', described as 'the sense of being overwhelmed by the complexity and enormity of the problems and not knowing where to go or what to do.' (Dallos & Draper, 2010, p.176). In contrast, participants who had made active future plans were able to adopt a position of 'safe uncertainty'.

The sub-process of 'accepting' captured how parents managed the discovery that their child had an ID before fully accepting their role as a caregiver. This links with the theme 'a life not foreseen' in a previous study (Cairns *et al.*, 2012). Systemic literature recognises an association between loss and protection. Families who strive to protect the person with ID from the perceived consequences of their disability may restrict the individual as they mature into adulthood (Goldberg *et al.*, 1995; Pote *et al.*, 2011). In the

current study, parents engaged in strategies to protect their child from the perceived dangers of unfamiliar care, for example many rejected opportunities of respite care for fear that carers would not be as responsive to their child's needs.

The parents in this study faced many challenges, leading them to feel restricted in their personal, social and working lives. This finding resonates with previous research suggesting that parents may experience depression as a consequence of their caregiving role (Chou *et al.*, 2010; Taggart *et al.*, 2012). Parents and adults with ID found support was invaluable in helping them to overcome the challenges they faced. However, some expressed frustration that the support was inadequate and made them feel isolated, identifying with findings from previous literature (Bibby, 2012). In contrast, adults with ID did not report these concerns to the same extent as their parents did and instead reflected more positive experiences of services. The meaning of support for parents and individuals with ID may be very different. An activity experienced as meaningful by the person with ID may not offer support or a break to the parent and vice versa.

Todd & Shearn's (1996) concept of the 'perpetual parent' may explain the parents' feelings of isolation. 'Perpetual parents' limit social contact and doubt other's capacity to care for their children. Most parents in this study could be viewed as 'perpetual parents' since they described having limited social contact with people outside of the ID context and few opportunities for time alone or quality time with their spouse. Many felt their individual identity had been overshadowed by their identity as a carer.

Complementing the 'perpetual parent' is the notion of the 'eternal child' (Todd & Shearn, 1996), referring to how parents may view their adult-child as remaining in infancy or adolescence stages. While it was clear that parents had their son/daughters best interests at heart, most cast them in the role of an 'eternal child'. For example, in parent interviews, the 'voice' of their adult with ID was often missing. There was little recognition that their son/daughter may have desires or wishes about the future, or indeed that

these might be different to their own desires. Two individuals with ID in the study did in fact express aspirations for the future and a desire for independence, connecting with previous findings (Bowey & McGlaughlin, 2005). For one individual with ID, discussing the future was an unfamiliar concept. Avoidance of this topic by parents held implications for their adult-children who are not given with the opportunity to develop new ideas and possibilities. Allen (2011) notes that the wider system (family and services) can 'unwittingly stifle movement towards independence if it remains unaware of the shifting needs of adults' (p. 30) as they mature into adulthood.

The category 'meaning making' captured how participants' appraisals of their ability to overcome challenges and adversity affected their ability to cope. Parents gained tremendous satisfaction and pride from their caregiving role, which enabled them to continue in their caregiving role and cope with the uncertainty of the future. Deriving satisfaction from the caregiving role is a consistent finding in the literature (Dillenburger & McKerr, 2010; Rowbotham *et al.*, 2011; Yoong & Koritsas, 2012). Hill & Rose (2009) found that parents who attributed positive meaning to their ability to cope during times of adversity gained a sense of control over their ability to manage challenges and reported lower levels of stress.

Most parents and adults with ID in this study expressed anxieties about the future, which supports previous research (Griffith & Hastings, 2013; Ward, 2012). Parents grappled with the dilemma of relying on formal services for future support for their son/daughter whilst at the same time having little faith in the services offered. They expressed hopelessness about the future and anticipated loss of services owing to the financial cuts to services. Existing literature supports the finding that distrust and dissatisfaction in services is an obstacle to future planning (Cairns *et al.*, 2012).

In contrast to previous research, which suggests that many parents have desires for their non-disabled offspring to take over the future care of their son/daughter with ID (Heller & Arnold, 2005), this study did not find this. Most parents felt that passing over this role would be unfair.

Previous studies have frequently demonstrated how barriers to future planning have centred on parents' fears of letting go and anxieties around the care not being good enough (Taggart *et al.*, 2012). A striking finding in this study was that despite these barriers, some parents were willing to explore alternative options for the future if their son/daughter initiates this request. Kate and Susan represented an example of where this had happened. The onus on the individual to initiate decisions about their future potentially creates difficulties in family systems which utilises a strategy of avoiding thinking about the future, perhaps stifling the person with ID to be able to generate ideas about a different future.

Bowey & McGlaughlin (2007) found that adults with ID might find it difficult to plan for the future because of the mutually supportive relationships that often exist in older families. It was possible that this was also a feature in the current study given the positive experiences that individuals reported about living with their parents. However, given the small sample of participants with ID, this interpretation is offered tentatively. Baum and Lynggard (2006) suggest that families may avoid life cycle transitions, such as moving home, in order to prevent further loss. Parents may protect their son/daughter from vulnerability whilst the person with ID may protect his/her parents from the consequences of old age by remaining at the family home and avoiding grief of the 'empty nest.'

### *Methodological issues*

This study includes the voices of both mothers and fathers. The experience of fathers is often neglected in caregiving research. The study also offers the unique perspective of individuals with ID. However, the small sample size makes it difficult to meaningfully explore gender differences between mothers and fathers, and make comparisons between the perspectives of parents and adult-children. In addition, the interviews that were carried with individuals with ID out did not produce sufficient amounts of rich data, limiting generalisability of findings.

Meeting with individuals with ID on only one occasion may have been a hindrance to gaining rich interview data. Building rapport with participants is good practice when working with seldom-heard groups (BILD, n.d). Whilst attempts to meet communication needs were made (i.e. simplifying language and using visual aids), meeting the individual beforehand may have allowed the researcher to become more familiar with the persons preferred methods of communication and make adaptations accordingly.

Regardless of these methodological constraints, the three individuals with ID that did participate provided three unique experiences and perceptions of the future.

#### *Limitations and directions for future research*

One main limitation was that theoretical saturation was not achieved, the point at which no additional data can be found to gain any new insights (Glaser and Strauss, 1967). However, there is debate as to when saturation is achieved. Dey (1999) argues that 'theoretical sufficiency' may be a more useful term in GT research. The categories in this study were deemed theoretically sufficient allowing relationships to be explored and conclusions to be drawn. Utilising theoretical sampling to seek out more voices that have not yet being heard would be helpful in further defining the GT produced. For example, speaking to families where the son/daughter with ID has moved out of the family home may have developed fresh insights and further refined the categories 're-evaluating' and 'confronting the future'.

All of the participants were white British. This makes the findings from this study difficult to generalise. It is possible that families who have been exposed to different cultural norms, the transition to becoming an older parent/adult with ID may be very different. Furthermore, all participants had involvement with formal services. The voice of families not known to services is therefore missing from this study. Their experiences may represent use of different coping strategies.

A further limitation is through the use of purposive sampling. Families who chose to participate may have extreme positive/negative views, making the findings difficult to generalise to other older families. Recruiting people via their family inevitably meant that parents decided whether their adult-child participated. This was coupled with a professional's judgment about the cognitive ability of a person with ID to participate. Although consent from adults with ID themselves was gained, they may have been open to suggestibility from parents and professionals. Approaching adults with ID directly, perhaps through an advocacy service, may have empowered individuals to make informed decisions about whether or not to take part.

Future research could include participants from a wider range of backgrounds in order to determine the influence that such factors have on the experience of an older parent. For example, examining potential differences between; (i) younger and older parent subgroups (e.g. 60-year-old parents and 80-year-olds); (ii) older parents from minority ethnic groups and (iii) older parents with an adult-child with specific ID/additional diagnoses (i.e. Down syndrome or autism). Further qualitative investigation into the views of both older parents and their son/daughters with ID who have successfully made the transition to leave the family home would be helpful in informing practice on how to best support families considering this transition in the future.

Whilst this paper went some way to addressing the gap of the perspectives of people with ID, the methodological issues described above, made gaining rich narratives of their experiences difficult. Ethnographic methods could be considered as a possible alternative to interviews. Moreover, longitudinal research is needed to represent variations in experiences of families with ID over time.



### *Clinical implications*

A variety of clinical implications can be drawn from this study. Professionals need to be mindful of the needs of older families and therefore training is key. Some families in this study did not feel that they had been listened to and felt that they had no choice but to cope on their own. Empathic listening of professionals in understanding the needs of older families would allow their voices to be heard. It is important that interventions are tailored to meeting the needs of these older families in order to reduce psychological distress, enhancing their well-being and quality of life. It is important that professionals pro-actively review future planning across stages of the life cycle. This will help ease anxieties about the future and avoid crisis care situations.

The findings also revealed that older families lack support, information and practical resources, despite policy improvements over the years to better support their needs. More importantly, many families had lost trust in services. The implications of these findings are that a holistic approach to service delivery is needed, working within and external to the family in enabling people to consider different future possibilities. Health and social care professionals should (re)build levels of trust by listening to families concerns and signposting to sources of advice. Tailored psychosocial interventions may be beneficial in enabling older parents to continue within their caregiving role. Systemic therapy may be considered useful in helping families with the transition to becoming older parents/adult with ID and moving towards positions of safe uncertainty, where options about the future can be explored and discussed openly.

### **Conclusions**

The exploratory GT showed how families with ID tolerated uncertainty about the future. Older parents in this study spoke of their unconditional love for their son/daughter with ID; the strains and satisfactions of their caregiving

role. How families' were supported and gave meaning to their role as a caregiver affected their ability to cope with the challenges they were faced with and continuing to face as they age. Many families expressed profound anxieties and fears about the future. Adults with ID were able to express desires for a different future in the context where the topic was discussed openly within the family system. They did not have the same concerns regarding future care provision as their parents did. The small sample size of the ID group, however, made it difficult to draw meaningful comparisons. Future research is needed that directly engages adults with ID. It is vital that services respond to the needs of these families and implement interventions that aim to reduce psychological distress and enhance well-being amongst parent caregivers who continue caring well into their old age. This in turn will enhance the well-being of the adult with ID for whom they are caring for. It is important that services support such families in planning for the future so that crisis-care responses to changing life events are avoided and individuals with ID are able to process loss in a healthy and effective way.

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### **Chapter three: Reflective Review**

This paper will offer reflections on the literature review and the research study. There will be a discussion of the methodology, ethical issues and the clinical implications of the research. The reflexivity section will discuss the researcher's epistemological position, the effect of the research on her and key lessons learnt. Due to the personal nature of reflections, the first-person narrative mode will be used at times throughout this paper. Reference to any service users or participants will be given pseudonyms in order to protect their anonymity.

#### **Reflections on choosing the topic**

My initial interest in the topic came about from my encounters with older families of adults with intellectual disabilities (ID) when I worked as a speech and language therapy assistant and later as an assistant psychologist in a Community Learning Disability Team (CLDT) context. I wondered how these parents coped with their life-long parental role, what impact caring had on them psychologically and what made them want to carry on caring? Or did they feel that they had no choice? Encounters with adults with ID who had been moved out of their family home and into residential care following a 'crisis' where their parent (and primary caregiver), had taken ill or had died made me question whether they had any say in this process.

I particularly remember one service user, Paul, a 56-year-old gentleman with a moderate ID, who moved into a residential home following the death of his mother. When I met Paul he seemed confused and agitated, not surprisingly since his life had suddenly been turned upside down and he was living in unfamiliar surroundings with people much older than himself. He was unable to attend his mother's funeral since carers felt protecting Paul from this would be in his best interest. He was referred to a clinical psychologist for 'challenging behaviour' a couple of months after moving into the residential home. Paul's grief had become more complicated since he

was not only restricted from grieving the loss of his mother in a healthy way (i.e. attending rituals, such as funerals) but he was also experiencing the loss of an environment and routine that was familiar to him. There has been much research into the effect of bereavement of loss for people with ID and how it can often result in unrecognised or disenfranchised grief if they do not receive the support that they require (Doka, 2002). I wondered how Paul's experience may have been different had he been involved in the process of moving home? Had anyone ever spoke to him before about what would happen when his mother became no longer able to care? And if he had any desires of his own about where he would like to live?

My first placement as a trainee clinical psychologist was within a systemic practice team in an ID context. I soon realised that Paul's situation was not uncommon. Conversations with my placement supervisor further stimulated my interest in the area of older families with ID and she kindly agreed to be my clinical supervisor.

### **Reflections on the literature review**

There is a dilemma within Grounded Theory (GT) about when the literature review is carried out and how much prior knowledge and available literature should inform the analytic process (McGhee, Marland & Atkinson, 2007). Ideally the literature is reviewed after the GT has been produced and compared with developing categories and theory to see how much the emerged GT supports or deviates from existing theory. Consequently researchers remain open-minded and sensitive to participants' stories without pre-conceived ideas and assumptions. In reality most researchers conduct a preliminary scoping search of the literature to justify further exploration using a GT approach (Willig, 2008).

Whilst I acknowledged the reasons for delaying the literature review, the demands of the DClinPsy thesis did not allow for this. For example, peer and ethics committees required details of existing literature when submitting

the research proposal. The time-scale for the research meant it was not feasible to delay the literature review. As a compromise, a reflective diary was maintained throughout to enable me to consider any pre-conceived ideas or assumptions I had and take steps to limit these as far as possible throughout the data collection and analysis stages of the research study. For example, one early entry in my reflective diary reads:

*“Given my encounters with older families in my clinical work I expected to find in the literature review that life-long caregiving was stressful and burdensome. However, I was surprised to see that caregiver satisfaction featured as a common theme in recent studies. Reflecting on this, I wonder whether my clinical experiences of working with older families have been biased to families who are experiencing distress and stressful life cycle transitions. Most families tend to come into services at a point of ‘crisis’ in their lives.”*

Due to having less experiences of working with older parents, I risked making an assumption that all older parent caregivers felt overwhelmed and stressed as a consequence of caregiving. I may have missed the more positive aspects of the data had I not explored my assumptions.

The literature review also confirmed some of my expectations based on my experiences of working within this clinical area. I had anticipated to find that depression and anxiety were associated with life-long caregiving, that older parents would have anxieties for the future and that most do not plan for when they are no longer able to care. The consequences of this seemed very real when I reflected on Paul’s situation. I became more interested in older families perceptions of the future and what they perceived as the barriers to future planning. Some of the literature suggested that lack of information, alternative options and lack of trust in services contributed to this. Few studies had addressed this issue with older parents (aged 65 and over) and it warranted further qualitative investigation. The literature review revealed a paucity of research involving the views of the person with ID. I was keen to include these experiences in my research. The limited evidence

base was anxiety provoking and exciting. Some colleagues had warned that including people with ID would be a difficult task. However, I felt these voices were too important to ignore. This fitted with my desire to empower people with ID to share their experiences and influence service delivery.

