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Living at Home with Family:

Psychological Adaptation and Well-being Among Family Carers and Adults with an Intellectual Disability

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Living at Home with Family: Psychological Adaptation and Well-being Among Family Carers and Adults with an Intellectual Disability

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March, 2015

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Table of Contents

List of Tables

List of Figures

"Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community."

Article 19, Convention on the Rights of Persons with Disabilities, p.13

Summary

The purpose of this thesis was to examine well-being among family carers and adults with an intellectual disability (ID). In a series of four studies, I examined 1) parents' experiences and feelings during the process of seeking out-of-home accommodation for their adult child with ID, 2) how adults with an ID who live at home report on their own well-being, 3) the physical and psychological health of family carers and 4) factors related to the process of moving out of the family home in adulthood. Chapter 1 provides a background picture of adulthood with an ID, examining health and support issues and what has been achieved in terms of policy and strategies in the UK. Estimations of future need for adults with ID have also been explored.

Adopting a qualitative design, Chapter 2 examines the experiences of families seeking out-of-home accommodation for their relative with ID. Little attention has been given to the first-hand experiences of families as they undertake this process. Thematic analysis identified implicit themes in the data, which included families' reasons for seeking housing and experiences within a process which families reported as stressful and frustrating.

In Chapter 3, secondary data analysis was undertaken on a large national survey of adults with an ID in England (Emerson, Malam, Davies, & Spencer, 2005). An examination of adults' self-reported health and well-being was undertaken exploring associations with living circumstances. Results of multivariate modelling showed those who lived at home were more likely to report better well-being and health. The latter, however, only when their support needs were lower. Results highlight the important role of families to the emotional development of a relative with ID, whilst also highlighting potential disparities in access to health care for these individuals.

Chapter 4, a large scale quantitative project was undertaken to examine both positive and negative aspects of the caregiving experience and explore the self-reported health and well-being of family carers co-residing with an adult relative with ID. Families in the UK report experiencing poorer health outcomes than non-caregivers. Psychological resources (coping and support received) were associated with better psychological adjustment and more positive gains from the caregiving role. Overall factors associated with physical health appear to differ from those associated with psychological health. Further research with more representative non-caregiving peers is needed.

Chapter 5 adopted a prospective design to examine the dynamics of placement tendencies of families of adults with ID and factors associated change in placement decisions and behaviours. The majority of families who had placed their relative out-of-home had initially recorded higher scores on the Placement Tendency Index (PTI, Blacher, 1990). The rate of placement of adults appeared to occur more rapidly than previously demonstrated with children. This may result from the more normative context of seeking a placement for an adult relative. Unadjusted ORs indicated only families' coping strategies were significantly associated with continued home care. Other factors were not significantly related to changes in PTI scores. Changes in placement decision of families of adults with ID may be more affected by factors external to the family, such as availability of appropriate accommodation.

Findings from these empirical studies were discussed in relation to their implications to policy and practice and recommendations for future research were made.

Chapter 1: Introduction

Background

The main focus of the present thesis is on families who co-reside with an adult relative with an intellectual disability (ID) and assume the main caregiving responsibilities for them. Many adults with ID live at home with family carers into their middle years (Yamaki, Hsieh, & Heller, 2009; Rowbotham, Cuskelly, & Carroll, 2011; Seltzer, Floyd, Song, Greenberg, & Hong, 2011), when carers themselves potentially need support (Williams & Robinson, 2001). This continued residency is not always the choice of either party, but often a practical measure due to the absence of appropriate community housing (Bowey & McGlaughlin, 2005).

Research suggests that providing care for an adult family member with an ID within the family home long term can have an adverse effect upon carers' physical and psychological health (Chou, Chiao, & Fu, 2011; Chou, Fu, Lin, & Lee, 2011; Hill & Rose, 2009; Rowbotham, et al., 2011; Seltzer, et al., 2011; Yamaki, et al., 2009). Much of what is known about the longer term impact of providing care and experiences of exploring alternative residential options has been derived from studies which have taken place within international contexts (Taiwan, U.S., Australia; Chou, et al., 2011; Chou, et al., 2011; Rowbotham, et al., 2011; Seltzer, et al., 2011; Yamaki, et al., 2009; Vassos, Nankervis, & Rosewarne, 2012; Weeks, Nilsson, Bryanton, & Kozma, 2009). Less is known about the health of families providing care within family homes to an adult relative with ID in a UK context. With the current austerity drive impacting on service support to families (Duffy, 2013), it would seem a particularly pertinent time to gain a better understanding of the current needs of family carers and their adult relative with ID in the UK.

To set the context for the research presented in this thesis, it is necessary to initially give a brief overview of adulthood and ID, before further discussing the contribution of the remaining chapters.

A brief definition of Intellectual Disability

Whilst scientific and social definitions of ID have evolved over many years (Odom, Horner, Snell, & Blacher, 2007), the current broad definition is an individual having: "significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills" (Schalock et al., 2010, p.5). These deficits originate during childhood, before the age of 18. Limitations in functioning should be considered within community, cultural and age peer contexts. An ID is defined as an IQ falling approximately two standard deviations or more below the general population mean of 100, i.e., below 70 or more. An IQ between 55 and 69 is classified as a mild ID, between 40 and 54 a moderate ID, 25 to 39 a severe ID and below 25 a profound ID (Hodapp & Dykens, 2004). Various aetiologies are associated with ID, including hereditary and genetic factors which manifest as syndromes such as Down syndrome (DS), the most common chromosomal cause of ID, Fragile X (FXS) the most common inherited cause of ID, Rett syndrome (RS), Williams syndrome (WS) and Prader-Willi syndrome (PWS) (Rondal, 2004; Tartaglia, Hansen, & Hagerman, 2009). Environmental and sociocultural factors such as low socio-economic status (SES) and childhood poverty are also known risk factors to a child's cognitive development (Emerson, 2007; Katz & Lazcano-Ponce, 2008). The primary purpose for identifying individuals with ID is for the provision of appropriate support services, education, and funding.

Prevalence and residential status of adults with ID living in the UK

The estimated number of adults with ID in the UK is just under one million (962,874) (Emerson et al., 2012; Northern Ireland Assembly, 2014; Scottish Consortium for Learning Disability, 2013; Statistics for Wales, 2014). Worldwide estimated prevalence rates of people with ID are around 1% to 3% of the population (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011; McConkey, Mulvany, & Barron, 2006). An examination of the administrative prevalence (i.e., proportion of people with ID that are known to public services) of children and adults with ID suggests a wide disparity between the estimated total population prevalence and the administrative prevalence, especially for adults with ID. In addition, disparities in estimated prevalence exist even within administrative records across the life span. A 'transition cliff' which occurs during the transition from children's to adult public services (Emerson & Glover, 2012) is an appropriate description of the substantial drop in administrative prevalence rates of around 40-50 children with ID per 1,000 of the total population to 6-7 adults with ID per 1,000 which cannot be explained by mortality alone (Emerson et al., 2011). It is more likely explained by the discontinuation of educational support and lack of social care and health support as individuals with milder ID transcend the public service system (Emerson & Glover, 2012; Emerson & Hatton, 2008; Emerson et al., 2011). Therefore, the overall global prevalence rates are thought to be significantly higher than recorded administrative data would indicate (Emerson & Glover, 2012; McConkey et al., 2006). Among the population who have ID, 85% are thought to have mild ID, 10% moderate, 4% severe and 2% profound ID (Maulik & Harbour, 2010). A breakdown of the latest known administrative and estimated figures for each of the four countries of the UK, together with residential status, is given below.

The number of adults with ID aged 16 years or over in Wales registered with local authority ID registers as at 31st March 2014, was 12,272 (Statistics for Wales, 2014). Forty six percent (5,709) were living in family homes and 53% were living in out-of-home residential and community settings. Community residencies included 2,434 (20%) living in lodgings or supported living, 1,948 (16%) in their own homes, 1,358 (11%) in private and voluntary care homes, 131 (1%) in health service accommodation, 99 (0.8%) in foster homes or adult placements, 81 (0.7%) in local authority care homes and 512 (4%) living in other, non-specified accommodation. Since 2002, the number of adults known to local authorities with an ID living in Wales has increased from 9,819 to 12,272, an increase of almost 20%.

Whilst there is no definitive record of the number of adults with ID living in England, nor the rest of the UK, by combining information collected by Government departments on the presence of ID among people using public services, overall population predications for England and the results of epidemiological research, Emerson et al., (2012) estimated that 908,000 adults in England have an ID. Thirty eight percent are registered as living with family and friends (Mencap, 2011). As with Wales, other accommodation includes registered care homes (22%), supported accommodation (16%), local authority or housing association accommodation (12%), private rented sector (3%) and other accommodation (9%) (Mencap, 2011).