## **Reflections on the research project**

### *Design*

I chose to use GT methodology because little was known about this topic. GT is suited to a heterogeneous sample and allows for comparisons between groups (older parents and adults with ID). Other qualitative approaches, such as IPA (Interpretive Phenomenological Approach) require a homogenous sample. Charmaz's (2006) constructivist approach to GT fitted with my personal and epistemological position. This is discussed further in the reflexivity section.

Including the voices of marginalised and disempowered groups (both older carers and individuals with ID) is strength of this research. The semi-structured interview was carried out in a conversational manner to allow for co-construction of the data and empower participants to discuss meaningful experiences. However, a narrative approach may have been less restrictive, liberating participants to tell their stories in their own way. Interviews with adults with ID presented a challenge to gain rich enough data to inform the analysis. The potential reasons for this will be discussed. Ethnographic research methods may have allowed people with to express their views without linguistic constraints.

### *Sampling*

Initially there were two recruitment routes; NHS Community Learning Disability Team and an independent respite service. However all of the participants were recruited via the NHS route. Recruitment from the respite

service proved more difficult; many parents did not want to be involved in the research, owing to their involvement with court case appeals contesting the closure of day services around the same time. Despite attempts to reassure potential participants that the research would not interfere with any services they currently receive nor their court cases many did not feel comfortable with doing this. In hindsight I acknowledge parents' feelings of vulnerability at a time when services were being taken away from them.

Despite attempts to approach individuals directly by sending invitation letters and asking professionals to discuss the research with individuals with ID, frequently parents decided whether the family would participate. Professional judgments were made about an individual's ability to participate in terms of their communication skills and their circumstances. A health care professional who identified a family that met the inclusion criteria for the research requested that I did not interview the individual with ID because she said "talking about the future may be too distressing for him and could put ideas in his head". Whilst I understood these concerns I felt that it was important not to dismiss this individual and their potential involvement in the research. This highlighted how services can unintentionally disempower people by protecting them from the perceived consequences of their disability.

I encountered far more difficulties in recruiting people with ID than I did older parents, despite attempts to recruit from an additional CLDT in a neighbouring county. This may have been connected to recruiting people via their families. Approaching individuals with ID directly, perhaps through advocacy services, may have been more helpful. The majority of older parents had children whose severe level of ID meant that they were unable to participate. It may have been helpful to seek more voices of individuals of ID living at home as well as people with ID who had moved out of home, along with their parents, in order to further refine the emerging categories within the GT.

Theoretical sampling, where the researcher seeks specific individuals to clarify questions and expand the developing theory, was not possible in this time frame. Whilst more time may have enabled more individuals with ID to participate, be identified and given them the opportunity to take part, time constraints for this study meant that this was not possible.

### *Procedure*

Despite attempts to engage people with ID by simplifying language and using communication aids, collecting data was challenging. During the interviews was reminded of the importance of building rapport and understanding an individual's preferred communication methods. Building rapport in a one-off interview was difficult. Whilst multiple meetings were not feasible due to time constraints, I did, however, make attempts to speak to the professionals involved with each person to gain insight into their methods of communication. One participant with ID appreciated the easy-read material, whilst another told me they didn't need to look at the pictures. This served as a reminder not to assume that all individuals require the same level of communication support and may feel patronised by easy-read and visual communication aids.

Prior to the interview I asked families how I could adapt interviews to best suit their needs. One person with ID informed me that he was having difficulties concentrating. I suggested that he took breaks whilst I interviewed his parents and explained that he could stop the interview at any time. An older parent with visual difficulties asked if I could read the information sheet and consent form out to her. I hoped this helped participants to feel more relaxed and have more control over the interview process.

Two participants had a diagnosis of autism in addition to their ID. People with autism may struggle with the concept of time and future thinking (Jackson & Atance, 2008). Indeed for Ian, the concept of the future appeared to be too abstract. However Kate had made plans to move home and was able to express these views because this was happening in the 'here and

now'. Alternatively, participants with ID, who have never had the opportunity to think about the future, may not possess the language to generate alternative future possibilities, despite the researchers attempt to make communication adaptations to the interview.

All participants chose to be interviewed in the family home. Whilst this helped participants to feel relaxed, it may have presented challenges. Participants may have felt uncomfortable knowing that their relative was in the same house. Whilst parents seemed at ease during the interviews, participants with ID may have been reluctant to say things that they think their parent would not want them to say. They may also have given answers that they thought the researcher wanted to hear.

To limit researcher bias, supervision was used to reflect upon and challenge decisions and conclusions drawn from the data (Norris, 1997). During supervision I became more aware of such issues and errors in my interview technique. For example, in one of my earlier interview transcripts my academic supervisor noted that I had asked a series of closed, potentially restrictive questions. In subsequent interviews I used questions, prompting participants to elaborate on their experiences. This enhanced the richness of the data and enabled me to gain confidence in my interview technique.

### *Analysis*

Transcribing interviews was time consuming and I often rushed to transcribe each interview before commencing the next, in line with GT principles of simultaneous data collection and analysis. However, transcribing the interviews myself allowed me to become immersed in the data; I noticed aspects of the participant's stories that I might otherwise have missed and felt their narratives were more emotive when I listened back. For example, one participant with ID said very little but displayed passion when he said he was unhappy that his day centre was closing. I began to consider what had not been said, the absent but more implicit understandings in narrative terms. Would he be so passionate about the change in day services

if he didn't value and appreciate them? Could I assume meaning from the passion in his words?

Having never done GT research before, I was unfamiliar with the analysis process. My realisation that constructivist version of GT did not come with 'how to' manual and was more of a framework for working with the data was initially anxiety provoking but allowed me to appreciate the creativity of GT research.

Data saturation, where the researcher ceases to gain any new insights from the data (McLeod, 2001), was not achieved. Given more time, theoretical sampling could have enabled data saturation of the emerging categories to be achieved. However, there is debate about whether categories should be 'data saturated' or 'data sufficient' (Dey, 1999). The categories were viewed theoretically sufficient in that they allowed relationships to be explored and conclusions to be drawn.

### *Findings*

Whilst involving adults with ID was strength of this research, the small sample size made it difficult to integrate the findings and make comparisons with older parents. I wondered whether keeping the analysis just to the older parents would have been easier. However, this conflicted with my values of empowering people with ID and I did not want to dismiss their meaningful contribution to the research. In supervision I explored ways to tentatively integrate their perspectives in the analysis.

The findings highlighted that the majority of older parents had considered the future needs of their children. Most actively avoided talking about this, as it heightened their awareness of their own mortality and raised fears about the suitability of alternative care. Most families had not made any explicit plans for the future, a finding that resonated with previous research. Talking about such a sensitive topic raised some ethical issues, which are later discussed.



## **Clinical implications and directions for future research**

One striking finding of the research study was that if the person with ID initiates the wish to leave home, parents may support this. I was surprised to find one couple had encouraged their son's independence but he wished to remain at home. I had assumed that parental difficulties with 'letting go' and need to protect would prevent the person with ID from becoming more independent. I reflected on the implications of this for services, which could support the family to consider different future possibilities, perhaps using systemic family therapy or educational information on options available. However, most parents had not considered that their children might have different perspectives, which raised the question of how do services support people with ID to make informed decisions while also supporting parents to tolerate alternative perspectives to their offspring?

It may be helpful to evaluate the long-term impacts of few intervention programmes that exist internationally (Heller *et al.*, 2005), which target the issue of future planning for older families with ID. This may provide UK services with some direction for tackling this issue and uncover areas of good practice. Omitting grey literature from the literature review may have, in hindsight, compromised the discovery of intervention programmes that exist within the UK but perhaps might not be published in peer reviewed journals.

Future research with families who had successfully managed the transition of the person with ID moving out of the family home may yield further insights into this process. A strength of this study was that it involved the perspective of fathers, often neglected in caregiving research. Although I was not struck by any specific gender differences, further examination of these in future studies may be helpful.

Despite the small sample size of people with ID in this study, the three people that did participant represented three unique possible experiences for this population. Kate had chosen to leave home; Ian had not had the

opportunity to consider an alternative future; Oliver had decided to stay at home. Some of the older parent's son/daughter with an ID could not be interviewed for various reasons, including their level of cognitive ability. I wondered whether they had had the opportunity to consider the possibility of change.

### **Ethical issues**

Peer review and ethics processes were complicated and stressful. It felt time-consuming, spending many hours form-filling and chasing signatures, and I can see why professionals in the NHS may be put off conducting research. However, when I was eventually ready to submit my proposal to the NHS committee I qualified for proportionate review, which was helpful in fast-tracking my research proposal through the ethical review process.

Some ethical issues and dilemmas were raised throughout the research. During one interview, a participant with ID expressed that he had recently been having suicidal thoughts. This highlighted the tensions between my roles as a researcher and clinician. I wanted to ask more questions than perhaps was necessary as a researcher. I was grateful that the participant was known to services as I was able to highlight concerns to professionals within the CLDT. I wondered how different this might be if a participant was not known to services. To some extent the older parents were not explicitly service users, their son's/daughters were. At times during the interview I became aware of the costs of discussing sensitive topics. The interview may have caused reflection on the caring role, precipitating anxiety or the expression they could not carry on caring and highlighted issues of mortality. I tried to remain sensitive to these issues and debriefed and offered information on support. A one off session with clinical psychologist was offered although none of the participants opted to do this. Sensitivity to these aspects is critical (Davies & Dodd, 2002). I endeavoured to empathise and show understanding of the parents' concerns even when strong opinions

were expressed. For example, one father commented that he thought parents who allowed their sons/daughters' to move into supported living accommodation were "selfish" – a view that I did not personally share.

I reflected on issues around informed consent (British Psychological Society, 2010). Although participants were aware of the sensitive nature of the interview, many parents' stories encompassed multiple losses and bereavements of spouses or children that had died. I wondered if they were fully prepared to recall such stories when they consented to take part in the research.

I wondered how individuals with ID could decline to participate in research despite their parent's consent. Perhaps approaching adults with ID directly, e.g. through advocacy services, may have empowered them to make a more independent decision.

In some instances I was curious as to whether the interviews were acting as an intervention in themselves. Many parents discussed their anxiety and avoidance around thinking about the future. Had talking about the future enabled some of their fears to subside? For participants with ID, I wondered whether this was the first time where they had been enabled to think about the future and new possibilities? Had the interviews opened up new conversations within the family around future planning?

### **Personal reflexivity and learning**

The core category which emerged within the GT, 'tolerating uncertainty', resonated with my journey of the thesis. Having no prior experience of GT, the constructivist approach increased my uncertainty. As trainee clinical psychologists we are taught the value of 'safe uncertainty.' This means holding a belief of 'authoritative doubt', one that encompasses both expertise and uncertainty" (Mason, 1993 p.191). This is characterised by respectful curiosity and recognition that therapy is a mutually influencing

process between clients and therapist. I adopted a position of safe uncertainty within my research, taking a curious, 'not-knowing' and co-constructing data with my participants. Supervision helped me tolerate the uncertainty of the analysis process. Supervisors assured me that the overwhelming mountain of data and codes would eventually weave back together to form the GT. Reflexive diaries and memo-writing helped me to explore my own assumptions and limit these influencing the data.

I was surprised at how much the research impacted on me as the researcher. It was difficult to hear stories of loss and bereavement. At the same time I felt privileged to bear witness to participant's experiences, their heartaches, challenges, successes and triumphs. I felt pride when I learnt how services had helped some families and anger at how services had let them down. I admired Kate as she rejected the status quo and actively sought an independent future. I respected Ian's passion as he described his experiences of services and desires for the future. His interview taught me to 'listen' to the things that were not said as well as the things that were.

One older parent became tearful when she described her wish that her son would die before her and avoid the pain of bereavement. She feared that 'outside' care would not be as responsive and loving as the care she provides. Listening to this was very emotive and I empathised with this mother's plight. As a clinician I was able to utilise skills of containing her emotions and recognise her distress. I realised that supervision was valuable in both research and clinical contexts. These stories reminded me of the importance of this research and motivated me at points where the thesis felt too overwhelming.

The most enjoyable aspect of the research was conducting interviews with participants and I am now more open to the possibilities of conducting research in the future in a clinical or academic role. I appreciate the constructivist GT approach which fosters the interaction between the researcher and participant, leading to co-constructed data. This version of GT complimented my epistemological position of constructivism since it fits

with my own assumptions as a therapist of taking a curious, non-expert stance and valuing a collaborative process between the therapist and the client. My clinical experience of working with marginalised groups has led to a passion for empowering people. Working within a systemic family therapy team has emphasised the importance of empowering people with ID within families. Including people with ID in my research was exciting and I hoped that this might encourage services to acknowledge the desires and ideas of people with ID and their older parents. I intended to create an equal balance of power and encouraged participants to clarify my questions or decline if they did not wish to respond.

The most challenging aspect of the research was conducting a research project as part of the Clinical Psychology Doctorate course, particularly in terms of time. The competing demands of attending clinical placement and teaching alongside conducting the research project meant that I had to be realistic about the amount of data that could be collected, transcribed and analysed in time for the deadline. Ideally I would have liked to recruit more people with ID but conducting interviews with nine older parents and three individuals with ID seemed to be an acceptable trade-off between getting enough data and allowing enough time for analysis and write-up.

In writing this final paper I have reflected on the personal things that I have learnt throughout the journey of completing the thesis. I have learnt to become more realistic in my expectations of myself and what can be achieved within the context of a doctoral training programme. I have also learnt that I am more resilient than I thought; both in terms of my perseverance through the long journey of the thesis but also in terms of being able to hear first-hand some very personal, distressing experiences and contain other people's emotions as well as my own. Whilst some stories have particularly been difficult to hear, I feel privileged to bear witness to their narratives of loss, distress, joy, and unconditional love. I would like their stories to remain with me so that I continue to have an appreciation for the parent-carers in society and am reminded of the importance of empowering

people with ID to make their own choices. As the journey of my thesis ends I foster mixed feelings. I feel relieved that a long journey is nearly over, whilst at the same time feel protective towards the research and anxious about the critique it awaits.