Figures for Scotland show that 26,236 adults with an ID were registered on local authority registers in 2013. Just under 35% (9,142) were living with family, which was a rise of 0.5% since 2012 (Scottish Consortium for Learning Disability, 2013). Just over a third (9,142) live with family, whilst just over 46% (12,073) live in other out-of-home community settings. Over half (53% or 12,945) live in 40% of the most deprived areas of Scotland.

Information gained from Health and Social Services Trusts shows that the number of adults over the age of 20 years, who were registered as having an ID in Northern Ireland in 2003 were 8,215 (McConkey, Spollen, & Jamison, 2003; Northern Ireland Assembly, 2014). More recent estimates put the number at 8,340 (McConkey et al., 2006). Almost 62% (5,160) were living with family, 23.6% (1,970) in residential settings, 9.2% (770) in their own accommodation and 5.3% (440) in hospital accommodation.

While there is wide variation across UK countries, between 35% and 62% of adults with ID live with family, with Wales and Northern Ireland reporting the higher proportion of adults with an ID living at home (53% and 62%, respectively). Prevalence rates for Wales, Scotland and Northern Ireland were all based on the number of adults with ID registered with local authority and/or health trusts. They therefore do not include those who are not registered as public services users, many of who are thought to have mild ID and reside mainly in family homes (Emerson, 2011). True prevalence rates for these countries are likely to be considerably higher when taking account of this 'hidden' population (Emerson, 2011; Emerson, et al., 2011; Emerson & Glover, 2012).

Quality of life and living circumstances of adults with ID

Quality of life is a multi-dimensional concept which relies not only on objective factors such as material resources, physical health and social status, but also encompasses the subjective personal appraisal of those objective life conditions (Felce, 1997; Schalock et al., 2002). Most conceptions of quality of life include the domains of physical and psychological health, level of independence, social relationships, environments, civic well-being and spiritual/personal beliefs (Felce,

1997; Schalock et al., 2002; WHOQOL Group, 1998). Quality of life of people with ID was a key factor of the 'normalisation movement' and subsequent de-institutionalisation, which saw adults with ID living in the UK and the majority of other Western cultures, move into smaller community housing, living circumstances which were thought to be more conducive to well-being (Emerson & Hatton, 1996). It has since been fairly well evidenced that, when performing well, community based settings afford adults with ID a better quality of life than large scale institutions (Emerson & Hatton, 1996; Perry, Felce, Allen, & Meek, 2011; Mansell, Beadle-Brown, Skidmore, Whelton, & Hutchinson 2006). In general, evidence suggests that living in smaller community-based staffed accommodation provides adults with ID greater opportunities for social and community participation, more variety of community and household activities and a better quality of life than larger settings (Felce, Perry, & Kerr, 2011; Kozma, Mansell, & Beadle-Brown, 2009).

A strong association has been found between adaptive behaviours and residential status of adults with ID (Felce et al., 2011; Woolf, Woolf, & Oakland, 2010). People with greater adaptive behaviour skills are more likely to reside in independent community living environments than those with lower adaptive behaviour skills, who are more likely to reside in group homes (Woolf et al., 2010). It is also thought that a large number of adults with mild ID, often referred to as a 'hidden majority', as they are not registered to receive public service support, reside with their families (Emerson, 2011; Emerson et al., 2011; Emerson & Glover, 2012). Living independently in the community has been associated with increased involvement in household activities compared to those living in staffed accommodation or family homes. However, living in staffed accommodation has been found to provide residents more opportunity for participation in a greater number of

household activities and more variety of community activities when compared to people living with family (Felce et al., 2011).

Living in less restrictive home environments has been associated with increased health adverse behaviours such as smoking and consuming a poor diet and higher levels of obesity. However, living environments which offer residents greater self-determination have also been associated with less physical inactivity (Kozma et al., 2009; Robertson et al., 2000; Sutherland, Couch, & Iacono, 2002). Living in private households, including family homes, has also been associated with greater feelings of helplessness, whilst living in registered care homes or supported living has been associated with increased levels of happiness and confidence (Emerson & Hatton, 2008).

Health and well-being of adults with ID

Improvements in health care have led to increased longevity for both ID and general populations (Bittles et al., 2002; Ouellette-Kuntz, 2005; Patja, Mölsä, & Iivanainen, 2001). Whilst adults with mild ID are now reaching near parity in life expectancy with non-ID populations (Bittles et al., 2002; Patja et al., 2001), life expectancy for people with lower functionality remains relatively low (Heslop et al., 2014; Ouellette-Kuntz, 2005). A significant cause of early mortalities are associated morbidities such as mobility problems, seizure disorders, sensory impairments, cancer and problems relating to feeding issues such as obesity (Evenhuis, 1997; Ouellette-Kuntz, 2005). Factors thought to influence the health status of adults with ID not only relate to the presence of a genetic syndrome associated with ID but also include personal characteristics such as older age, socio-economic status, residential status, behavioural and lifestyle characteristics and poor management of health care

(Emerson & Hatton, 2007, Jansen, Krol, Groothoff, & Post, 2004; Kapell et al., 1998; Robertson et al., 2000).

Severity of ID is associated with poorer physical and psychological well-being and higher rates of mortality (Bittles et al., 2002). Evidence has shown that adults with lower IQ and greater support needs report higher rates of physical health problems and depressive symptoms (Emerson & Hatton, 2007; Seltzer et al., 2005). Increased frequencies of epilepsy, skin conditions, sensory problems, incontinence, hypothyroidism, heart disease, gastrointestinal disorders, constipation, cancers, sleep disorders, hepatitis, tuberculosis and psychiatric disorders have been identified in adults with ID (Evenhuis, 1997; Jansen et al., 2004; Ouellette-Kuntz, 2005). Due to the susceptibility of biological and neuropsychological premature ageing (Vicari et al., 1994, as cited in Rondal, 2004, p.94) adults with Down syndrome are at increased risk of early onset dementia (Ball et al., 2006), increased likelihood of seizures (Roizen & Patterson, 2003) and musculoskeletal problems (Janicki et al., 2002).

The prevalence of epilepsy among people with ID is generally greater than that of the general population. Estimated prevalence rates are somewhere between 20-30% (Buelow, McNelis, Shore, & Austin, 2006; Matthews, Weston, Baxter, Felce, & Kerr, 2008) compared to a worldwide prevalence rate of around 1% in general populations (Thurman et al., 2011). The presence of epilepsy in this population has been associated with lower adaptive behaviours, higher levels of challenging behaviour (Matthews et al., 2008) and the risk of developing psychotic disorders (Matsurra et al., 2005). Family carers of individuals with co-morbidity of ID and epilepsy have reported difficulties in managing these associated behaviours (Beulow et al., 2006).

Exact prevalence rates of mental illness among adults with ID remain unknown due, in part, to the comparatively recent recognition that adults with ID were cognitively able to experience mental health problems (Smiley, 2005). Evidence suggests that adults with ID may, however, be more vulnerable to psychiatric illness than previously thought (Cooper et al., 2007; Hiraiwa, Maegaki, Oka, & Ohno, 2007; Smiley, 2005; Soni et al., 2008). In a large scale study (N = 245,749) aimed at gaining a better understanding of the potential co-occurrence of ID and mental health problems, Morgan, Leonard, Bourke and Jablensky (2008), cross-linked the Western Australian Population-Based Psychiatric and Intellectual Disability Registers in order to examine the estimated prevalence of dual diagnosis of ID and mental health problems. Whilst the results of this study suggest that total psychiatric morbidity among people with ID may be comparable with estimates of life-time prevalence among the general population, rates of psychosis, particularly, schizophrenia were found to be over three times higher than population estimates (Perälä et al., 2007). Cooper et al., (2007) also found the point prevalence of psychotic disorders for adults with ID was ten times higher than reported in the UK general population. Visual impairments, having previously lived in a long-stay hospital, smoking and the absence of epilepsy were also independently associated with psychosis.

Overall, having a lower level of ID, being female, living in less restrictive environments have all been identified as risk factors to being overweight, whilst being male, having lower functionality and living in more restrictive environments have been associated with being underweight (Emerson, 2005). Living in less restrictive home environments has been associated with increased health adverse behaviours such as smoking, consuming a poor diet and physical inactivity (Robertson et al., 2000; Sutherland et al., 2002).

Health inequalities of adults with ID

With a greater number of adults with ID in Western economies living independently, in smaller community settings or in family homes, a challenge for policy makers, medical professionals, social care professionals and families has been not only to ensure good access to community based health care but the continuity of care by practitioners who are familiar with an individual and their health needs (Krahn, Hammon & Turner, 2006). A review of the literature suggests that adults with ID have a tendency to lack engagement in health promotion and disease prevention, especially with regard to physical exercise and oral health care (Ouellette-Kuntz, 2005). As a post-institutionalisation health intervention, annual health checks for adults with ID were introduced into the UK in 2006. However, only those in receipt of social care services are currently eligible for this intervention. Whilst this excludes those who reside in family homes who are not in receipt of public service support, evidence has also shown that less than 50% of eligible adults with ID in England received a health check in 2010/11 (Emerson, Copeland & Glover, 2011). Health checks for this population of adults have resulted in the successful identification and treatment of new and unmet health needs (Cooper et al., 2006; Emerson et al., 2011; Robertson, Roberts, Emerson, Turner, & Greig, 2011). However, the limited evidence we have of the experiences of adults with ID within the health care system suggests the system is, on the whole, failing to meet the needs of this population (Mencap, 2004).

Families co-residing with an adult with ID

Due to the prolonged worldwide economic recession, it is now become frequent for adults in the general population to remain living with their family for

longer, often until their late twenties (Aassve, Arpino, & Billari, 2013; Cobb-Clark, 2008). The percentage of young adults between the ages of 20 and 34 from the general population living with family in the UK in 2013 was 26% (Office of National Statistics, 2014). The trend for later home leaving for the general population has not, however, brought parity with adults with ID, a higher percentage of who often remain living with their families into their mid-life, as I described in the section above. Some with increasingly elderly parents who themselves have support needs (Bibby, 2012; Bowey & McGlaughlin, 2005, Cuskelly, 2006; Dillenburger & McKerr, 2010; Heller, 2008; Heller, Caldwell, & Factor, 2007; Shaw, Cartwright, & Craig, 2011; Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012). The estimated prevalence of adults with ID under the age of 35 who live with family ranges from around 40% to 60% (Emerson, 2011; Mencap, 2011; Northern Ireland Assembly, 2014; Scottish Consortium for Learning Disability, 2013; Statistics for Wales, 2014).

Evidence suggests that families who provide care to an adult relative with ID experience poorer physical and psychological health outcomes than non-caregiving peers (Chou et al., 2011; Rowbotham, Cuskelly, & Carroll, 2011; Seltzer et al., 2011). Higher levels of stress, anxiety and depressive symptoms (Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsi, 2009; Seltzer et al., 2011) and high blood pressure, BMI, cardiovascular disease, arthritis, diabetes and activity limitation have been found for carers compared to non-caregiving peers (Seltzer et al., 2011; Yamaki, Hsieh, & Heller, 2009). Lifelong caregiving not only impacts the health of family carers but can also affect families' economic and social well-being (Heller, Caldwell, & Factor, 2007). Many carers experience the ongoing care role in the context of their own ageing, when they themselves are adjusting to the challenges of older age and the potential deterioration in their own functioning (Bowey & McGlaughlin, 2007;

Dillenburger & McKerr, 2010; Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012).

Families caring for an adult relative with ID encounter changes not evident when caring for a child with ID. Parents may themselves only identify as carers to their children during adulthood when the deviation from the normal life cycle of increasing independence for both parties becomes more apparent (Todd & Jones, 2005). The caregiving role can also become more challenging as statutory services, such as education, end and families become more reliant on non-statutory services such as day care and respite services (Todd & Jones, 2005), funding for which is not ring-fenced from spending cuts (Sully & Bowen, 2012). The physical demand of caring can also become more challenging as care recipients become larger and heavier in adulthood (Nankervis, Rosewarne, & Vassos, 2011). Increases in mental health problems, dementia, declining physical abilities and increased challenging behaviours have been evidenced in adults with ID (Ball et al., 2006, Janicki et al., 2002; McManus et al., 2009; Nankervis et al., 2011; Roizen & Patterson, 2003), all factors which have been associated with caregiver burden (Chou et al., 2010; Minnes, Woodford, & Passey, 2007; Etters, Goodall, & Harrison 2008). Care burden can also increase as support in the guise of other children leave the family home (Todd & Jones, 2005). Mid-life female carers have also reported depletion in energy both during and after the menopause (Todd & Jones, 2005). The percentage of activity limitation reported by older carers has been found to be almost twice that reported by their non-caregiving age peers (56% vs 30.2%) (Yamaki et al., 2011). Higher rates of diabetes (12.4%) and high blood cholesterol (40.3%) have also been reported by middle-aged carers compared to their counterparts from the general population (7% and 33.2% respectively) (Yamaki et al., 2011).

Changing climate of social care and housing in the UK

It has been over a decade since the launch of Valuing People (Department of Health, DoH, 2001), a Labour Government document which set out policy intentions for people with ID encompassing the principles of rights, independence, choice and inclusion. Valuing People (DoH, 2001) and the subsequent Valuing People Now (DoH, 2009) and Independent Living Strategy (Office for Disability Issues, 2008), set out policies to strengthen the roles of people with ID as citizens within their communities, with more choice and control over their lives including where and with whom they lived. However, subsequent major changes have occurred both politically and economically. With the dual impact of the global recession and change of UK Government in 2010 and the instigation of harsh austerity measures as a response to prolonged economic decline, local authorities have faced difficult challenges to both their housing and social care budgets (Duffy, 2014; Hastings et al., 2013). Between 2011 and 2013 approximately £1.89 billion was removed from local authority social services budgets (SCIE, 2013). Therefore, much of what was proposed under Valuing People (DoH, 2001) has not been realised and the emphasis of supporting people with ID into out-of-home accommodation has become less of a priority. Care to adults with ID has increasingly continued to be provided by families with diminishing support from external agencies.

The needs of people with ID are predicted to increase (Emerson & Hatton, 2011). Based on figures from the Department of Education's school census of the number of children currently undertaking special needs education (SEN) in England, which was adjusted for the effect of mortality, Emerson and Hatton (2011) have estimated that the need for social care services will increase annually by approximately 3.2%. By 2030, it is estimated there will be a 14% increase in the

number of adults with ID over the age of 50 using social care services, and that adults aged 70 and over using social care services will more than double. Increases in lone parent households and older people with ID whose parents are either deceased or too frail to continue providing care have also been predicted.

The results of a Freedom of Information request to 174 local authorities in England and Wales revealed that 143 (82%) recognised there was a housing crisis for adults with ID and 116 (67%) reported the situation getting worse in a 12 month period prior to 2011 (Mencap, 2011). Mencap (2011) also reported that 8,578 adults with ID were newly referred to local authorities for housing support in 2011, and nearly 10,000 people are known to be on housing waiting lists in England and Wales. Whilst 70% of adults with ID who were surveyed reported a desire to live more independently, the strain on local authority budgets prevented this from becoming a reality (Mencap, 2011). Recent initiatives have been introduced in response to the housing problem. Organisations such as Golden Lane Housing (The housing arm of Mencap) are providing housing for adults with ID through their Big Lottery Fund social investment bonds which have raised in excess of £20 million over a two year period. This will be invested to develop around 60 homes for approximately 100 adults with ID across England and Wales. The UK Government has also pledged £200 million over a five year period to support the development of housing for older people and people with disabilities in England (H.M. Government, 2012).

With an increase of people with ID known to local authorities as needing housing support of 3% for the year 2011 and a further 5.7% increase expected over the next two years, it has been suggested that an additional 1,324 registered care home places and 941 supported living places would need to be created every year until 2026 (Mencap, 2011). With a predicted annual increase of 2,257 until 2026 of people with

ID living with friends and family who are known to local authorities, the concern is that families will have no choice but to continue providing care for their relative until they reach crisis situations where the continuation of care is no longer possible.

The provision of support for older adults with ID raises serious concerns. In a review of Government policies on accommodation support for older people with ID across five countries including the UK, Bigby (2010) highlighted a severe lack of specific policy frameworks on how to best meet accommodation and specialist support needs of an ageing population with ID, which, to our knowledge, is yet to be addressed. Bigby (2010) also highlighted the admission of ageing adults with ID to general residential homes for older people which occurs in the absence of other, more appropriate alternatives. With forecasts predicting lower mortality rates and an increase in the number of adults with ID reaching older age (Emerson & Hatton, 2011), reliance on families to provide this support will no longer be a viable option. As Bigby (2010) highlights, initiatives for an ageing general population, such as 'ageing in place' where support is offered in their homes, cannot simply be transferred to an ID population, who require more complex programmes of support.

Research aims

Much of what is known about the impact of long term co-residency of adults with ID in family homes come from studies conducted outside of the UK. Relatively little is known about the impact of this co-residency and issues faced by families in a UK context. This project begins to address this gap by increasing our understanding of how families are experiencing providing care in the current financial climate.