## **Conclusion**

In conducting this thesis I have learnt a host of things; academically, professionally and personally. I am extremely grateful to the participants that took part in the research. I plan to publish and disseminate the research findings and promote the clinical implications. In doing so, I hope that this will aid to a difference being made in the lives of older families with ID now and in the future.

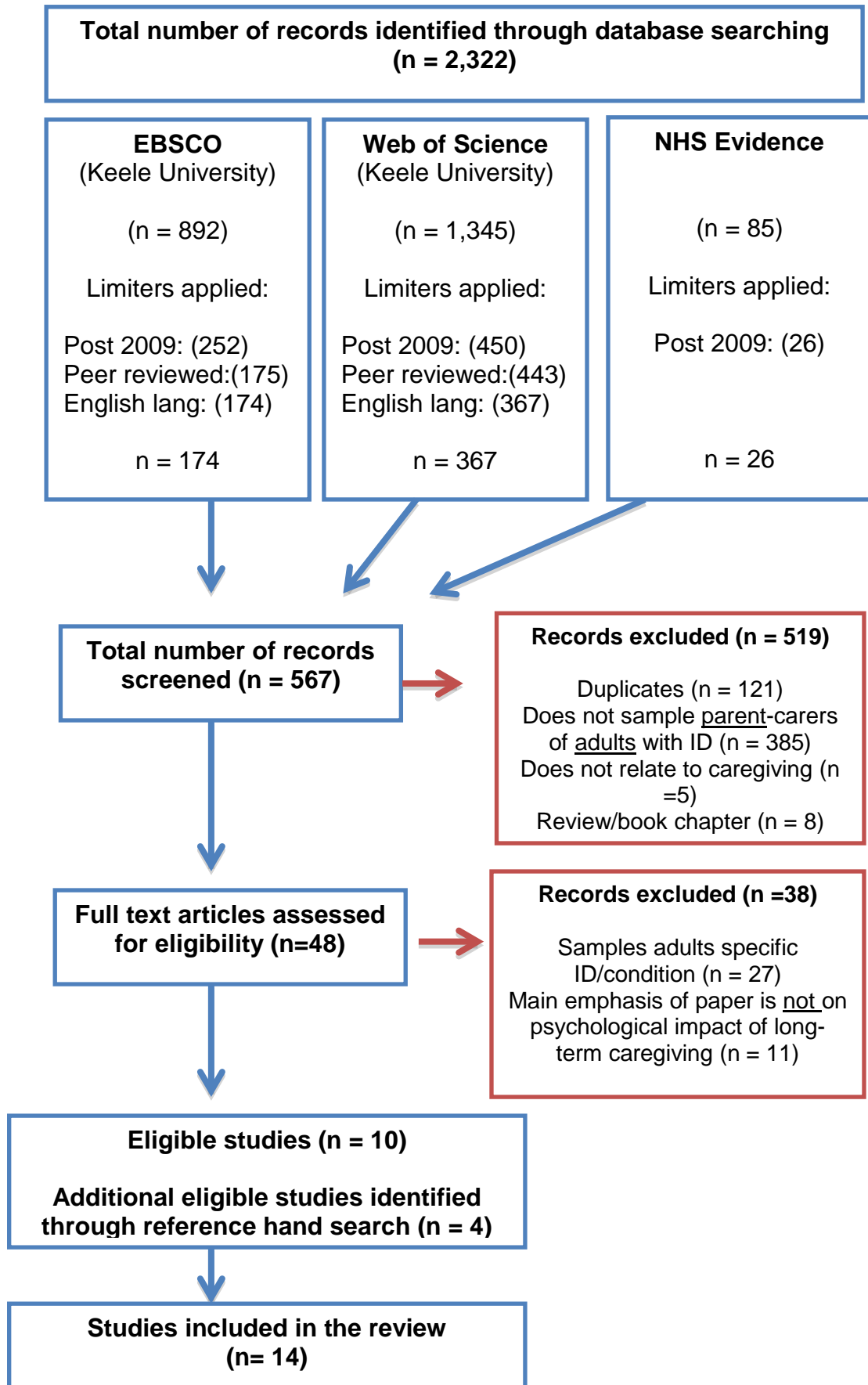
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**Appendix 1: Search strategy process flow diagram and papers excluded from final analysis (n = 11)**



**Studies (n=11) excluded from the final analysis for not meeting criteria item: 'main emphasis of paper focuses on the psychological impact/ experience of caregiving'**

	<b>Study reference</b>	<b>Abstract</b>	<b>Reason for exclusion</b>
1.	Chou, Y.C., Fu, L.Y., & Chang, H.H. (2013). Making work fit care: Reconciliation strategies used by working mothers of adults with intellectual disabilities. <i>Journal of Applied Research in Intellectual Disabilities</i> , 26 (2), 133-145.	Background This study explored the experiences of working mothers with an adult child with intellectual disabilities to understand how they reconcile paid work and care responsibilities. Methods Fifteen working mothers in Taiwan with an adult child with intellectual disabilities were interviewed, and an interpretative phenomenological approach was adopted for data collection and analysis. Results All included mothers prioritized their caregiving role over paid work. The strategies used by these mothers to make paid work fit with caregiving included having strong social networks and informal support for their care work, use of formal services, personal religious beliefs and positive attitudes towards care, as well as having flexible working hours due to self-employment, good relations with employers, working positions and work locations. Conclusions Formal systems, which include both welfare and labour policies, need to be responsive to and involved in supporting these working mothers, especially those who lack good personal networks.	Emphasis of the paper was specifically exploring impact of employment on care responsibilities rather than the psychological impact of long term caregiving.
2.	Chou, Y.C., Pu, C.Y., Kroger, T., & Fu, L.Y. (2010). Caring, Employment, and Quality of Life: Comparison of Employed and	The effects of caregiving on mothers of adults with intellectual disability was examined by determining whether there are differences in quality of life and related factors between mothers with different employment status. Study participants were 302 working-age mothers who had adult children with intellectual disability based on the 2008 census survey on intellectual disability carried out in Hsinchu, City, Taiwan. Results revealed that nonemployed mothers are more likely to have a lower level of	Main aim of paper was to specifically explore the effect of employment on quality of life of caregivers. Focus was not on psychological impact of caregiving.

	<p>Nonemployed Mothers of Adults With Intellectual Disability. <i>American Journal on Intellectual and Developmental Disabilities</i>, 115 (5), 406-420.</p>	<p>health status, including the WHOQOL Physical Health domain, than are mothers employed fulltime. Multiple regression analysis showed that mothers' quality of life was significantly determined by the availability of a person with whom they could share care work, family income, social support, and employment status.</p>	
3.	<p>Eley, D., Boyes, J., Young, L., &amp; Hegney, D. Adults with intellectual disability in regional Australia: Incidence of disability and provision of accommodation support to their ageing carers. <i>Australian Journal of Rural Health</i>, 17 (3), 161-166.</p>	<p>This project aimed to identify a population of adults with intellectual disability and their carers in a defined regional area of Australia to determine their prevalence in this setting, their current accommodation situation and their future accommodation needs. Mixed method cross-sectional design employed a survey to collect data from both quantitative (Likert type) and qualitative (free response) questions. Regional town and its contiguous shires in Queensland. Adults (over 18 years) with an intellectual disability and their primary carers. Identification of adults with intellectual disability and a description of their accommodation situation and perceived needs. Adults with intellectual disability (n = 156) were male (60%), mean age of 37.2 years (range 18-79). Carers (n = 146) were female (78%), mean age of 61.5 years (range 40-91). The majority of adults with intellectual disability (56%) are cared for at home (mean age = 35 years). Mean age of those who live away from home was 39.8 years. The levels of support required by those living at home and those living away from home were not different, nor were the age ranges of their carers. Findings show that the majority of primary carers are over the age of 50 years and continue to provide medium-high levels of support within the family home. The advancing age of both carers and the people they support, combined with the location of that support, is a major issue in the provision of adequate services for this population.</p>	<p>This is a prevalence study, examining the number of adults with ID being cared for by older family carers, and the characteristics of these families including living arrangements.</p> <p>Findings from this study was included in the introduction section of the literature review but was not felt to be included as a main paper for review since its focus was primarily on identifying prevalence.</p>

4.	Hewitt, A., Lightfoot, E., Bogenschultz, M., McCormick, K., Sedlezky, L. & Doljanac, R. (2010). Parental Caregivers' Desires for Lifetime Assistance Planning for Future Supports for Their Children with Intellectual and Developmental Disabilities. <i>Journal of Family Social Work</i> , 13 (5), 420-34.	Future life planning is a growing concern among families with children with disabilities. This article presents a needs assessment evaluating feasibility of a new model for future life planning for family caregivers, Lifetime Assistance, which will provide ongoing planning and monitoring for individuals with intellectual and developmental disabilities. Using surveys informed by a series of focus groups, data were gathered from older and younger parents in one midwestern state regarding the potential program. Study results indicate that respondents did not feel the current system of support was adequate for planning for their child's future, nor sufficient for monitoring the quality of life for their children in the future. Although almost all families had identified a person to support their family members when they were no longer able to do so, parental caregivers overwhelmingly identified the need for the Lifetime Assistance program and many were willing to pay for this service themselves.	This study was an evaluation of an intervention programme and therefore exploration of the caregiving experience and the psychological impact this can have was not the main emphasis of the paper.
5.	Jecker-Parvex, M. & Brietenbach, N. (2012). Tracking an Elusive Population: Family Carers of Older Adults with Intellectual Disabilities in Romandy (Switzerland).	Despite a long-standing tradition of institutional placement in Switzerland, many older adults with intellectual disabilities continue to be supported by aging parents and siblings. For various reasons, these carers and the adults concerned have been over-looked up to now. To find out how many such families are providing housing and care of this kind, and what characterizes such family units in French-speaking Switzerland, a university-level training center undertook a study of this population. Qualitative information was obtained through questionnaires and interviews, providing information on the family history, the types of care which the families currently provide, and their short- and long-term needs. The results suggest that in the Cantons concerned, 27% of adults with intellectual disabilities aged 35–64 reside with family carers, 80% of the latter being elderly parents among whom 16% are aged 77 or older. The	This was a prevalence study which set out to find out how many families are providing housing and care, the profile of such families and their living conditions. Therefore, this study did not measure/explore the psychological impact of long-term care on these older parents.  The findings from this study were included, however, in

		adults involved are relatively autonomous, requiring direct assistance only for complex tasks. Some 88% participate in day activities including employment in ordinary settings. In general, expectations for the future do not include residence in congregate care; furthermore, the current network of residential services is insufficient to accommodate this population's members as they age. The authors conclude that local social services providers must plan for enhanced community services to accommodate this growing group in the years to come.	the introduction section of the literature review and also within the introduction section of the empirical paper.
6.	Jingree, T., & Finlay, W.M.L. (2012). 'It's got so politically correct now': parents' talk about empowering individuals with learning disabilities. <i>Sociology of Health &amp; Illness</i> , 34 (3), 412-428.	Over the last decade the UK Government has made proposals to empower individuals with learning disabilities. Strategies have been implemented to reduce institutionalisation and social segregation. Consequently, some learning disability services are being phased out and the focus of care has moved away from institutions and into the community and family domain. Focusing on discourse as a site for social action and identity construction, we used critical discursive psychology to examine focus group discussions between family carers about facilitating the independence of adult family members with learning disabilities. Unlike official UK Government and learning disability services constructions of empowerment policy, we found that parents invoked empowerment talk: (1) as a resource to construct the facilitation of independence as an abstract, irresponsible, politically correct professional trend; (2) dilemmatically with meritocratic or practical arguments to undermine notions of facilitating choices; and (3) as a resource to construct new service developments as contrary to the preferences of people with learning disabilities. Parents also described individuals with learning disabilities as unable to cope, and drew stark contrasts between their practice and those of service-professionals when	Focus of study was on empowering individuals with ID and facilitating independence. It did not explore the psychological impact of long term caregiving and therefore did not meet the final inclusion criteria.

		expressing concerns about empowerment. We discuss possible implications of such discourses and contrasts on opportunities for empowering individuals with learning disabilities.	
7.	Mansell, I., & Wilson, C. (2010). 'It terrifies me, the thought of the future': Listening to the current concerns of informal carers of people with a learning disability. <i>Journal of Intellectual Disabilities, 14</i> (1), 21-31.	The aim of this article is to report findings from a study that asked carers for their views on a wide range of topics. Issues relevant to the current concerns of carers are reported here. A mixed method triangulated design yielded both quantitative and qualitative data. A total of 647 members of a parent/carer federation were sent a questionnaire with a section on 'current concerns'. The response rate was 23 percent (151 participants). Two focus groups were held with 15 carers who had completed the questionnaire. Issues of concern to carers included access to health and social care information and services; quality and quantity of respite care; suitable educational provision; independence and quality of life (for a person with learning disability); and what would happen to the person with learning disability when the carer was no longer able to carry out their caring role.	The focus of the paper was to explore parents' preferences for housing and care options for their sons and daughters in the future. The main emphasis was not on psychological impact of life term caregiving. Paper cited in empirical paper.
8.	Walsh, M., Morrison, T.G., & McGuire, B.E. Chronic pain in adults with an intellectual disability: prevalence, impact and health service use based on caregiver report. <i>Pain, 152</i> (9), 1951-1957.	This study examined chronic pain in adults with an intellectual disability (ID), in terms of its prevalence, impact on physical and psychological functioning, and treatments used. Questionnaires were distributed to 2378 primary caregivers (caregivers) of community-dwelling adults with an ID. The questionnaires were used to gather data on demographics, general health, nature of pain, impact of pain, treatment, and health-related decision making. Responses were received from 753 caregivers (31.6% response rate). Caregivers reported that 15.4% of this sample was experiencing chronic pain, for an average of 6.3 years. Significantly more females than males were reported to experience chronic pain, although age, communication ability, and	The study examines chronic pain in adults with ID. The study does not explore the psychological impact/experience of long term caregiving and therefore did not meet the final inclusion criteria.