The aim of this thesis was, therefore, to gain a better understanding of how families experience providing long term care to an adult relative with ID within their homes. In particular, the PhD focuses on:

(a) The experiences of families who are in the process of seeking out-of-home accommodation for an adult son or daughter with ID.

(b) The well-being of adults with ID who live at home compared to other community settings.

(c) The well-being of family carers who co-reside with their adult relative with ID.

(d) Processes and factors associated with placing an adult relative with ID in out-of-home accommodation.

Methods and Research

The thesis comprises four chapters which report on research studies and a final discussion chapter. Quantitative and qualitative methodologies were utilised during the course of this research which set out to examine the experiences of families co-residing with an adult relative with ID. Chapter 2 examined the first hand experiences of families as they proceed through the process of seeking out-of-home housing for their adult son or daughter. This used a qualitative design, using a semi-structured questionnaire as a guiding framework, chosen to allow for an in-depth exploration from a family carer perspective of seeking housing for a relative with ID in Wales, of which we know little about, and to explore factors which led to the decision to seek alternative accommodation. Thematic analysis (Braun & Clarke, 2006) was used to analyse the data. Thematic analysis is a common method of analysis in qualitative research which can be used to identify patterns within data without a pre-existing theoretical framework (Braun & Clarke, 2006). An inductive or 'bottom up' approach

was adopted to identify themes emerging from the data (Boyatzis, 1998; Braun & Clarke, 2006).

Chapter 3 reports on a secondary data analysis of data from the English survey of adults with ID in England 2003-2004 (Emerson, Malam, Davies, & Spencer, 2005). This large scale study adopted a quantitative design to explore whether the living environment of 2,402 adults with a variety of levels of ID (N = 1,528 living with family and N = 874 living in residential care homes, supported living or alone) was associated with self-reported health and well-being. Response mode (independently, or assisted by a carer) was controlled for in regression models, due to the potential confounding influence of proxy reports upon subjective phenomena (e.g., Perry & Felce, 2002).

Chapter 4 examines the physical and psychological health of family carers co-residing with an adult relative with ID across the UK. Few studies have examined the impact of providing care to an adult relative with ID in family homes within the UK. In a primary data collection study of 110 family carers, levels of subjective health and well-being were compared to population norms. Multivariate analyses were undertaken to explore factors associated with physical and psychological health outcomes taking account of both positive and negative factors. Using a framework of adaptive theories of family stress (McCubbin, Olson, & Larsen, 1981; McCubbin, Olson, Larsen, Corcoran, & Fisher, 2000; Townsend, Noelker, Deimling, & Bass, 1989) psychological resources of coping and satisfaction with available support were also considered.

Chapter 5 reports on a prospective follow-up study with a cohort of participants from the study reported in Chapter 4 (Physical and psychological health of family carers co-residing with an adult relative with ID). Using the Placement

Tendency Index (PTI, Blacher, 1990; Blacher & Hanneman, 1993) this study examines changes in the placement tendencies of families of adults with ID (N = 75) over a 12 month period. An examination of adult relative and family factors assessed at time 1 are explored in multiple regression analyses to examine associations with subsequent changes in families' placement thinking and behaviours. To our knowledge, this is the first study to examine the dynamics of placement tendencies of families of adults in a UK context.

Chapter 6 forms a general discussion chapter for this thesis, which summarises and discusses implications of the findings of the four studies. Directions for future research are also discussed.

Chapter 2: *"You never reach the end of the process":* Families' Experiences of Seeking Out-of-home Accommodation for their Adult Child with an Intellectual Disability

Orientation Chapter

We undertook this study to explore the first-hand experiences of families as they negotiated the process of seeking out-of-home accommodation for their adult son or daughter with ID. Much of the research around accommodation for adults with ID has focused on factors influencing families' decisions to place their adult child out-of-home, waiting list use or placement tendencies (Blacher, 1990; Balcher & Hanneman, 1993; Essex, Seltzer, & Krauss, 1997; Freedman, Krauss, & Seltzer, 1997; McConkey, Kelly, Mannan, & Craig, 2011; Seltzer, Greenburg, Krauss, & Hong, 1997; Taggart et al., 2012). To our knowledge this is the first study to explore direct ongoing experiences as families were seeking out-of-home accommodation for their adult child in Wales.

As little is known about families' experiences of this latter part of the placement process, an a priori design was thought inappropriate. Therefore a qualitative design using a semi-structured interview schedule with open ended questions to guide interviews was adopted. This enabled parents to talk freely about their experiences of the housing system in Wales without the constraint of a structured questionnaire.

The aim was to speak with family carers across different local government areas of Wales in order to avoid a narrow focus on the housing processes operating in one local government area only.

Thematic analysis allowed us to explore themes implicit in the raw data without the need for a pre-existing theoretical framework (Braun & Clarke, 2006).

Abstract

Research exploring the experiences of families during the process of seeking out-of-home accommodation for an adult son or daughter with intellectual disabilities is scarce.

Methods: Nine families currently seeking out-of-home accommodation for their adult son or daughter were interviewed. Interview data were analysed using thematic analysis.

Results: Two main themes were identified: 1) Moving on: reasons for seeking housing: 2) A long road: experiences of seeking housing. Parents' aging and increased health problems along with the offspring's wish for greater independence were the main reasons for seeking out-of home accommodation. The experience of looking for a house was not straightforward. Parents wanted to plan ahead, but were prevented from doing so as the housing system prioritises housing crises.

Conclusion: Families currently experience seeking housing as stressful and frustrating. Parents would like to see social care and housing professionals acknowledging them as collaborative partners in the process. There also needs to be greater clarity of expectation of the duration of finding suitable accommodation: a process that needs to be started early in a young adult's life.

Key Words: Families, adults, intellectual disabilities, out-of-home placement, qualitative research, social care, housing

In many countries, there has been an increasing policy focus on the right of adults with an intellectual disability (ID) to live independently in the community and the right to choose where and with whom to live (Department of Health, 2001; United Nations, 2006; Welsh Assembly Government, 2007). In practice, even though the age for leaving home for the general population has increased as a result of prolonged economic difficulties impacting on cultural norms (Aassve, Arpino, & Billari, 2013; Cobb-Clark, 2008; Mitchell, 2000), adults with ID are still more likely to remain longer in their family homes well into middle age, with increasingly elderly parents (Bibby, 2012; Bowey & McGlaughlin, 2005, 2007; Cuskelly, 2006; Dillenburger & McKerr, 2010; Heller, 2008; Heller, Caldwell, & Factor, 2007; Seltzer & Krauss, 2001; Shaw, Cartwright, & Craig, 2011; Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012). A lack of available community housing has been put forward as one of the reasons contributing to this continued reliance on family accommodation (Department of Health, 2011; Mansell, Beadle-Brown, Skidmore, Whelton, & Hutchinson, 2006).

Improvements in health care have led to an increased life expectancy of people with ID with many outliving their parents (Yen, Lin, & Chiu, 2013; Heller, 2008; Heller & Caldwell, 2006; Weeks, Nilsson, Bryanton, & Kozma, 2009). This increased longevity means that parents can no longer be expected to assume a care role for the duration of their child's life. Services will likely need to provide input at some point in the lives of these vulnerable adults.

Existing research suggests that some families defer making long term accommodation plans due to concerns about future care and well-being (Bibby, 2012; Mansell & Wilson, 2010; Prosser, 1997) and the stressful and emotional nature involved in making such plans (Bigby, 1996; Heller & Factor, 1991; Taggart et al., 2012). Many parents prefer to continue caring for their son or daughter in their family home for as long as possible (Bigby, 1996;

Chou, Lee, Lin, Kröger, & Chang, 2009; Prosser, 1997; Taggart et al., 2012). Factors likely to increase future planning behaviour and hasten the end of co-residency include poor functional skills and the presence of maladaptive behaviours for the adult with ID, and caregivers' health problems, age, financial worries, single carer status, caregiver burden and the use of respite care and formal services (Bigby, 1996; Essex, Seltzer, & Krauss, 1997; Freedman, Krauss, & Seltzer, 1997; Heller & Factor, 1991; McConkey, Kelly, Mannan, & Craig, 2011; Seltzer, Greenburg, Krauss, & Hong, 1997; Taggart et al., 2012). Socio-economic status has also been found to be a factor related to parents' decision to make future plans, with higher socio-economic status being associated with increased likelihood of parents making financial plans for their son or daughter's future (Freedman, Krauss, & Seltzer, 1997). Greater involvement with specialist disability services seemed to contribute to parents actively making comprehensive plans (Bigby, 1996; Essex et al, 1997). Parents who have greater optimism and higher hope for their child's future are most likely to have made plans (Freedman et al., 1997). In a qualitative study exploring the nature and effectiveness of parental planning for the future of adults with ID, Bigby (1996) identified four types of plans or arrangements which parents were likely to make for their son or daughter with an ID. These comprised 1) implicit key person succession plans, 2) explicit key person succession plan, 3) financial plans and 4) residential plans. Implicit key person succession plans were characterised by parents' unspoken expectations of the future role other relatives, usually siblings, would assume once they were no longer able to continue their care role. Explicit key person succession plans involved the same expectations, but are more formal and usually written into a document such as a financial plan or will. Implicit plans were most common and a way of ensuring future advocacy and support for relatives with ID. Whilst advocating the advantages of these key person plans, Bigby acknowledges a need to prioritise formal service support for families who do not have extended support networks.