		<p>level of ID were not found to be associated with the presence of pain. However, the presence of pain was associated with cerebral palsy, physical disability, and reports of challenging behaviour. A significant proportion of individuals with chronic pain also experienced limitations in several aspects of daily living, and more than 78% of caregivers reported that the service user had become upset or distressed by pain. More than 80% of service users were receiving some form of treatment for their pain, with most seeing a family physician and using analgesics as the primary form of pain treatment. Results indicate that chronic pain is a significant problem for persons with an ID, with a proportion of service users living with daily pain for many years and experiencing limitations in daily functioning, emotional well-being, and quality of life. (C) 2011 International Association for the Study of Pain.</p>	
9.	<p>Weeks, L.E., Nilsson, T., Bryanton, O., &amp; Kozma, A. (2009). Current and future concerns of older parents of sons and daughters with intellectual disabilities. <i>Journal of Policy and Practice in Intellectual Disabilities</i>, 6 (3), 180-188.</p>	<p>Increasingly greater numbers of older parents are providing care at home for their sons and daughters with intellectual disabilities. As attention needs to be paid to the supports needed by such families to assist them with their caregiving activities, it is prudent to identify the types of supports that will be needed when the parents are no longer able to provide care. Working with a cohort of older parent carers in Prince Edward Island, Canada, the authors undertook to examine older carer concerns and planning issues. Using both qualitative and quantitative methods to explore the key issues that older parents of sons and daughters with intellectual disabilities are currently facing and their preferences for care in the future, the authors initiated a population-case-finding process, undertook pilot interviews with a sample, and then used the resultant qualitative data to form the quantitative component of the study. Of 132 identified families in the province, 10 parents voluntarily participated in pilot interviews, and 33 parents agreed to complete in-depth interviews. Analysis of qualitative data resulted in the following five themes: (1) worry</p>	<p>Main emphasis of the paper was to explore concerns about the future and planning issues. The paper did not explore the experiences and/or psychological impact of long term caregiving, thus did not meet the final inclusion criteria.</p>

		<p>about the future care of son or daughter; (2) concern about services funding; (3) having housing and care options; (4) lack of provider understanding of carer's needs; and (5) helping son or daughter become a productive and active member of society. Key issues identified through quantitative analysis included interactions with the government, the need for respite care, and meeting social and emotional needs. Preferred types of housing and care options included "small option homes" and services that provide care to both older parents and their sons and daughters. The authors' results emphasize the necessity of adequate supports being made available to older parents who wish to support their sons and daughters with intellectual disabilities at home and to ensure that desired supports are available in the future when they are no longer able to provide care.</p>	
10.	<p>Wei, Y.S., Chu, H., Chen, C.H, Hsueh, Y.J., Chang, Y.S. et al. (2012). Support groups for caregivers of intellectually disabled family members: effects on physical-psychological health and social support. <i>Journal of Clinical Nursing</i>, 21 (11-12), 1666-1677.</p>	<p>Aims. This study aimed to examine the effectiveness of support groups for people caring for family members with intellectual disability with the goal of improving their physical/psychological health and social support. Background. Little is known about how differences in the support group context influence either the nature of the social support available to caregivers of family member with intellectual disabilities or the effects on caregivers physical/psychological health in eastern cultures. Design. An experimental, preintervention postintervention control group design was used in this study. Methods. The experimental group received intervention consisting of eight weekly support group meetings for caregivers of people with intellectual disabilities. A total of 72 participants were recruited by permuted block randomisation and evaluated before intervention, after intervention and at four-week follow-up. Participants were blinded to the arrangement. Longitudinal effects were analysed by means of generalised estimating equations. Results. (1) Physical-psychological health (somatic, depressive and anxiety symptoms)</p>	<p>The aim of the study was to examine effectiveness of intervention support groups. Therefore the study did not meet the final inclusion criteria since the main emphasis was not on the psychological impact of the long term caregiving experience.</p>



		<p>of participants in the experimental group was significantly improved after the intervention and four-week follow-up. (2) After the support group, the experimental group scored better than the control group on measures of social support (positive social interaction, emotional, informational and material social support). At four-week follow-up, the differences between the two groups persisted except for positive social interaction support, suggesting a continued positive effect of the support group on caregivers of family members with intellectual disabilities. Conclusions. The results of this study confirm the experimental hypotheses that caregivers benefit from participating in support group interventions. Relevance to clinical practice. The support group is an effective alternative intervention for promoting caregivers physical and psychological health status as well as their social support. Therefore, the support group should become a routine component of the caregiver of people with intellectual disabilities.</p>	
11.	<p>Yamaki, K., Hsieh, K. &amp; Heller, T. (2009). Health profile of aging family caregivers supporting adults with intellectual and developmental disabilities at home. <i>Intellectual and Developmental Disabilities</i>, 47 (6), 425-435.</p>	<p>The health status of 206 female caregivers supporting adults with intellectual and developmental disabilities at home was investigated using objective (i.e., presence of chronic health conditions and activity limitations) and subjective (i.e., self-perceived health status) health measures compared with those of women in the general population in 2 age groups: middle age (Ages 40-59 years) and older ages ( :60 years). Prevalence of arthritis, high blood pressure, obesity, and activity limitations for the caregivers in both age groups was significantly higher than that for women in the general population. Middle-age caregivers reported a higher prevalence of diabetes and high blood cholesterol than their age peers from the general population. Despite the potential health challenges, the caregivers generally perceived their health better than that of women in the general Population. Older caregivers' perceptions on their psychological</p>	<p>Focus of the study is on the prevalence of health conditions amongst this population group. Main emphasis is not on the psychological impact of long term caregiving.</p>

		well being, however, appeared to an exception. Implications regarding potential health risks for caregivers and residential services for persons with intellectual and developmental disabilities are discussed.	
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## Appendix 2: Example of completed data extraction sheet

### DATA EXTRACTION SHEET

**Date of extraction:** 03.11.13

**Title:** The need for future alternatives: an investigation of the experiences and future of older parents caring for offspring with LD over a prolonged period of time

**Authors:** Cairns, Tolson, Darbyshire & Brown (2012)

**Publication details:** British Journal of Learning Disabilities

**Background to the study:**

Family caregiving –historically informed by caregiver stress/burden. More recently-awareness of the potential sources of satisfaction in caregiving.

**Aims and objectives:**

- 1) To present an conceptual framework, grounded in the experiences of older parent carers who participated in this research
- 2) To come to a more in-depth understanding of older parent carers' experiences of caregiving, and views on their own future.

**Sample characteristics:** (Population / Setting/ Design / Method/ Sample/ Age/ ethnicity/ Rate of attrition)

Convenience sample: 8 participants (6 mothers and 2 fathers)

Parents age: 65-89 years old. \*No mention of age of adult offspring\*

6 widowed, 2 married.

All offspring :moderate to severe LD

**Recruitment methods:**

2 Scottish local authority regions. snowballing technique -contacting social workers and voluntary organisations.

5 recruited

**Procedure/interventions:**

All at participants home, semi structured interviews, audio recorded. 50-100 min

Information sheets and consent forms given. Interview guide - conversational manner (Anonymity protected)

Participant summary to comment on

Constructivist GT (Chamaz, 2006)

Immersion in the data

Nvivo to unithise and categorise data

Trustworthiness and authenticity criteria were adhered to -table in paper to demonstrate examples of how criteria was met in this study.

**Results/findings:**

Key themes: 'a life not foreseen', 'going it alone', 'reaching a decision', and 'nearing the end'  
Highlighted need for future alternatives to be made available to better support them as parent carers. Recommendations made for future research and clinical implications

**Strengths:**

- Rigour of qualitative research addressed
- Recommendations for health and social care practice given.
- Quotes grounded in data
- Use of interview schedule, memo writing, reflective journal etc
- Trustworthiness and authenticity criteria demonstrated in table form how it was met
- Research diary used

**Limitations:**

- Purposive approach. Conceivable that those 8 carers were extreme cases, either positive or negative. – Cannot be representative of all older parent carers
- Failure to include the perspective of the offspring with ID (although not aim of study)
- No mention of researchers reflexivity
- No mention of who interviewed – same interviewer or different ones?

### **Appendix 3: Critical appraisal questions for cross-sectional quantitative studies**

- 1) Did the study address a clearly focussed issue? (*CASP*)
- 2) Did the authors use an appropriate method to answer their question? (*CASP*)
- 3) Is the eligibility criteria for participants stated? (*STROBE*)
- 4) Were the subjects recruited in an acceptable way? (*CASP*)
- 5) Was the study sample clearly defined? (*Young & Soloman*)
- 6) Was a representative sample achieved (e.g. was the response rate sufficiently high?) (*Young & Soloman*)
- 7) Were the measures accurately measured to reduce bias? (*CASP*)
- 8) Were the data collected in a way that addressed the research issue? (*CASP*)
- 9) Does the study report the number of outcome events or summary measures? (*STROBE*)
- 10) How are the results presented and what is the main result? (*CASP*)
- 11) Was the data analysis sufficiently rigorous? (*CASP*)
- 12) Is there a clear statement of findings? (*CASP*)
- 13) Can the results be applied to the local population? (*CASP*)
- 14) How valuable and clinically relevant is the research? (*CASP*)

Questions derived from the *CASP* (Public Health Resource, 2006), *STROBE* (Elm et al., 2007) and Young and Soloman (2009).

**Appendix 4: Table showing summary of reviewed studies**

Author, date, study country	Sample, size, age	Research methodology	Major findings in context of psychological impact	Strengths (✓) and limitations (-)
Cairns, Tolson, Darbyshire & Brown (2012)  UK	N= 8 parent caregivers (6 mothers, 2 fathers)  Age range: 65-89 years	Qualitative (Grounded Theory). Semi – structured interview data, using interview guide to cover key points; experiences of caregiving and future perspectives, with contributions from researchers’ field notes and reflective journal.	<ul style="list-style-type: none"> <li>• Four themes: ‘A life not foreseen’, ‘going it alone’, ‘reaching a decision’ and ‘nearing the end’.</li> </ul>	<ul style="list-style-type: none"> <li>✓ Some measures taken to ensure rigour in data collection and analysis</li> <li>– Reflexivity of the researchers not reported</li> <li>– Purposive sampling, not representative</li> </ul>
Chou, Pu, Fu & Kroger (2010)  Taiwan	N= 350 female caregivers  Age range: 55-87 years	Cross sectional. Multiple linear regression analysis of survey interview data comprising self-rated measures of depression, social support, caregiving burden and physical health and disease as well as carer and adult with ID socio-demographic data.	<ul style="list-style-type: none"> <li>• 64-72% - high depressive symptoms</li> <li>• Physical health was strongly associated with depressive symptoms</li> <li>• Level of the adult with ID’s behavioural functioning and carer age, marital status, education and income were not significantly associated with carer depression</li> </ul>	<ul style="list-style-type: none"> <li>✓ Provides cultural perspective</li> <li>– Voluntary nature of sample may limit generalizability of findings</li> <li>– Self-report measures might have greatly inflated the prevalence of depression compared with clinical diagnosis</li> <li>– Does not represent male caregivers</li> </ul>

<p>Chou, Lee, Lin, Kroger &amp; Chang (2009)</p> <p>Taiwan</p>	<p>N = 787</p> <p>Older caregivers n=315</p> <p>Age range: 55-86 (m=66.8)</p> <p>150 male, 162 female</p> <p>Younger caregivers n=472</p> <p>Age range: 16-54 (m=43.3)</p> <p>155 male, 317 female</p>	<p>Cross sectional. Structured interviews comprising of self-reported measures of perceptions of having a family member with ID, social support, quality of life and future caregiving planning.</p> <p>Socio-demographic of carers and adults with ID data obtained</p>	<ul style="list-style-type: none"> <li>Older caregivers reported a lower quality of life, less family support, a more negative perception of having a family member with ID, and greater worries about future care.</li> </ul>	<ul style="list-style-type: none"> <li>✓ Provides cultural perspective</li> <li>– Generalizability concern</li> <li>– Self-report measures used</li> <li>– Did not obtain data regarding potentially important variables e.g. the adults with ID behavioural problems</li> </ul>
<p>Dillenburger &amp; McKerr (2010)</p> <p>UK</p>	<p>N= 29</p> <p>Age range 48-94 (m=65.17)</p> <p>8 male, 21 female</p>	<p>Qualitative (Interpretive Phenomenological Analysis-IPA). Semi-structured interview exploring views and experiences regarding the long-term carer and service arrangements, health and psychological needs and future planning.</p> <p>General Health questionnaire (GHQ-12)</p>	<ul style="list-style-type: none"> <li>Four themes: 'everyday positives and everyday challenges', 'caregivers physical and psychological health', 'family social and agency support' and 'future planning'.</li> <li>Average GHQ-12 score: 3.61, 35% participants scored over 4-threshold for 'cases'.</li> </ul>	<ul style="list-style-type: none"> <li>✓ Mixture of qualitative and quantitative data, increases validity</li> <li>– Failure to acknowledge researchers' potential bias and influence during the interviews, and data analysis.</li> <li>– Majority of interviews not audio-recorded (reliance on field notes alone)</li> </ul>

Hill & Rose (2009)  UK	N= 44 mothers Age range: 51-84years (m=68.67)	Cross sectional. Structured interviews comprising of self-report measures of carers perception of adults with ID's adaptive and maladaptive behaviour, social support, maternal self-efficacy, parental locus of control and parenting stress.	<ul style="list-style-type: none"> <li>• Parental cognitive variables predicted 61% of variance in parenting stress</li> <li>• Satisfaction mediated the relationships between adaptive behaviour and parenting stress and between family support and parenting stress.</li> <li>• Maladaptive behaviour of adult -not a significant predictor of parenting stress</li> </ul>	<ul style="list-style-type: none"> <li>✓ Indicates importance of cognitive variables in the stress of mothers with ID</li> <li>- Self-report measures can be less valid</li> <li>- Small sample size</li> <li>- Low return rate</li> <li>- All English white mothers (not representative)</li> </ul>
Llewellyn, McConnell, Gething et al  (2010)  Australia	N= 64 Age range 55-90 years Majority female	Cross sectional. Conversational interviews as well as series of self-report questionnaires measuring health status, coping strategies, care load and social support.	<ul style="list-style-type: none"> <li>• The younger parent-carers reported significantly poorer mental health.</li> <li>• Better health associated with having a partner, a larger and closer support network and a lower care-load.</li> <li>• Satisfaction as well as stress</li> </ul>	<ul style="list-style-type: none"> <li>✓ Follow up telephone interview</li> <li>- Self-report measures used</li> <li>- Small sample size</li> </ul>
Perkins & Hayley  (2010)  USA	N= 91 Age range: 50-92 years (m= 60.8)  91% female	Cross sectional. Semi-structured interviews utilising survey instruments measuring caregiver quality of life, physical health mental health, depressive symptomology and life satisfaction. Compound caregiving status identified by interview questions.  Demographics of carer and adult child with ID also collected.	<ul style="list-style-type: none"> <li>• 34 participants -compound carers to an additional care recipient to father, mother or spouse.</li> <li>• No group differences were apparent in life satisfaction.</li> <li>• Compound caregivers reported having little time and a lack of adequate support.</li> </ul>	<ul style="list-style-type: none"> <li>✓ Variety of recruitment methods</li> <li>✓ Provides preliminary evidence for compound caregiving</li> <li>- Not a random or diverse sample. Convenience sampling can lead to biases in the research</li> <li>- Self-report measures used</li> </ul>
Perkins & Hayley	N = 91  (m = 60)	Cross sectional. Semi-structured interviews (in person or telephone), utilising survey instruments measuring	<ul style="list-style-type: none"> <li>• More tangible and emotional support was given than received from their adult</li> </ul>	<ul style="list-style-type: none"> <li>✓ Variety of recruitment methods</li> <li>✓ Detailed demographic</li> </ul>