In a large scale, longitudinal study using both qualitative and quantitative analyses Essex et al., (1997) explored predictors of waiting list use and placement by families of adults with ID. They identified three distinct profiles for families' reasons for waiting list use and out-of-home placement: 1) Normative placements, whereby families viewed placement as a normal launching process not dissimilar to that observed in the general population. Fewer than 18% of the study sub-sample (N = 67) who had placed their son or daughter during the study period, could be categorised in the normative placement category. 2) Non-normative placement, where placement decisions are driven by unplanned circumstances such as a parent's failing health, age related changes in adult son or daughters' health/behaviour which have resulted in new caregiver challengers, or the death of a parent. Almost 80% of families from the sub-sample sought placements for 'non-normative' reasons. 3) Anticipatory planning, where parents proactively take steps to ensure a secure future placement for their son or daughter, with the aim of avoiding crisis placement. Just over 30% of families from within the non-normative sub-sample were identified under this profile. These families have often postponed launching until later life.

Considering the range of factors associated with the decision to seek an out-of-home placement, it is clear that this is a dynamic, multidimensional and complex process. Blacher (1990) proposed six sequential stages that relate to parents' behavioural intentions to place a child out-of home. These stages run from 1, 'never having considered a placement', to 6, 'son or daughter has 'been placed' or 'acquired accommodation'. In constructing a scale to measure these intentions (Placement Tendency Index/PTI: Blacher, 1990, Table 2.2), Blacher reported a stage in decision making which, once reached, parents did not tend to go back from. She proposed that once parents had reached the enquiry stage (score 4 on the PTI) or beyond, initiated paperwork (score 5), a placement would tend to take place at some point thereafter. Blacher (1990) states that actual placement may occur several years subsequent to

parents initiating action. However, parents' commitment to seeking out-of-home accommodation does not tend to diminish once they have reached these latter stages of the placement thinking.

Specific aims

Whilst a large body of literature exists exploring factors associated with placement decisions and relinquishment of care for adults and children with ID (Bigby, 1996; Blacher, 1990; Essex et al., 1997; Freedman et al., 1997; Heller & Factor, 1991; Llewellyn, Dunn, Fante, Turnbull, & Grace, 1999, Llewellyn, McConnell, Thompson, & Whybow, 2005; McConkey et al., 2011; Seltzer et al., 1997; Taggart et al., 2012), fewer studies have focused on experiences of families undertaking the latter stages of the placement process. Studies have largely focused on children and adolescent populations (Blacher, 1990, Blacher & Hanneman, 1993; Hanneman & Blacher, 1998; Hostyn & Maes, 2007; Llewellyn et al., 1999; Llewellyn et al., 2005; Mirfin-Veitch, Bray, & Ross, 2003), are retrospective in nature (Mirfin-Veitch et al., 2003), or do not directly involve families (Nankervis, Rosewarne, & Vassos, 2011). Qualitative research methods have only very rarely been applied to understand the relinquishment of care and housing placement of adults with ID by their parents (Alborz, 2003; Vassos, Nankervis, & Rosewarne, 2012; Werner, Edwards, & Baum, 2009). The aim of the current study was, therefore, to adopt a qualitative design to gain a better understanding of the dynamics of the latter stages of the placement process within families who were actively seeking out-of-home accommodation for an adult son or daughter currently living in the family home. We focused on families living in Wales, a small country within the United Kingdom where responsibility for housing and social care is devolved from the UK Government (Welsh Assembly Government, 1998, 2006).

Method

Participants

The nine families who participated in the study lived across six local government areas throughout Wales. Nine primary caregivers were interviewed, eight mothers and one father. In one family, both parents took part in the interview together. Families lived in rural, semi-rural and suburban areas of larger cities, with two families living in small towns. All families were white British in ethnicity. Parents' age ranged from 52 to 70 years (M = 57.2 years, SD = 7.91), whilst adult sons' and daughters' ages ranged from 18 to 38 years (M = 24.44 years, SD = 6.11). Whilst not a criterion for the research, all families were two parent families and were all at the same stage of having placed their adult son or daughter's name on local government and housing association waiting lists for placement outside of the home. Further demographic information (Appendix 4) about these families is summarised in Table 2.1. All names are pseudonyms.

Table 2.1: Family demographic information

Parent(s)	Parent's age in years	Son or daughter	Son/ daughter's age in years	Son/daughter's Diagnosis	Location of family home	Reported duration on housing waiting list
Susan	52	Debbie	22	Down Syndrome	Rural	2-3 years
Laura	47	Mandy	18	Autistic Spectrum Disorder with ID and mental health difficulties	Suburban	1 year
Linda and Stephen	Mother - 65 Father - 70	Sophie	38	Cerebral Palsy & mild ID	Rural	2-3 years
Jane	57	Ben	29	Moderate ID	Semi-rural	2-3 years
Claire	46	John	20	Profound ID & physical disabilities	Suburban	3 years
Ann	53	Ashley	25	Profound ID & physical disabilities	Suburban	6 years
Alison	59	Lucy	21	Down syndrome	Rural	2 years
Tony	65	David	21	Autistic Spectrum Disorder with ID	Town	5 years
Liz	58	Mike	26	Mild ID	Town	5 months

Measures

A semi-structured interview schedule (Appendix 5) was developed as a guiding framework for parents to discuss their experiences of seeking housing, to explore what factors led to the decision to seek alternative accommodation and to discuss any support received to assist in this quest. The interview schedule was developed ensuring questions were open-ended and wording was kept neutral so as not to influence parents' responses. Questions which required 'yes/no' answers and which made assumptions or appeared to draw conclusions about participants' experiences were also avoided (e.g. 'How do you feel services listened?' was used in favour of 'Did you feel services listened?'). Parents were asked to evaluate their overall experiences of seeking accommodation, their experiences of service support and how they envisaged their families' future once their son or daughter had acquired accommodation. Questions were open-ended to allow an in-depth exploration of parents' experiences with follow up or prompts to optimise responses and ensure parents were kept on track and the same topics were covered with all parents.

The Placement Tendency Index (PTI, Blacher, 1990; Blacher & Hanneman, 1993; Hanneman & Blacher, 1998) (Appendix 6) was used to ensure all families matched the criteria for placement thinking (stage 5, initiated paper work) for recruitment into the present study. The PTI is a single-item measure with a six-point response. The response points are hierarchical, and, theoretically, parents cannot jump points without having at some time passed through earlier points on the scale (Blacher, 1990). The PTI score was originally designed to predict parents' thinking of placement of their child out-of-home (Blacher, 1990; Blacher & Hanneman, 1993; Hanneman & Blacher, 1998). Parents were instructed to '*Circle <u>one</u> of the numbers next to the statements below which indicate your current thinking on finding a place (housing) for your son or daughter to live outside of the family home'*. We made some amendments to the PTI to take account of the local context (see Table 2.2).

Table 2.2: Placement Tendency Index (adapted from Blacher, 1990)

Score	Item
1	No, we have never thought about it.
2	Occasionally we have given it a thought.
3	Yes, we have thought a lot about it, but have done nothing about it.
4	We have thought about it and made enquiries. We have talked with the Local Authority/ housing association/local voluntary organisation (or other organisation/agency) but we have not done anything yet.
5	We have started to put into action the process (including any paperwork) of finding accommodation for our son/daughter.
6	Our son/daughter has moved out of our home.

All parents taking part in the current study were at stage 5 on the PTI which, according to Blacher (1990), signifies a placement was highly likely to occur at some point in the near future. Thus, all families shared the experiences of having made a decision to seek placement outside of the home and waiting for that decision to be enacted by services.

Procedure

The research was approved by the University's Research Governance and Ethics Committee. Recruitment of families was facilitated by local government adult intellectual disability teams and voluntary organisations. These organisations were asked to send an information pack (Appendices 1 to 3, English and Welsh language versions) to families who were registered on local Government or housing association registers as requiring housing for their adult son or daughter with ID. Inclusion criteria were: 1) All families were required to have an adult son or daughter (aged 18 years or above) with ID who was living in the family home at the time of the study, and 2) had registered their names with a housing provider as requiring out-of-home accommodation (stage 5 of the PTI, Blacher, 1990). Upon receipt of consent forms (Appendix 3a and 3b) via surface mail, the researcher contacted families to

arrange interviews. All interviews took place face-to-face and were recorded for transcribing. Interview times averaged 90 minutes in duration. The longest interview was over three hours, and the shortest was forty five minutes.

Data Analysis

Interviews were audio recorded using a digital recorder and transcribed verbatim by the first author who was responsible for conducting all interviews. Extensive hand written notes were also taken during interview. Data were coded manually and analysed using thematic analysis (Braun & Clarke, 2006). Thematic analysis is a flexible method which can be used to identify patterns within data without a pre-existing theoretical framework (Braun & Clarke, 2006). An inductive or 'bottom up' approach was adopted to identify themes emerging from the data (Boyatzis, 1998; Braun & Clarke, 2006). Initially the principal researcher read and re-read each transcribed interview line by line to systematically identify interesting and relevant information embedded within the data. Themes emerging from the data relevant to the subject under investigation were coded. Preliminary notes were made in the margins of each script during each reading and a theme table constructed for each interview (see Appendix 7 for initial theme table for family 01), identifying and describing relevant sections of data (see Tables 2.3a and 2.3b for an example theme table). Themes were subsequently grouped through analysis of each interview script and a coding framework devised for the complete dataset (Braun & Clarke, 2006). To reduce bias, two manuscripts were separately analysed in the same manner by the second author, and a triangulation process occurred. Investigator triangulation involves using more than one data analyst in the analysis process. Emerging themes were then discussed and compared by the authors. This process ensures greater exploration of the data and increases both validity and reliability of resulting themes (Banik, 1993; Denzin, 1970).

Table 2.3a: Initial coding framework for interview 07 with mother of a 21 year old woman with Down syndrome

Themes/subthemes and accompanying notation	Page of interview script	Quote demonstrating theme
1) Factors associated with decision to seek out-of-home accommodation		
1.1 Increasing difficulty with care role		
Behaviour becoming increasingly challenging as daughter develops into adulthood	3	There have been one or two issues with Kirsty with regard to her behaviour.
Parent's age influencing factor in seeking out-of-home accommodation	9	My husband is 73 this year and a very capable and healthy 73 year old, but he is older.
Sandwich care role influencing decision	10	Plus the fact that I have an elderly mother, 15 minutes away who is getting more dependent.
1.2 Freedom from responsibilities of care role		
Parent prolonged respite from care role during daughter's attendance at residential college	9	I just think that while she was at college it was easier for us. I suppose from our point of view we had more freedom and it was, not that you ever get rid of the responsibility, but the day to day, there's no doubt that it does bring stresses when you've got a child with learning difficulties and they are not there. So you relax more. I think it will be easier for us. Finding appropriate accommodation where she'd be safe, it would be a weight off us.
1.3 Self-determination of individual with ID		
College preparation for independent living.	1	It started when Kirsty went to residential college. The idea with these colleges for young people with ID is to prepare them for independent living.
Return to family home, curtailing daughter's independence.	8	She had that level of independence and she wanted to continue to be so but she'd moved back into the home, where there are restrictions of a home.

Table 2.3b: Initial coding framework for interview 07 with mother of a 21 year old woman with Down syndrome (contd.)

Themes/subthemes and accompanying notation	Page of interview script	Quote demonstrating theme
2) Experiences of housing system		
2.1 The 'maze' of the housing system		
Desire for 'key person' to help parents negotiate complex transition system	15	When you start going through transition you almost need a carer contact who is going to just be your point of liaison, who is going to, not to spoon feed you, but just to say to you, "are you aware of this?" This needs to happen or that needs to happen. Or this potentially needs to happen. To help you be aware of where to tap into information. But again that's probably me in my ideal world.
Parent's perceived lack of available information and guidance	14	I think what partly has frustrated me is that with regarding independent living, you've got Social Services but that's it really. There should be a way of getting you information I think on independent living. Maybe they don't know and that's what the problem is. But what possibly could be available, what is available. Looking at regard to independent living it's like banging your head against a brick wall actually getting any other information that's available for independent living.
2.2 Disillusion with housing system		
2.3 Obstacles to gaining suitable housing		
Lack of available housing preventing successful transition from family home.	2	The biggest issue that we can see is that there is nothing available. There was nothing available that was suitable. Well, not just suitable, there was nothing available.
2.4 Cycle of gaining placement		
Continuous offer of inappropriate properties	2	So now we are back to the position where there was a property with a lady in it, but the lady is in her 50s. Then there was another property (…) with a man in his 40s. It was not appropriate at all. We are back to the drawing board really.
Getting right balance of accepting offers on behalf of daughter, emotionally traumatic	15	But I honestly say that this period over the last few years is the most traumatic and the hardest. Because it's getting a balance between being her carer and making decision for her and wanting things right for her. But allowing her to be part of that process and allowing her to be independent.

The first stage of analysis resulted in a table of developed themes for each interview, which were then subsequently examined for recurring and contrasting themes across all interviews (Braun & Clarke, 2006). Finally, a table of 'master themes' incorporating all interviews was constructed (see Table 2.4). The second author undertook analysis of the identified master themes and supporting data for consistency and agreement. Where researchers disagreed on themes, a discussion was had with close reference to the raw data, and themes were subsequently revised until agreement was reached. Disagreements about the data happened very rarely, and the researchers were largely congruent throughout the analysis. This discussion and re-analysis process continued during all stages and throughout the writing of this paper, until all researchers were satisfied with the final themes.

Results

Two main themes and six sub-themes emerged from the thematic analysis (see Table 2.4).

Table 2.4: An example of a table of master themes and sub-themes

Master theme	Subtheme	Supporting quotes
Moving on: reasons for seeking housing	Parents' decreasing ability to cope at home	'He's now 6'5" and has epileptic seizures which are increasing in severity. He has severe autism which leads to challenging behaviours.' (p.9 – interview script).
	Parents' desire for a life outside of their care role	'I actually discovered a life of my own when she was away at college and it was quite hard having her back home.' (p.10 - interview script).
	A taste of independence: perceived aspirations of offspring	'If Debbie hadn't been away to college we might not be as keen to get her out of the house and living independently. But she's had a taste of it and it's what she wants.' (p.11- interview script).
A long road: experiences of seeking housing	Parents' expectations of process versus experienced reality	'I think possibly we were very naïve. Possibly we were just very optimistic. But somehow we thought all of this would just happen. That somebody, somewhere was making plans and taking care of it [post college-accommodation].' (p.12).
	Increasing disillusion with the housing system.	'You believe in the services, you can't distrust them from the start.' (p.14).
	Families in stasis: Obstacles to gaining suitable housing	'She's not priority one, but two or three. But you'd think she'd move up the priority list, when there are less emergency cases, but that never seems to happen.' (p.14).
	On-going cycle of accommodation offers.	'They offered another plot [of land]. Again it was sub-standard, it was terrible. Right by the side of a motorway, they had to have triple glazing. Nowhere to take him out in the wheelchair. Again I had to turn it down.' (p.15).

Theme 1. Moving on: reasons for seeking housing

Two broad categories of driving factors for seeking out-of-home accommodation for an adult son or daughter with intellectual disabilities were identified. 1) *Parent factors* which related to the impact upon parents of caring for an adult son or daughter, including both physical and psychological time demands. 2) *Child factors* which related to parents' perceptions about what their children's desired for their own futures.

1.1 Parents' decreasing ability to cope at home. An inability to cope at home with their son or daughter was the main reason parents cited for seeking alternative accommodation for their children. Parents spoke of their support role as occupying the majority of their time and how caregiving became increasingly difficult as their son or daughter became physically bigger and heavier as an adult. Although this was identified by all families, three parents had additional difficulties as their son or daughter's high physical health needs and/or behaviour difficulties became more severe as their offspring got older. As Toni, the father of a 21 year old man told us, "*He's now 6'5" and has epileptic seizures which are increasing in severity. He has severe autism which leads to challenging behaviours. (…) I'm his paid carer but he needs two-to-one support care."* The increased demands of caregiving co-occurred with the parents' advancing age. The primary caregivers' ages ranged from mid-forties to mid-sixties, and three of their spouses were over 70 years of age. Parents were, therefore, experiencing increased difficulties in their care role in the context of their own and their partners' ageing, lower energy levels and associated health difficulties. Claire, the mother of a son with profound disabilities explained, *"He's getting bigger, getting heavier, he practically needs two-to-one [support] all the time. He does. I mean I'm getting older, but we are all getting older*." Parents were aware that their own age-related health difficulties were factors that increased their motivation to seek out-of-home accommodation, and five families questioned their own ability to continue providing full time

care of their son or daughter. Steve described his concerns for his daughter's future accommodation as, *"A worry, the idea gets less of a priority for Sophie [daughter] but more of a priority for us. I'm hobbling around the place [after hip replacement surgery]*.