<p>(2013)</p> <p>USA</p>	<p>91% female</p>	<p>demographic information, reciprocity, carer quality of life, physical and mental health, depressive symptomology, life satisfaction and desire to place adult child in a residential placement.</p>	<p>children</p> <ul style="list-style-type: none"> <li>• Despite varying levels of ID and functional impairments of care recipient, carers did report receiving considerable support</li> <li>• Relative disadvantage in tangible reciprocity was associated with increased depressive symptomology and poorer mental health but also reduced desire for seeking an alternative residential situation for the person for whom they are caring.</li> <li>• Emotional reciprocity was not associated with any of the outcome measures</li> </ul>	<p>information of carer and son/daughter with ID reported.</p> <ul style="list-style-type: none"> <li>- Small sample size</li> <li>- Self-report measures used</li> <li>✓ Sample unrepresentative (predominately female, white and highly educated)</li> </ul>
<p>Rowbotham, Cuskelly &amp; Carroll</p> <p>(2011a)</p> <p>Australia</p>	<p>N= 27 female family caregivers</p> <p>Age range: 45-85years</p>	<p>Cross sectional. Semi-structured interview eliciting information about participant's views of the demands they experienced in their daily lives, the social and emotional support available to them and how satisfied they were with this support.</p> <p>Questionnaires completed which included measures of physical health, satisfactions of caregiving, uplift and burden, coping strategies and psychological well-being.</p>	<ul style="list-style-type: none"> <li>• 26% of caregivers -clinical range on severe depression scale.</li> <li>• 92% in the clinical range on the Social Dysfunction measure and more than three quarters were in the clinical range on the Somatic and Anxiety/Insomnia scales.</li> </ul>	<ul style="list-style-type: none"> <li>✓ Uses validates measures</li> <li>- Unrepresentative sample (does not include mothers who are caring for adult children with higher levels of maladaptive behaviour)</li> <li>- Volunteer nature of the sample limits the generalizability of findings</li> <li>- Self-report measures</li> <li>- Small sample size, insufficient power</li> </ul>



Rowbotham, Cuskelly & Carroll (2011b)  Australia	N= 4 female family caregivers Age range: 45-65	Longitudinal study. Interviews utilising self-report measures from initial study (detailed above). Semi-structured interview for five consecutive months concerning additional caregiving stressors that had occurred since first interview and ratings of their stress levels on a likert scale.	<ul style="list-style-type: none"> <li>• Direct relationships between caregiving difficulties and satisfaction, as well as evidence that for some individuals there was development of competence in meeting the demands of caregiving as carers aged, whereas for others, the demands of caregiving depleted their resources.</li> </ul>	<ul style="list-style-type: none"> <li>✓ Longitudinal data</li> <li>– Small sample size</li> <li>– Self-report measures</li> </ul>
Rowbotham, Cuskelly & Carroll (2011c)  Australia	N=12 Anglo-Australian mother and father couples Age range: 45-65	Cross sectional. Semi-structured interviews about their caregiving difficulties and satisfaction, hassles and uplifts, and general health, utilising some validated questionnaire measures.	<ul style="list-style-type: none"> <li>• An extremely high proportion of in clinical range for social dysfunction, anxiety/insomnia, and somatic complaints, although depression were relatively low.</li> <li>• Mothers - significantly more caregiving difficulties and satisfaction</li> </ul>	<ul style="list-style-type: none"> <li>✓ The involvement of middle-aged fathers</li> <li>– Small sample, limits generalisability</li> <li>– Unrepresentative sample</li> </ul>
Taggart, Kennedy, Ryan & McConkey (2012)  UK	<p>Stage 1 n= 112 family caregivers, 91 female, 21 male Age range: 60-94 years</p> <p>Stage 2 n= 19 family carers Age range: 65-89 years</p>	Mixed methods design. Stage 1: structured questionnaire to collate information on the health, caregiving demands and future planning preferences of family caregivers. Stage 2: semi-structured interviews with 19 family caregivers to explore a range of issues around future planning. Analysed using thematic analysis.	<ul style="list-style-type: none"> <li>• A third of carers -caregiving resulted in high levels of anxiety.</li> <li>• Four main themes : unremitting apprehension, the extent of planning, obstacles encountered and solutions for future planning.</li> </ul>	<ul style="list-style-type: none"> <li>✓ Innovative study utilising mixed methods design</li> <li>✓ Various checks undertaken to make sure the issues identified by participants were accurate truthful and credible</li> <li>– Self-report</li> <li>– Self-selected cohort</li> <li>– Small sample size</li> <li>– Majority of participants were females</li> <li>– Lacks reflexivity</li> </ul>

Unwin & Deb (2011)  UK	N= 44 family caregivers, 34 mothers  Age range not reported	Cross sectional. Participants were interviewed using questionnaires and assessment scales to capture information on aggressive behaviour, demographics on adult with ID, mental health, physical health and quality of life.	<ul style="list-style-type: none"> <li>• Caregiver burden significantly higher in caregivers of 'more aggressive' group</li> <li>• Strong association between caregiver uplift and caregiver burden</li> </ul>	<ul style="list-style-type: none"> <li>✓ Detailed recruitment process, inclusion and exclusion criteria</li> <li>– Small sample</li> <li>– Unrepresentative sample</li> <li>– Self-report-subjective bias of measures limiting validity</li> </ul>
Yoong & Koritsas (2012)  Australia	N= 12 10 mothers, 2 fathers  Age range: 55-77 (m=66.4)	Qualitative (thematic analysis). Semi structured interviews exploring the impact of caring for an adult with ID on the quality of life of parents.  Demographic information collected about participants and their offspring.	<ul style="list-style-type: none"> <li>• Seven key themes: 'Relationships and support', 'leisure participation', 'personal satisfaction', 'A more positive appraisal of their quality of life', 'restrictions on employment and financial security', 'service failures', 'advocacy role' and 'fear and uncertainty over the future'</li> </ul>	<ul style="list-style-type: none"> <li>✓ All interviews conducted by same researcher-enhanced validity</li> <li>– Convenience sampling – unrepresentative</li> <li>– Small sample size</li> <li>– Lacks reflexivity</li> </ul>

**Appendix 5: Table showing properties of outcome measures**

<b>Study</b>	<b>Outcome measures</b>	<b>Measure details</b>	<b>Internal consistency (Cronbach's alpha)</b>	<b>Test retest reliability</b>	<b>Validity</b>
Chou, Pu, Fu & Kroger (2010) Taiwan	Centre for Epidemiologic Studies Depression Scale (CES-D) – Short Form (CES-D-10; Anderson, Malmgren, Carter & Patrick, 1994)	Self-report measure of depressive symptoms during the previous week	0.85	r=0.71	“shows good predictive accuracy”
	Barthel Index and the Philadelphia, Lawton and Brody index (Mahoney & Barthel, 1965)	Measures adult with IDs functional behaviour	0.93	Not reported	Not reported
	The Philadelphia, Lawton and Brody index (Lawton & Brody, 1969)	Measures adult with IDs functional behaviour	0.90		
	Social Support Scale (Tang, Mao, Chou, Chen & Liu, 1992)	Measure of carer social support, which consists of three major categories of social support: instrumental, emotional and informational	0.85	Not reported	Not reported

	EQ-5D Chinese version (Agency for Healthcare Research and Quality, 2005).	Measure of physical health status	0.75	Not reported	Not reported
	Caregiver Burden Scale (Song, 2002)	Measurement of caregiver burden	0.85	Not reported	Not reported
Chou, Lee, Lin, Kroger & Chang (2009) Taiwan	Family Explanation Scale (FES; Chou, 1992)	Measures caregivers perception of having a family member with ID	0.67	Not reported	Not reported
	Family Support Scale (FSS; Dunst, Jenkins & Trivette, 1984)	Self-report measure of caregiver's levels of informal and formal support. Likert scale contains 18 items and each item scores ranges from 0 (never) to 3 (very helpful)	0.88	Not reported	Not reported
	World Health Organisation Quality of Life Instrument – Abbreviated, Taiwan version (WHOQOL-BREF; World Health Organisation, 2004)	Measures how caregiver feels about his/her quality of life over last 2 weeks. Questionnaire contains 28 items and four domains (physical, psychological, social relationships and environment).	0.93	Not reported	Not reported
Dillenburger & McKerr (2010) UK	General Health Questionnaire (GHQ-12; Goldberg, McDowell & Newell, 1996)	Measures psychological health	Not reported	Not reported	Not reported
Hill & Rose	Survey Form of the	Semi-structured interview measure	0.90 for 148 of	Between	Not reported

(2009) UK	Vineland Adaptive Behavior Scales-II (VABS; Sparrow, Cicchetti & Balla, 2005)	contains 297 items that provide an assessment of adaptive behaviour, useful for determining areas of strength and weakness.	the 154 sub-domain reliabilities	0.88 and 0.92	
	The Vineland Maladaptive Behavior Domain (Sparrow, Balla & Cicchetti, 1984)	Measure of the individual's level of behavioural difficulties. Raw scores are used in the analysis of the data.		"Split half reliability between 0.77 and 0.88"	
	Family Support Scale (FSS; Dunst, Jenkins & Trivette, 1984)	Measure of social support available to the caregiver. It consists of five subscales that include support from partner and partner's family, informal kinship support, formal kinship support, social organisations and professional services.	0.79	Not reported	Not reported
	Parenting Sense of Competence Scale (PSOC; Gibaud-Wallaston & Wandersman, 1978 as cited in Johnston & Mash, 1989)	Measure of maternal self-efficacy. Contains 16 items that are scored on a six-point likert scale ranging from 'strongly agree' to strongly disagree'	0.79 and 0.76	Not reported	Not reported
	The Parental locus of Control-Short Form Revised (PLOC; Hassall, Rose & McDonald, 2005)	Measures parental locus of control. Consists of 24 items within four subscales; Parental Efficacy (PLOC-PE), Parental Responsibility (PLOC-PR), Child Control of Parent's Life (PLOC-CC) and Parental Control of Child's Behaviour (PLOC-PC)	0.82	Not reported	Not reported
	Parenting Stress Index-Short Form (PSI-SF; Abidin, 1990)	This measure reflects the stressors experienced by the mother of the adult with ID and their perceived efficacy in dealing with them. The measure provides a total stress score and three subscale scores. These are Parental Distress (PSI-	Between 0.80 and 0.91 for the various scales	Not reported	Not reported

		PD), Parent-Child Dysfunctional Interaction (PSI-CDI) and Difficult Child (PSI-DC).			
Llewellyn, McConnell, Gething et al. (2010) Australia	MOS 12-item Short Form Health Survey (SF-12; Ware, Snow, Kolinski & Gandek, 1993)	Self-report measure of health status. It contains 12 questions in two subscales. The two scores represent participants' perceived physical health and perceived mental health and their effects on daily life.	0.77 and 0.80 for the physical and mental health component scales respectively.		"This is a well validated and widely used self-report health survey, for which Australian norms have been published"
	The Carer's Assessment of Difficulties Index (CADI; Nolan, Grant & Keady, 1998)	Self-report measure of carers perceptions of the difficulties associated with caring. Contains 30 statements	Ranging from 0.72 to 0.90 are reported for CADI subscales	Not reported	Not reported
	The Carer's Assessment of Managing Index (CAMI; Nolan, Grant & Keady, 1998)	Self-report measure to assess coping strategies. Contains 37 statements	Ranging from 0.64 to 0.80 are reported for CAMI subscales	Not reported	Not reported
	Wenger's Support Network Typology (Wenger, 1994)	Self-report measure to identify support network type	Not reported	Not reported	Not reported
Perkins & Hayley (2010)	Comorbidity Scale (Bayliss, Elliss & Steiner, 2005)	Self-report measure of comorbidity in the caregiver. The scale has a checklist of 23 items that details chronic medical conditions and determines both the	Comorbidity conditions: 0.63	Not reported	Not reported

USA		presence of the condition as well as a 5-point likert scale to report the level of interference each of these conditions had on regular daily activities	Comorbidity interference 0.61		
	Maladaptive behavior subscale of the Scales of Independent Behavior-Revised (Bruininks, Woodcock, Weatherman & Hill, 1996)	Self-report measure of challenging behaviour of the care recipient. Measures the number of challenging behaviours and the severity of each behaviour as specifically perceived by the caregiver.	0.80 (total sum of challenging behaviours score) and 0.90 (severity score)	Not reported	Not reported
	Activities of Daily Living (Katz, Ford & Moskowitz, 1963)	Self-report measure of functional ability of the care recipient. Consists of 6 items with yes/no responses to questions that determine whether functions such as bathing, dressing and feeding oneself, are able to be done independently.	0.92	Not reported	Not reported
	The instrumental Activities of Daily Living Scales (Lawton & Brody, 1969)	Self-report measure comprising of 8 items that assesses the level of independence in a variety of areas including use of telephone, shopping, using transport, ability to manage finances etc. A lower score indicates less independence.	0.86	Not reported	Not reported
	Compound Caregiving (Perkins, 2010b)	Self-report measure to assess compound caregiving status. Determined by caregiver response to the question "So you currently have caregiving tasks and responsibilities to another family member, other than your child?" The relationship of the compound caregiving recipient is also noted, as well as the duration and weekly hours spent in this role. Also comprises of 8 potential problems that compound	0.86	Not reported	"Content validity of the items were demonstrated by their derivation from issues previously identified in a care study

		caregivers might encounter. Each item is rated from 1 to 5 with 1 representing 'not a problem' through to 5 representing 'a very serious problem'			on compound caregiving (Perkins, 2010).
	Medical Outcomes Short Study Form (SF-36; Ware & Sherbourne, 1992)	Self-report measure of health related quality of life. This is a 36-item instrument and has two major subscales, the physical component summary (PCS) and mental component summary (MCS), which are the scales used to assess global physical health and global mental health.	0.91 (PCS) and 0.87 (MCS)		"Has been widely validated as a summary measure of health-related quality of life"
	Centre for Epidemiological Studies-Depressive Scale, 20-item version (Radloff, 1977)	Self-report measure of depressive symptomology.	0.89	Not reported	Not reported
	The Life Satisfaction Index-Z, 13 item short form version (Wood, Wylie & Schaefor, 1969)	Self-report measure designed to indicate levels of self-perceived morale and general life satisfaction. Scores range from 0-26 with higher scores indicating greater life satisfaction	0.77	Not reported	Not reported
	Desire-to-Institutionalize Scale (Morycz, 1985)	Self-report measure indicating the caregivers desire to which they have either considered, discussed with their adult child the possibility, or with other family members, through to actively seeking it and making steps to find alternative residential placement.	Not reported	Not reported	Not reported
Perkins & Hayley	Medical Outcomes Short Study Form (SF-36; Ware & Sherbourne, 1992)	Self-report measure of health related quality of life. This is a 36-item instrument and has two major subscales, the physical component summary (PCS) and mental	0.91 (Physical health) and 0.87 (Mental health)	Not reported	Not reported