1.2 Carers' needs: parents' desire for a life outside of their care role. The all-consuming nature of providing on-going support to a son or daughter with high support needs meant parents did not have time to pursue their own interests. Parents spoke of their own need for *"a life outside of their {offspring} and {their} caring duties"[Toni]*. Two mothers whose daughters had attended residential college, had experienced a three year break from their full-time care role and found it difficult to relinquish this freedom to resume full-time care upon their daughters' return to the family home, as Susan told us how she, *"Actually discovered a life of my own when she was away at college and it was quite hard having her back at home. (…) Carers do have needs as well."* Parents referred to how their care role could be *"mentally very, very wearing."* They spoke of how, once their son or daughter was settled in out-of-home accommodation, they would have greater freedom to fulfil relationships with other family members. Jane told of how her and her husband would, "*Have a lot more freedom to do the things that we have wanted to do."* Ann spoke of how gaining a supported living place for her son would have a major impact on the lives of her entire family. She recalled a frequent dialogue with her grandchildren, *"Even my grandchildren, say, "Nana can we do this?", but it's always [Ann says]: "No, I can't because of your uncle". It's all about putting him first still. You still have to and it would be strange not to. If it ever happens, it would be strange not to and be able to say "Yes, I can do that". Not, [grandchildren say]:"Can you come to Guides or Brownies?", [Ann says] "No, I can't". Or I have to be home by a certain time. So supported living will have a huge impact on our lives."*

1.2 A taste of independence: perceived aspirations of offspring. Parents spoke of their own belief that their son or daughter desired greater independence. Several parents talked of observing behaviour which they believed was a striving for self-determination as their son or daughter developed into adulthood. This was most evident for parents of individuals with milder ID where they were able to experience greater independence from the parent-child dyad. Three daughters had attended residential college with two completing a full three year college programme. Both of these young women's mothers spoke at length about their daughters' positive experiences of residential college and that their daughters had expressed a wish to move out of the family home and become more independent, which was fully supported by their parents. As one mother put it "*If Debbie [daughter] hadn't been away to college we might not be as keen to get her out of the house and living independently. But she's had a taste of it and it's what she wants. (…)She does want to live independently. I ask her from time to time."*

These mothers also spoke of how their daughters had experienced college in a similar way to non-disabled peers, and both had become involved in romantic relationships while living away. Susan spoke of how she had always tried to keep her daughter "*on some sort of level with her [non-disabled] sister",* and how both sisters would compare their experiences of being away at college and even talk about their own '*independent living'* arrangements together. Susan felt this enabled her daughter to develop similar aspiration of her own future independence in line with her sister and other non-disabled peers, as she recalled, "*So she was comparing notes with her sister really. Having seen her sister in her house (…) it just became something that she could relate to (…) and I think she does imagine herself living by herself."* Tony, whose son has severe autism and ID felt that, whilst his son had not explicitly demonstrated a desire for greater independence, he would benefit from living with peers, "*We*

are aware that he needs something more than we can give. He needs to be in the company of others like him."

Theme 2. A long road: experiences of seeking housing

All families spoke of the process of gaining appropriate housing for their adult son or daughter as a very long process. On average, families had been on a housing waiting list for between two and three years, with two families waiting to gain appropriate housing in excess of five years. With the exception of one family who had recently initiated the process of seeking alternative accommodation, the majority of families reported progression towards their goal as taking a lot longer than they had expected when starting the process.

2.1 Parents' expectations versus experienced reality. All nine families spoke of the experience of finding accommodation as being far more difficult than they anticipated. Parents used words to describe their past selves such as *'optimistic'* and *'naïve',* in their expectation of finding suitable out-of-home accommodation for their adult children with relative ease. As one mother recalled, "*I think possibly we were very naïve. Possibly we were just very optimistic. But somehow we thought that all of this would just happen. That somebody, somewhere was making plans and taking care of it [post college-accommodation]."*

When commencing the process of looking for alternative accommodation, five families reported that staff at adult ID services had given them the impression that finding appropriate accommodation would not be a difficult or long process. Linda told us how, *"The community learning [intellectual] disability people have always given us the notion that finding a place for Sophie [daughter] would not be difficult. But apart from one [inappropriate] offer, there's been nothing."* Susan spoke of her belief that because her daughter had attended residential college, that she had entered a social care system whereby plans for future post-college accommodation would be '*taken care of*'' on behalf of the

family. This aspiration was chiefly influenced by the [service providers'] large financial investment towards the development of her daughter's independent living skills during her three years at residential college, and she assumed that services would automatically provide a placement where these skills could be utilised. *"I know that the costs were tens of thousands of pounds a year [residential college]. It was a significant investment, we thought in Debbie's [daughter] future. An independent future is what we saw for her."* Families did not believe they had been deliberately misled into thinking that it was going to be a smooth process, rather they were aware that they had made this assumption, guided by their own 'optimism', and, for some, by positive experiences of residential college.

2.2 Increasing disillusion with the housing system. All nine families referred to communication with social services and housing staff as being the most frustrating part of the process, as getting information was like '*banging your head against a wall'*, and that while professional staff appear to listen during meetings, the lack of follow up action made parents question whether their opinions were taken into account, as Laura recounted, *"I suppose we are not really being listened to either. Listening maybe but not hearing because they've not come back to me on the points or requests I've made. So I suppose really they are not listening."* One father felt that the failings operated at a systematic level as staff within the local government were continuously '*shuffled around'* into different jobs and there were a limited number of personnel dealing with families' cases. Steve re-enacted a typical telephone conversation with staff at social services, "*You 'phone up and say, "Can I speak to whoever?". [Staff member says] "No, they are on holiday." [I say] "Is there anybody else dealing with it [daughter's case]?" [Staff member says] "No, they are the only person dealing with it." [Steve] "So it stays in their in-tray until they come back. I usually get it thrown at me": [Staff member says] "You realise there are over 300 people with disabilities in the county and only a small group dealing with them."*

All nine parents made reference to a growing disenchantment and distrust of social service and housing department staff due to their difficulties in making progress with a housing application. Ann, who had first been approached by an adult ID team regarding out-of-home accommodation for her 26 year old son over six years ago, commented, "*You believe in the services, you can't distrust them from the start. I distrust them now."* Due to a build-up of distrust, parents had become disillusioned with the system. Claire spoke on behalf of herself and Ann, both seeking accommodation for their sons with profound disabilities, of their reluctance to engage with both social services and housing services staff in the future, *"I just do not want to even think about it [offer of second plot of land] because of what we've been through in the past [protracted negotiations with social services]."*

2.3 Families in stasis: obstacles to gaining suitable housing. At the time of the interviews, all families still had their son or daughter living at home, and none felt they were anywhere close to getting suitable accommodation. They partly attributed this to knowing their son or daughter was not a priority for the housing system. Parents observed that housing services were perpetually dealing with emergency housing requests, meaning that their own requests did not seem to be actively dealt with. Parents recognised that emergency housing needed to be a priority, whilst noting the lack of attention paid to families like themselves. Families who could cope, albeit in a situation which became increasingly difficult to maintain, and who wished to get housing sorted out now to prevent an emergency housing situation in the future, did not seem to rate as a priority for services. As Steve considered, *"She's not priority one, but two or three. But you'd think she'd move up the priority list, when there are less emergency cases, but that never seems to happen."* Parents spoke of feeling marginalised due to this lack of urgency and felt that whilst they had the resources to continue providing support in the family home, this disadvantaged them as they felt they were rated as an extremely low priority within the local authority housing system. Susan told

us, "*I just don't think there was any intention [by local authority] to give it [housing for daughter] any serious thought. I don't know if there is a sort of unspoken policy within the local authority either, but Debbie is from a 'good home' isn't she, we live in a big house. I'm sure there are people with greater needs in a sense."*

All families felt that looking for housing for their son or daughter was an exhausting process. The slow progress of finding suitable housing and perceived lack of support in achieving this aim gave them the feeling they had entered a state of '*limbo'.* Laura spoke of how major family plans were suspended due to the all-consuming nature of seeking housing for her daughter, *"We feel stranded. We are only renting this place. We are looking to buy a house. We've been looking over 6 months. You start looking, see something, but haven't got the energy to do so. When she's sorted we can take a step back and think now it's our turn, but at the moment it's chaos all around. It's very unsettling*."