(2013) USA		component summary (MCS), which are the scales used to assess global physical health and global mental health.			
	Centre for Epidemiological Studies-Depressive Scale, 20-item version (Radloff, 1977)	Self-report measure of depressive symptomology.	0.89	Not reported	Not reported
	The Life Satisfaction Index-Z, 13 item short form version (Wood, Wylie & Schaefor, 1969)	Self-report measure designed to indicate levels of self-perceived morale and general life satisfaction. Scores range from 0-26 with higher scores indicating greater life satisfaction	0.77	Not reported	Not reported
	Desire-to-Institutionalize Scale (Morycz, 1985)	Self-report measure indicating the caregivers desire to which they have either considered, discussed with their adult child the possibility, or with other family members, through to actively seeking it and making steps to find alternative residential placement.	Not reported	Not reported	Not reported
Rowbotham, Cuskelly & Carroll  (2011a)  Australia	The Adaptive Behavior Scale – Residential and Community Second Edition (ABS-RC-2; Nihra, Leland & Lambert, 1993)	Comprises of two scales pertaining to maladaptive behaviour; social adjustment (a measure of challenging behaviour) and personal adjustment ( a measure of stereotypes and disturbed behaviour)	Not reported	Not reported	Not reported
	The Carers' Assessment of Difficulties Index (CADI; Nolan, Grant & Keady, 1998)	Self-report measure comprising of 30 items of caregiving difficulties Possible scores range from 0 to 90 with higher scores indicating greater experience of difficulty.	0.95	Not reported	Not reported

	Hassles and Uplifts Scale (Delongis, Folkman & Lazarus, 1988)	Self-report measure of demands associated with life roles and tasks, generally unrelated to caregiving role. Each of the 53 items is rated on a 4-point likert scale with higher scores indicating that the respondent experiences higher levels of hassles.	0.87	Not reported	Not reported
	The Family Index of Life Events (FILE; McCubbin, Patterson & Wilson, 1983)	Self-report measure of family life events. Comprises of 71 items cataloguing changes that may occur in the life of a family or its individual members. Items are all weighted with more difficult events carrying more weight than less-demanding life experiences.	Not reported	Not reported	Not reported
	The Carers' Assessment of Satisfaction Index (CASI; Nolan, Grant & Keady, 1998)	Self-report measure of satisfactions derived by caregivers from their caregiving role. Comprises of 30 statements relevant to the person cared for and also the caregiver are rated according to their applicability to the caregivers' experience.	0.96	Not reported	Not reported
	The Life Orientation Test-Revised (LOT-R; Carver & Scheier, 2003)	Self-report measure to assess the dispositional characteristic of optimism,. Six relevant items and four filler items are presented on a 5-point likert scale, anchored by strongly disagree and strongly agree. High scores indicate high optimism.	0.77	Not reported	Not reported
	The Ways of Coping Questionnaire (WOCS; Folkman & Lazarus, 1998)	Self-report measure comprising of 66 coping strategies representing eight different ways of coping: Confrontive, Distancing, Self-Controlling, Seeking	Confrontive (0.81), Distancing (0.68), Self-	Not reported	Not reported

		Social Support, Accepting Responsibility, Escape-Avoidance, Planful Problem Solving and Positive Reappraisal. Respondents are required to think about a specific stressful incident that occurred in the last week and to rate the frequency with which they used each strategy to cope with the associated stress.	Controlling (0.40), Seeking Social Support (0.80), Accepting Responsibility (0.37), Escape/Avoidance (0.43), Problem Solving (0.79), Positive Reappraisal (0.76). Only the four scales with alphas above 0.70 were retained.		
	The Bradburn Affect Scale (BAS; Bradburn, 1969)	Self-report measure comprising 10 items describing positive and negative experiences. Respondents indicate if they have, or have not, had those experiences in the past few weeks. High scores indicate positive affect.	0.78	Not reported	Not reported
	The General Health Questionnaire-28 (GHQ-28; Goldberg, 1981)	Self-report measure to evaluate carer psychological wellbeing. Comprises of 28 items, which are clustered into four subscales: Somatic Symptoms, Anxiety/Insomnia, Social Dysfunction and Severe Depression. Respondents rate on a likert scale how much they have experienced each health event over the	GHQ-28: 0.88 Somatic Symptoms (0.77), Anxiety/Insomnia (0.77), Social Dysfunction (0.75) and	Not reported	Not reported

		past few weeks.	Severe Depression (0.75)		
Rowbotham, Cuskelly & Carroll (2011b) Australia	Bradburn Affect Scale (BAS)  Carer's Assessment of Difficulties Index (CADI)  Carers' Assessment of Satisfaction Index (CASI)  Family Inventory of Life Events (FILE)  The General Health Questionnaire-28 (GHQ-28)   Hassles and Uplifts Scale  Ways of Coping Questionnaire (WOCS)	Same measures as previous study - see descriptions and references above.	0.78  0.95  0.96  Not applicable  GHQ-28: 0.88 Somatic Symptoms (0.77), Anxiety/Insomnia (0.77), Social Dysfunction (0.75) and Severe Depression (0.75)  Hassles: 0.68 Uplifts: 0.95  Confrontive (0.81), Distancing (0.68), Seeking Social	Not reported	Not reported

			Support (0.80), Problem Solving (0.79), Positive Reappraisal (0.76).		
Rowbotham, Cuskelly & Carroll (2011c) Australia	Carer's Assessment of Difficulties Index (CADI)  Carers' Assessment of Satisfaction Index (CASI)  Hassles and Uplifts Scale  The General Health Questionnaire-28 (GHQ-28)  The Adaptive Behavior Scale – Residential and Community Second Edition (ABS-RC-2)	Same measures as previous two studies-see descriptions and references above	Mothers/father's value 0.95/0.96  0.96/0.94  0.95/0.97  GHQ-28: 0.88/0.82 Somatic: 0.83/0.68 Anxiety/Insomnia: 0.75/0.83 Social Dysfunction: 0.73/0.65 Severe Depression: 0.83/0.56  Not reported	Not reported	Not reported

Taggart, Kennedy, Ryan & McConkey (2012) UK	Carer's Assessment Difficulties Index (CADI; Nolan, Grant & Keady, 1998)	Self-report measure comprising of 30 items of caregiving difficulties Possible scores range from 0 to 90 with higher scores indicating greater experience of difficulty.	0.72	Not reported	Not reported
Unwin & Deb (2011) UK	The Uplift/Burden Scale (Pruchno, 1990)	Measure of the psychological effects of caring in terms of caregiver uplift and burden. Caregivers rate 6 uplift items and 17 burden items for the last 4 weeks on a 3-point likert scale.	0.80 for uplift and 0.89 for burden	Not reported	Not reported
	The Modified Overt Aggression Scale (MOAS; Ratey & Gutheil, 1991)	Measure of aggressive episodes when they occur to assess the effectiveness of interventions. Four subscales (verbal aggression, physical aggression against objects, physical aggression against the self, physical aggression against others). Each type of aggressive behaviour is rated on a 5-point likert scale of increasing severity, from 0 for absent to 4, indicating the most severe type of this behaviour.	0.93	Not reported	"The MOAS has been validated to be a practical and effective frequency counter of aggressions in people with ID" (Oliver et al, 2007)
	Aberrant Behavior Checklist-Community (ABC-C; Aman, Burrow, & Wolford, 1995)	Scale developed to assess intervention effects in people with ID	0.63	0.96-0.99	Not reported

## Appendix 6: Findings synthesis matrix

(Screenshot to show first part of Excel spread sheet for example of how matrix was constructed)

	A	B	C	D	E	F	
1	Source:	Cairns et al (2012) Some parents continued in their role despite their deteriorating mental and/or physical health as there appeared to be no alternative	Chou et al (2009) Older caregivers compared with younger ones reported a lower QoL, less family support, a more negative perception of having a family member with ID and greater worries about the future arrangements	Chou et al (2010) Out of a sample of 350 female caregivers 64.72% had high depressive symptoms  Factors associated were: carers physical health, social support and caregiving burden  Level of the adult with ID's behavioural functioning and carer age, marital status, employment status, education and income were not found to be significant	Dillenburger & McKerr (2010) Findings show a severe lack of support, respite care and future planning which causes high stress levels for caregivers. IPA themes 'Everyday positives and every day challenges', 'caregivers physical and psychological health', 'family social and agency support', and 'future planning' Many described various health problems. 33% of participants scored over the threshold on GHQ-12 score	Hill & Rose (2009) Parental cognitions associated with parenting stress. Mothers with greater levels of social support and higher internal locus of control experience lower levels of parenting stress. Maladaptive behaviour was not a significant predictor, although approached significance (IN CONTRAST TO OTHER STUDIES)	Ulev You sam sign heal havi clos lowe Cor wert cont supp strat
2	Main Idea A: Prevalence of depression, anxiety and stress and factors associated with these						
3	Main Idea B: Caregiving Satisfaction				Every day positives and challenges' theme - many p's expressed that their family and their sons and daughters were most positive things in their lives.	Parenting satisfaction mediated the relationship between adaptive behaviour and parenting stress and between family support and parenting stress (mothers with greater levels of social support experience lower levels of parenting stress).	P's r and carir cour perc over
4	Main Idea C: Anxieties about the future	Appeared to be no alternative, lacked support, information and practical resources throughout their caregiving career. Themes: A life not foreseen, Going it alone, Reaching a decision and Nearing the end. Most had not made explicit plans	Older carers had greater worries about the future. 20-30% in both groups (younger and older) had never given any thought to their future caregiving plans. Similar to western studies -planned use of siblings as the anticipated successor caregiver in the future caregiving plan.		Findings show a severe lack of support, respite care and future planning which causes high stress levels for caregivers. The vast majority had not made long-term plans. Where some had discussed future provision with services, they had not found it to be helpful.		
5	Main Idea D: Interventions	Professionals should rebuild levels of trust and signpost parents to sources of advice. Awareness and training on needs of older families to professionals working with this population	development of a holistic health programme intervention approach that is able to support psychological and physical health of carers. Practitioners need to identify how carer perceives stress and determine their level of social support.	Services should help parents to plan ahead for care of person with ID.	A new theoretical approach is needed to help parents. Support network should be set up in advance of a crisis. Early behavioural support should be offered from birth of child with ID.	Holistic approach: Provide parent and staff training. Ensure sufficient support from services and encourage parent support groups. Tailored CBT around the way they view themselves and caring role.	
6							

## Appendix 7: Ethical approval documents

### Peer review approval letter



Faculty of Health/Faculty of Sciences

#### INDEPENDENT PEER REVIEW APPROVAL FEEDBACK

**Student Name** Laura Pryce  
**Title of Study** Adults with learning disabilities and their older parent-carer's experiences and perceptions of the future  
**Award Pathway** DClinPsy  
**Status of approval:** **Approved**

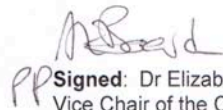
**Action now needed:**

You must now apply to the Local Research Ethics Committee (which serves the Trust within which you intend to complete your study) for approval to conduct your study. You must not commence the study without this second approval. To seek approval you will need to complete the application form for the committee and forward copies of your proposal.

Please forward a copy of the letter you receive from the L.R.E.C. to Pauline Whiston, Clinical Psychology, Leek Road as soon as possible after you have received approval. Once you have received L.R.E.C. approval you can commence the implementation phase of your study. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

It is now possible to begin writing your dissertation and you may wish to consult with your supervisor on this matter.

Thank you for forwarding the amendments requested by the Independent Peer Review Panel (IPR)

  
**Signed:** Dr Elizabeth Boath  
Vice Chair of the Clinical Psychology/ Faculty of Health/Faculty of Sciences IPR Panel

**Date:** 30<sup>th</sup> January 2013



Letter of Favourable Opinion with conditions from West Midlands REC  
(Page 1 of 5)



**Health Research Authority**  
**NRES Committee West Midlands - Edgbaston**  
The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 883 9390

27 August 2013

Miss Laura Pryce  
South Staffordshire and Shropshire Healthcare NHS Foundation Trust  
School of Psychology (Faculty of Health Sciences)  
Leek Road  
Stoke on Trent, Staffordshire  
ST4 2DF

Dear Miss Pryce,

**Study title:** |

her was going to ensure potential participants were not going to be re-approached during the six months, whilst waiting to hear back from them.

Letter of Favourable Opinion with conditions from West Midlands REC  
(Page 2 of 5)

- The committee discussed if potential participants would have good capacity to consent and if they would understand what they were consenting to as there would be a wide variety of disabilities.

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

1. The sub-committee request in the participant invitation letter under the expressions of interest, the "No – I do not want to participate in this study" taken out.
2. The Participant information sheet should be changed to "if you tell me anything that suggests to me that you or someone else is at risk of harm".

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

Letter of Favourable Opinion with conditions from West Midlands REC  
(Page 3 of 5)

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.**

**Approved documents**

The documents reviewed and approved were:

*Document*

cs Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Letter of Favourable Opinion with conditions from West Midlands REC  
(Page 4 of 5)

**After ethical review**

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.  
information is available at National Research Ethics Service website > After Review

13/WM/0362

*ryce*  
Ms Audrey Bright, South Staffordshire and Shropshire NHS Foundation Trust

Letter of Favourable Opinion with conditions from West Midlands REC  
(Page 5 of 5)

**NRES Committee West Midlands - Edgbaston**

**Attendance at PRS Sub-Committee of the REC meeting on 21 August 2013**

**Committee Members:**

Name

Miss Jessica Parfremment

stant Coordinator

Letter of Favourable Opinion (conditions met) from West Midlands REC  
(Page 1 of 2)

**NRES Committee West Midlands - Edgbaston**

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 883 9390

29 August 2013

Miss Laura Pryce  
School of Psychology (Faculty of Health Sciences)  
Leek Road  
Stoke on Trent, Staffordshire  
ST4 2DF

Dear Miss Pryce,

<b>Study title:</b>	<b>Adults with learning disabilities and their older parent-carer's experiences and perceptions of the future</b>
<b>REC reference:</b>	<b>13/WMM/0362</b>
<b>Protocol number:</b>	<b>N/A</b>
<b>IRAS project ID:</b>	<b>117769</b>

Thank you for your letter of 28<sup>th</sup> August 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 27 August 2013

**Documents received**

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		28 August 2013
Letter of invitation to participant	2	28 August 2013
Letter of invitation to participant	2	28 August 2013
Participant Information Sheet	2	28 August 2013
Participant Information Sheet: accessible version	2	28 August 2013

**Approved documents**

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		08 August 2013
Covering Letter		28 August 2013
Evidence of insurance or indemnity		16 July 2013
Interview Schedules/Topic Guides	1	23 July 2013
Investigator CV	Alison Tweed	27 June 2013
Investigator CV	Laura Pryce	04 July 2013
Letter of invitation to participant	2	28 August 2013
Letter of invitation to participant	2	28 August 2013

Letter of Favourable Opinion (conditions met) from West Midlands REC  
(Page 2 of 2)

Other: Summary CV for clinical supervisor - Amanda Hilton	1	30 May 2013
Other: GCP Certificate - Laura Pryce		24 October 2012
Participant Consent Form	1	23 July 2013
Participant Consent Form: Accessible version	1	23 July 2013
Participant Information Sheet	2	28 August 2013
Participant Information Sheet: accessible version	2	28 August 2013
Protocol	1	08 August 2013
Questionnaire	1	23 July 2013
REC application	117769/487361/1/41 9	08 August 2013
Referees or other scientific critique report		

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/WM/0362      Please quote this number on all correspondence


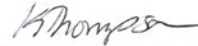
Yours sincerely,

**Rebecca Morledge**  
Assistant Committee Co-ordinator

E-mail: NRESCommittee.WestMidlands-Edgbaston@nhs.net

Copy to:      Ms Audrey Bright, South Staffordshire and Shropshire NHS Foundation Trust

## Letter of approval from R&D department

<b>South Staffordshire and Shropshire Healthcare</b> 	
<small>NHS Foundation Trust</small>	
Our Ref: AB/R242	Research and Development Block 7
	St George's Hospital Corporation Street STAFFORD ST16 3AG
8 October 2013	Tel: (01785) 221168 Email: <a href="mailto:audrey.bright@ssstf.nhs.uk">audrey.bright@ssstf.nhs.uk</a>
 Ms Laura Pryce Trainee Clinical Psychologist Staffordshire University School Of Psychology Science Building Leek Road ST4 2DF	
<hr/>	
Dear Laura	
<b>Study title: Adults with LD and older parent-carers perceptions of the future</b>	
We have considered your application for access to patients and staff from within this Trust in connection with the above study.	
On behalf of the Trust the Lead Officer for Research Governance, and the Responsible Care Professionals within the Psychology Directorate have now satisfied themselves that the requirements for Research Governance, both Nationally and Locally, have been met and are happy to give approval for this study to take place in the Trust, with the following provisos:	
<ul style="list-style-type: none"><li>• That all researchers coming into the Trust have been issued with either a letter of access or honorary contract by ourselves</li><li>• That you conform to the requirements laid out in the letters from the REC dated 27 August 2013, which prohibits any changes to the agreed protocol</li><li>• That you keep the Trust informed about the progress of the project at 6 monthly intervals</li><li>• If at any time details relating to the research project or researcher change, the R&amp;D department must be informed.</li></ul>	
Your research has been entered into the Trust database and will appear on the Trust website.	
<hr/>	
As part of the Research Governance framework it is important that the Trust are notified as to the outcome of your research and as such we will request feedback once the research has finished along with details of dissemination of your findings. You will be asked to provide a copy of the final report and receive an invitation to present final feedback via our research seminar series. To aid dissemination of findings, copies of final reports are placed on our Trust Website. To this end, please contact me towards the completion of the project to discuss the dissemination of findings across the Trust and a possible implementation plan.	
If I can help in any other way please do not hesitate to contact me.	
Yours sincerely	
	
Mrs Kim Thompson Acting R&D Manager Cc: Dr Rachel Lucas, Director of Psychological Services, Trust HQ, Stafford	



## Appendix 8: Participant invitation letter

(Page 1 of 2)



South Staffordshire and Shropshire Healthcare **NHS**

NHS Foundation Trust

A Keele University Teaching Trust

XXXXXXX  
XXXXX  
XXX

Tel: XXXXXXXXXXXX

Date:

**Study title: Adults with learning disabilities and their older parent-carer's experiences and perceptions of the future**

Dear

My name is Laura Pryce. I am a trainee clinical psychologist. I am conducting a research study as part of the requirements of my professional doctorate in clinical psychology training programme at Staffordshire and Keele Universities, and I would like to invite you to participate. I am interested in finding out more about the experience of life-long caregiving and parent-carers and adults with learning disabilities' perceptions of the future.

If you decide to participant, you will be asked to meet with me for an interview that will last approximately one to two hours. The interview will be informal, allowing us to discuss your experiences of care giving and your perceptions of the future for yourself and for that of your son or daughter. The meeting will take place at either XXXXXX or at your home. The interview will be audio-tape recorded so that I can accurately reflect on what is discussed. The tapes will only be transcribed and analysed by the research team, consisting of myself, Dr Amanda Hilton (clinical psychologist) and Dr Alison Tweed (clinical psychologist). They will then be destroyed. Please see the attached information sheet which gives more detail about participation and confidentiality.

You may feel uncomfortable answering some of the questions. You do not have to answer any questions that you do not wish to. Although you probably won't benefit directly from participating in this study, we hope that the information you provide will help health and social care professionals to understand the experience of older parent-carers and the perceptions of the future from the viewpoint of both carers and adults with a learning disability. It is anticipated that this will then in turn inform services of how best to support these families in planning for the future.

Participant invitation letter/version 2/Aug 2013

1

Participant invitation letter

(Page 2 of 2)

Taking part in the study is your decision. You do not have to be in this study if you do not want to. You may also quit being in the study at any time or decide not to answer any question you are not comfortable answering. Participation, non-participation or withdrawal from the study will not affect your relationship with health and social care services in any way. We will be happy to answer any questions you have about the study. You may contact Amanda Hilton on XXXXXXXX

Thank you for your consideration. If you would like to participate, please contact Amanda Hilton on XXXXXXXX to discuss participation. Alternatively, please complete the slip at the bottom of this letter and return it in the stamped self-address envelope. If we do not hear from you within two weeks from the date on this letter then we will telephone call you to see whether you are willing to participate.

Yours sincerely,

**Laura Pryce**  
Trainee clinical psychologist

---

**'Adults with learning disabilities and their older parent-carers' experiences of care-giving and perceptions of the future' study**

I have read the information contained in the letter and on the information sheet about the above titled study, which describes what I will be asked to do if I decide to participate.

Yes – I want to participate in the study and agree to being contacted by Laura Pryce, trainee clinical psychologist, to arrange an interview date and time.

\_\_\_\_\_  
Name and signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Telephone number



XXXXXXX  
XXXXX  
XXXX

Tel: XXXX XXXXXX

Date:

Dear

My name is Laura Pryce. I am a trainee clinical psychologist.

I am carrying out a research study as part of the requirements of the professional doctorate in clinical psychology training course, and I would like to invite you to take part.



**What is my work about?**

I am carrying out a project to look at adults with learning disabilities experiences of living with older parents and what their hopes are for the future.

I would like to invite you to meet with me to talk about your experiences.

**What will happen when we meet?**

We will meet for about 1 hour.

We will meet at XXXX or your home



Participant invitation letter: accessible version

(Page 2 of 3)



I would like to have a talk with you about your experiences of living at home with older parents and your hopes and fears for the future.

I would like to know this so that health and social care services will know how to best support adults with learning disabilities and their parents to plan for the future.



Please read the information sheet for more information about what will happen.



**Do you have to take part?**

You can say yes if you want to take part



You can say no if you do not want to take part.

Your answer will not change the care that you currently get from health and social care services.



If you would like to take part then please telephone my colleague, **Amanda on XXXXXXXX** and tell her.



Or you can fill the slip at the bottom of this letter and return it in the stamped envelope provided.



If we do not hear from you within two weeks then I will telephone you to ask you if you would like to take part. It is still ok to say no.

Yours sincerely,

**Laura Pryce**  
**Trainee Clinical Psychologist**



**'Adults with learning disabilities and their older-parent carers' experiences of care-giving and perceptions of the future' study**

I have read the information contained in the letter and on the information sheet about the above titled study, which describes what I will be asked to do if I decide to participate.



Yes – I want to participate in the study and agree to being contacted by Laura Pryce, trainee clinical psychologist, to arrange an interview date and time.

\_\_\_\_\_  
Name and signature

\_\_\_\_\_  
Date


\_\_\_\_\_  
Telephone number



## Appendix 9: Participant information sheet

(Page 1 of 4)



South Staffordshire and Shropshire Healthcare   
NHS Foundation Trust  
A Keele University Teaching Trust

**Study: Adults with learning disabilities and their older parent-carers' experiences and perceptions of the future.**

### Participant information sheet

#### **Part 1: Purpose of the study**

#### **Why have I been chosen to participate in this study?**

My name is Laura Pryce and I am a trainee clinical psychologist. I am studying at Staffordshire University and completing a piece of research as part of my doctorate. I am interesting in finding out more about the experience of life-long care giving and parent-carers and adults with learning disabilities' perceptions of the future. I am focusing specifically on families where the adult with a learning disability has been cared for and has remained living with their parent(s) since birth.

#### **What will participation involve?**

You will complete a one to one interview. The interview will be informal, allowing us to discuss your experiences at length if you are happy to do so (although there is no obligation to do this).

You will complete one interview at either XXXX or at your home.

Research participant information sheet/Version 2/Aug 2013

## Participant information sheet

(Page 2 of 4)

It is up to you whether you would like to take part in the study. Participation is entirely voluntary and your decision will not impact on any aspect of your usual health care. You are free to withdraw at any time during the study. However unless you state otherwise, any responses you have already given will be used in the study, anonymously.

Interviews will be audio recorded. Only myself, my project supervisor Amanda Hilton (clinical psychologist) and academic supervisor, Alison Tweed (clinical psychologist, Staffordshire University), will listen to the tape recording of the interview. Staffordshire University and Staffordshire & Shropshire NHS Foundation Trust may also require access for audit purposes.

### **How long will participation take?**

The whole interview usually lasts no longer than one hour.

### **Confidentiality**

Yes. All information about you will be handled in confidence.

However your responses are anonymous but not confidential. This means whilst no identifiable information (e.g. names) will be used anywhere in the study, any response you do give during your interview will be read by my clinical and academic supervisors, and if the study is published in an academic journal, other people will also be able to read your responses. This may include direct quotes. You will be assigned a pseudonym which will be used in place of your real identity for the remainder of the study. Any identifying information about you (such as family names) will be changed.

An audio recorder will be used to record the interview. Afterwards a written transcript will be produced. This is a written record of what was said during the interview, produced using the audio recording. After the study has been completed, the audio record of the interview will be deleted and no other copy will remain. The written transcript will not include information which could be used to identify you.

### **Risks and benefits**

It is possible that discussing your experiences may cause you to feel upset. If any questions make you feel uncomfortable or upset you do not have to answer them. Please let me know and we will move on to the next question.

If you tell me anything that suggests to me that you or someone else is at risk of harm then I will have to contact a member of the health and social care team for assistance. I may also need to inform your GP of any disclosures related to risk.

Although there are no guarantees that the study will help you, the information you provide will help health professionals to understand the experience of older-parent carers and the

Research participant information sheet/Version 2/Aug 2013

## Participant information sheet

(Page 3 of 4)

perceptions of the future from the viewpoint of both carers and adults with a learning disability.

**If the information in Part 1 has interested you and you are considering participating, please read the additional information in Part 2 before making any decision**

### **Part 2: Information about the conduct of the study**

#### **What happens if I wish to withdraw from the study?**

It is up to you whether you would like to take part in the study. Participation is entirely voluntary and your decision will not impact on any aspect of your usual health care. You are free to withdraw at any time during the study. However unless you state otherwise, any responses you have already given will be used in the study, anonymously.

#### **What if I have concerns about the study or would like to make a complaint?**

If you have any concerns about any aspect of the study, you should ask to speak to Amanda Hilton, clinical psychologist on XXXX XXX XXXX. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service on 01785 221469.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against South Staffordshire & Shropshire NHS Foundation Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

#### **How will my participation remain confidential?**

Identifiable information is not necessary and therefore will not be used. Data will be stored in a locked cabinet at XXXXX, when it is not in use. Only I, Amanda Hilton, clinical supervisor, and my academic supervisor, Alison Tweed will have access to the data. Audio records will be deleted after the study is completed in July 2014. Paper transcripts must be kept for a minimum of ten years on the premises of Staffordshire University, in a locked cabinet, but will contain no identifiable information.

#### **What will happen to the results of the study?**

It is hoped that the results of the study will help health professionals to support parent-carers and adults with a learning disability in planning for the future.

The results of the study may be published and will be shared amongst other health professionals. Direct quotes will be included, although identifiable information will not be used – participant pseudonyms will be used in place of names. If you are concerned about this please let me know.

#### **Who is organising the research?**

Research participant information sheet/Version 2/Aug 2013



## Participant information sheet

(Page 4 of 4)

I am completing this research as part of a doctorate course at Staffordshire University. The study is sponsored by Staffordshire University.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the West Midlands Research Ethics Committee.

### **Further information and contact details:**

If you would like general information about research please feel free to speak with me at any time during the study. I am available at p038833a@student.staffs.ac.uk. If you would like specific information about this study, please feel free to speak with me at any time during the study.

For advice as to whether or not you should participate, please feel free to speak to others, including your health professionals, alternatively you can speak to someone from the advocacy service by calling XXXX XXX XXXX

If you are unhappy with the study please approach Dr Amanda Hilton by calling XXXX XXX XXXX.