Another barrier was the reported severe deficiency of available housing stock. This led to a lack of appropriate housing options for adults with intellectual disabilities, which lead to them: 1) not being made a priority for services, and/or 2) receiving offers of unsuitable housing. Seven families had received at least one offer of housing that they felt was inappropriate. One mother recalled the options offered to her 21- year-old daughter: *"So now we are back to the position where there was a property with a lady in it, but the lady is in her 50s. Then there was another property with a man in his 40s. It was not appropriate at all."*

2.4 On-going cycle of accommodation offers. Five families had received more than one offer of accommodation. These families all spoke of the same cyclical process whereby: 1) their son's or daughter's name was put on a housing waiting list, 2) they would subsequently receive an offer, sometimes after a long initial wait, 3) Parents carefully and thoroughly investigated these offers, and found them to be unsuitable, 4) Parents would then turn down these offers on grounds of safeguarding their sons or daughters, and were then

back to stage 1) the start of the process of waiting for an offer. Ann spoke of her six year wait within the housing system during which the family received multiple offers of inappropriate housing for her son with profound disabilities. She recalled the council identifying a plot of land upon which accommodation could be built, *"They offered another plot [of land]. Again it was sub-standard, it was terrible. Right by the side of a motorway, they had to have triple glazing. There would be nowhere to take him out in the wheelchair. Again I had to turn it down."* Ann went on to speak about how she felt staff at social services would adopt an officious attitude to families when offering accommodation, which concerned her that more vulnerable families may feel pressurised into accepting inappropriate housing for their son or daughter. She recalled a conversation with the manager of her adult learning (intellectual) disability service, *"[Manager said] "If you say no, I can assure you I can find, there are other families [locally] who will take your place." [Ann] That's not happened. So if we'd been, not weaker, but more desperate to have said yes, it could have gone ahead."*

Another phenomenon, reported by four parents, was local authorities' reluctance to provide full details of properties, including very basic details such as location, prior to parents' acceptance of offers. As well as being highly frustrating, parents felt this showed that staff knew that the housing they offered was unsuitable. As Claire highlighted, "*There's a long process before they will tell you where the plot is (….). If we hadn't gone down to the council to look at that file we wouldn't have known that the police were obviously concerned about putting the home there."* Ann, whose son had a placement identified for him in an area of high social deprivation, recalled reading a police report kept on the social services' file (but not disclosed to families by services) on the recommended security for the house. *"The police security report [kept on file at social services] when they went to do a survey of the place, seeing the plans, was, you know, pages and pages long. They had to put all these security measures in on this place now and if we hadn't gone down [to the offices of social*

services] we would have been totally unaware and we would only have the information that social services were willing to give us."

Families felt they had no option but to refuse inappropriate accommodation to safeguard their adult children, this was always done after much discussion and careful consideration. Getting the right balance of what was appropriate for both adult children and families was emotionally traumatic, as summed up by Alison, "*But I honestly say that this period over the last few years is the most traumatic and the hardest. Because it's getting a balance between being her carer and making decisions for her and wanting things right for her. But allowing her to be part of that process and allowing her to be independent."*

This cyclical process of continuous offers of inappropriate housing and subsequent moves back to a waiting list, left families feeling they had entered a system whereby progression was laborious and slow and within which they felt they were making no progress. This resulted in parents feeling cynical and unsupported, and left to cope at home with an adult child who was becoming increasingly difficult to care for.

Discussion

The reasons given by parents for seeking out-of-home accommodation for their adult son or daughter with ID included both parent and adult child factors. Parents described the physical and psychological strain of providing care for their child, who, during adulthood, had become bigger and heavier. These difficulties were made harder as parents themselves got older and reported health difficulties and lower energy levels. Parents also spoke of their own desire for a life outside of their caring role, with some desiring greater freedom to spend more time with other family members. Similar difficulties encountered by parents in providing care as they get older have been highlighted extensively in the literature on family carers of adult children with intellectual disabilities (Bigby, 1996; Bowey & McGlaughlin, 2007; McConkey et al., 2011; Prosser, 1997; Seltzer, 1992; Seltzer & Krauss, 1989; Shaw et

al., 2011; Taggart et al., 2012). However, the ambitions of parents to have an existence outside of their care role and the development of an identity other than that of carer have been highlighted less by research (Todd & Jones, 2005).

Parents believed as their children grew older that they were demonstrating their own need for greater independence and a wish to move out of the family home. This was particularly prominent in families where a son or daughter had milder intellectual disabilities. Although it is well documented that adults with ID living with their families would like greater independence and choice of where they live (Deguara, Jelassi, Micallef, & Callus, 2012; Gardner & Carran, 2005; Griffiths et al., 2006; McConkey, Sowney, Milligan, & Barr, 2004; McGlaughlin, Gorfin, & Saul, 2004; O'Rouke, Grey, Fuller, & McClean, 2004; Shaw et al., 2011), the present study suggests that parents share this wish with their children and would like them to move on with their lives independently. Families wanted the lives of their sons or daughters to follow a normative family life cycle, with offspring leaving the home as young adults, which has previously been identified within the placement literature (Essex et al., 1997). The perceived success of transition to adulthood (including acquiring out-of-home accommodation) for young people with ID has also been cited as an influencing factor of family well-being (Blacher, 2001).

Families, however, experienced a mismatch between rights and reality. Despite global policy recognising the rights of people with ID to exercise personal agency and become independent members of their own communities (United Nations, 2006), families found that the housing system did not appear to deliver on this promise. Families felt that because they were able to support their son or daughter at home and were not in 'crisis', they were viewed as low priority by housing services.

Parents also reported that the process of acquiring housing lacked openness and transparency. Families felt that both social service and housing staff withheld information

about offers of property which would make apparent the fact that the proposed housing solutions were not suitable. Parents felt that the social care and housing systems could only respond to urgent needs for emergency housing and were unable to cope with families who planned for the longer-term. These findings are supported by McConkey et al., (2011) who concluded that economic constraints within the health and social care system resulted in emergency cases having to be prioritised over less urgent cases, although these less urgent cases were still judged to require out-of-home housing.

Parents also spoke of difficult relationships with housing and social services staff. Accounts of conflict and a lack of empathy experienced by families from professional staff within the social care system are consistent with previous research where families spoke of having to fight for service provision on behalf of their offspring (Griffith et al., 2011; Nowak, Broberg, & Starke, 2013; Todd & Jones, 2003; Weeks et al., 2009). These negative relationships with service professionals experienced by families can prove stressful and have a damaging effect upon the family carers' self-esteem and wellbeing (Nowak et al., 2013; Sloper & Turner 1992; Summers et al., 2007; Todd & Jones, 2003). Previous research has reported how families value services that are comprehensive, informative, respectful, supportive and recognise them as partners in the decision making process (Jansen, van der Putten, & Vlaskamp, 2012).

Historical and more recent research has revealed a reluctance on behalf of parents to plan for the future care of a son or daughter with an ID (Heller & Factor, 1991; Taggart et al., 2012). In the present study, we identified parents who had already made the decision to move their adult child out of the family home and were engaged with services to make this happen. However, the lack of suitable and available housing stock resulted in a 'bottlenecking' of families within the housing system. Families experienced a slow cycle of unsuitable offers which they turned down due to concerns over their son or daughter's welfare, only to re-start

the process over again. Parents found this process stressful, time consuming, and wearing. The low priority afforded to families who have made plans for future housing should be of great concern to policy makers and housing commissioners, as the current housing system seems only suited to dealing with families who have reached an emergency housing situation. So, in many ways, parents are criticised if they do not make plans for their son or daughter's future, but unsupported by the system when they do take positive steps to seek independence for their offspring.

The methodological limitations which are present in this study are common to many qualitative research studies, in that only a small sample of parents were interviewed. This makes it difficult to know to what extent these findings can be generalised to a wider population of families of adults with intellectual disabilities. However, the original aim of the study was exploratory in nature, to gain an initial understanding of the experience of families seeking out-of-home accommodation. Future studies may also wish to explore the housing system from the perspective of housing and social care staff.

Another methodological limitation may result from the targeted sample being families who were already at the advanced stages of the placement process and all desired an out-of-home move for their adult son or daughter. The families' lack of success in acquiring a placement may be why families were critical of the housing system. Adopting a prospective design with follow-up, post placement interviews or using a comparative group who had already undergone transition, may address this issue. Another limitation was that member checking or participant verification was not conducted as part of quality control