South Staffordshire and Shropshire Healthcare **NHS**  
NHS Foundation Trust  
A Keele University Teaching Trust

**Adults with learning disabilities and their older parent-carers' experiences and perceptions of the future.**

**Participant information sheet (accessible version)**

**What is my work about?**

My name is Laura Pryce and I am a trainee clinical psychologist.



I would like to find out about adults with learning disabilities experience of living with older parents and what their hopes are for the future.

**Do you have to take part?**



You can say yes if you want to take part



You can say no if you do not want to take part.

Your answer will not change the care that you get from the Community Adult Learning Disability Team.

**What will happen if I take part?**



I will ask you some questions about living at home and being cared for by your parent(s) and about your hopes for the future.



We will meet for 1 hour



You can ask me to stop at any time

If you tell me anything that suggests to me that you or someone else is at risk harm then I will have to tell someone else in the health and social care team. This is to keep everyone safe.

I will ask you if it is ok to tape-record our meeting



I will listen to the tapes

I will not show anyone else the tapes.

**What happens after you have seen me?**



I will write about the things you have told me in a report.  
Your name will be kept private.



I will take out your name and where you live so that people reading the report will not know who you are.

I will be the only person who will see your name.



To help you decide whether or not you would like to take part, please contact Dr Amanda Hilton on XXXXX.


Or you can contact your local advocacy service on XXXXX They can help you decide whether or not to take part and can offer you support during the interview if you would like it.

Thank you for looking at this.

## Appendix 10: Participant consent form

(Page 1 of 2)



South Staffordshire and Shropshire Healthcare   
NHS Foundation Trust  
A Keele University Teaching Trust

**Patient identification number:**

**Title of project: Adults with learning disabilities' and their older parent-carers' experiences and perceptions of the future.**

**Name of researcher: Laura Pryce**

### CONSENT FORM

*Please initial box*

- I. I confirm that I have read and understand the information sheet dated (version 2/Aug2013) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- II. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- III. If any questions make me feel uncomfortable or upset I do not have to answer them
- IV. I understand that relevant sections of the data collected during the study may be looked at by Laura Pryce, Amanda Hilton (Clinical supervisor) and Dr Alison Tweed (Academic supervisor). I give my permission for these individuals to have access to my data.
- V. I understand that my responses are anonymous but not confidential.
- VI. I give my permission for the researcher to use direct quotes in the published report and I am aware that any identifiable information will be changed.

Participant Consent Form/Version 1/July 2013

Participant consent form

(Page 2 of 2)

VII. I understand that the interviews will be recorded

VIII. I understand that data collected during the study may be looked at by individuals from regulatory authorities or from the NHS trust where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my data.

IX. I agree to take part in the above study

Name of participant..... Date.....

Signature.....

Name of person taking consent..... Date.....

Signature.....

Participant Consent Form/Version 1/July 2013



**Consent Form (Accessible version)**



• I have seen the information sheet about the study

• I understand the things the information sheet told me

• I was able to ask questions if I wanted to

• I understand it is my choice to take part in the study

• I understand that I can say No at any time if I want to stop

Participant consent form: accessible version

(Page 2 of 2)



• I understand that the interview will be tape recorded and will only be heard by the researcher. It is Ok for the interview to be tape recorded



• I understand that the researcher will type out the interview and then will delete the tape.



• I agree to my name being removed to stop people from knowing who I am.



• I would like to take part in the study



Name:.....

Signed:.....

Date:.....

Name of person taking consent:.....

Date:.....





## Appendix 11: Demographic questionnaire

(Page 1 of 2)



South Staffordshire and Shropshire Healthcare 

NHS Foundation Trust

A Keele University Teaching Trust

### Demographic Information:

Gender: Male  Female

D.O.B: .....

#### Ethnicity:

##### *White*

British   
Irish   
Any other White background

##### *Mixed*

White and Black Caribbean   
White and Black African   
White and Asian   
Any other mixed background

##### *Asian or Asian British*

Indian   
Pakistani   
Bangladeshi   
Any other Asian background

##### *Black or Black British*

Caribbean   
African   
Any other black background

##### *Other Ethnic Groups*

Chinese

Any other ethnic group (please specify)  .....

Demographic questionnaire

(Page 2 of 2)

**Current marital status:**

- Married
- Divorced
- Separated
- Single
- Living with another
- Widowed
- Would rather not say

**Is your home:**

- Owned
- Council / housing association rented
- Privately rented
- Other
- If 'other' Please give details.....

**Other members living in your household:**.....

*Additional questions for parent-carers:*

**Gender of adult-child with learning disability:**

Male  Female

**D.O.B of adult-child with learning disability** .....

*Additional questions for adults with learning disabilities:*

**Parent(s) you are living with:**

Mother  Father  Both

**D.O.B of parent(s)**.....

## Appendix 12: Interview schedule

Parent-carer participants:

### Interview Schedule

For parent-carers

1. **Can you tell me about your experiences of caring over the years?**  
*(prompts: how have you found being a carer over the years? When son/daughter was first born, what was it like?... as they were growing up?...now?)*
2. **What has been the advantages of caring?** *(prompts: what has been enjoyable, what aspects of caring for your son/daughter do you like? Have there been any positive impacts of caring on other aspects of your life?)*
3. **What has been the disadvantages about caring?** *(prompts: what has been difficult about caring? What aspects don't you like? Have there been any negative impacts of caring on other aspects of your life?)*
4. **What care/support do you provide...each day?** *(prompts: what kind of support – e.g. personal care/daily living/ transport/ emotional /physical/ financial/social etc.)*
5. **Does your son/daughter provide help/support for you? If so, what?**  
*(prompts: physical support ie.help with domestic chores etc, emotional support? Social support?)*
6. **Does your son/daughter have any form of support from social services or other providers?** *(prompts: e.g. Day care/respice/support worker/direct payments/short term breaks?)*
7. **What support do you/son/daughter have from others?** *(prompts: e.g. Family, neighbours and friends?)*
8. **What hopes do you have regarding the future of your son/daughter?**
9. **What fears do you have regarding the future of your son/daughter?**
10. **What do you think would happen to your son/daughter if you were no longer able to care for him/her at home?**
11. **Are you aware of what options could be available to you in these circumstances?**
12. **If you had the freedom to choose, what sort of accommodation and support would you want for your son/daughter if you were no longer able to provide care at home?**
13. **How could services support you more in planning for the future?**

!  
!

Adult with ID participants:

### **Interview schedule**

For adults with learning disabilities:

(Visual aids using photo symbols will be used during the interview)

- 1. Can you tell me about your experience of living with mum and dad?**
- 2. What things about living with your parents do you enjoy/like?**
- 3. Are there any things that you don't like about living with your parents?**
- 4. Can you tell me what support your parents give to you on a daily basis?** (*prompts: eg. with money, shopping, getting around, keeping safe, looking after yourself, cooking meals, taking to appointments, washing, dressing, with worries....*)
- 5. What help or support do you give your mom/dad?**
- 6. Can you tell me about support that you receive from others?** (*prompts: support workers? Relatives/friends etc? what kind of support?*)
- 7. What hopes do you have about the future?**
- 8. What fears do you have about the future?**
- 9. Have you ever thought about living somewhere else in the future?**
- 10. If you could no longer live with mum and dad, what do you think will happen?**
- 11. Have you ever thought about living somewhere else in the future?** (*prompts: has anyone ever talked to you about the future?*)
- 12. If you could choose where you would like to live in the future, what would this look like?** (*prompts: e.g. own place, with others, with friends, with other family....*)
- 13. How could services help you to plan better for the future?**

## Appendix 13: Example of memo

### Memo

#### Focused code: Avoiding future-orientated thinking

Many participants spoke of avoiding thinking about or openly talking about the future. By focusing on the present, parents can avoid or minimize thinking about their own mortality or becoming too ill to care and therefore allay their fears about what might happen to their son/daughter when they are no longer able to care for them. This is a passive process in which parents described 'waiting and seeing what happens' and 'taking things in your stride'. Some parents described having strong senses of faith which overrides making active plans and enhanced their capacity to cope with uncertainty. Many parents viewed 'living one day at a time' as a helpful strategy enabling them tolerate uncertainty.

Individuals with ID also were avoiding thinking about the future due to the profound fear of a future without their parents (Oliver and Ian). Kate, however represents a 'deviant' case – she was confronting the future head on and has made the decision to move into independent living and was looking forward to this. Open conversations within the family system about future alternatives allowed her to reach this decision.

#### Questions to ask of the data:

Was talking about the future too much of a difficult topic to even contemplate?

Does avoiding talking about the future stifle adults with ID to generate ideas/ possibilities of a different future?

#### Questions to ask in subsequent interviews:

Parents:

What were your expectations of the future when your child was born/young?

Deviant case: One family described having thought a lot about the future and had made active future plans to move into supported living. The parent was younger (60's) – is there a difference in terms of older versus younger parents who choose to 'let go'?

#### Examples of open codes and key quotes

	Open code	Key quotes
Nancy	Living for today	<p><i>"I think you have to live for today and let tomorrow do what it's going to do."</i></p> <p><i>"I hope that he will go before us.... But that we don't know do we? And I sort of feel that we must wait until it comes and then we will deal with it"</i></p>
Theresa	Taking it in your stride	<p><i>"I don't know, I mean, it's just something that we've always done, we've always coped with and you just take it in your stride and carry on don't you y'know"</i></p> <p><i>"We just take it in our stride and carry on, that's all you can do really"</i></p>

Barbara	Hoping and praying	<i>"Well all I can hope and pray is that he is cared for when I'm no longer here"</i>
Mary	Having faith overrides planning	<i>"I have enough faith to think that planning ahead is not necessarily useful.... I might find I'm wrong of course"</i>
Jack	Not wanting to discuss future	<i>"You can turn your back on it, can't you, when it's something you don't want to discuss."</i>
Oliver	Future being scary	<i>"If you think about the future it's scary so, I just take each day as it comes...sometimes when people ask me about the future it can push my buttons and make me a bit cross."</i>

Key thoughts and references

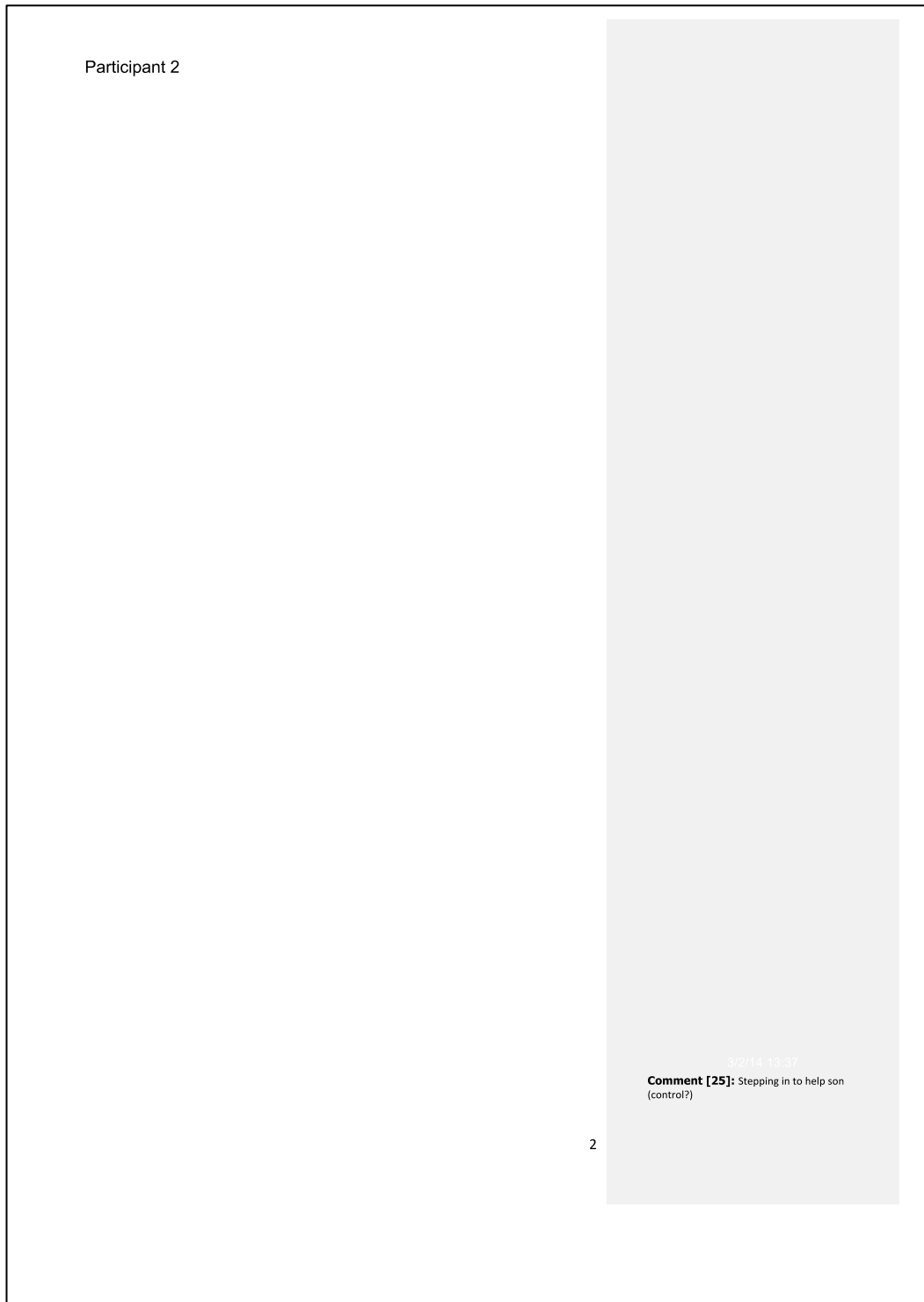
Mason (1993) concepts of 'safe uncertainty' and 'unsafe uncertainty'  
 Goldberg et al (1995) Protection and Loss

I found that in most of the interviews being asked a question was the first time that they had thought about it. They perhaps had never had to think about the future before? Perhaps they had not foreseen the situation they are currently in (were they told their children would have shorter life-expectancies?) Had been talking about the future being an intervention in itself?

## Appendix 14: Illustration of stages of analysis

### 1. Transcribing and open coding

Participant 2



3/2/14 13:37  
**Comment [25]:** Stepping in to help son  
(control?)

2

Constant comparison and memo writing

- Clustering/sorting codes, producing focused codes (e.g. 'Caring for someone as you know them best' code shown below).



- Theoretical coding. Comparing/linking focused codes led to the development of overarching categories. Diagramming helped to explore links between emerging categories and to identify the core category:

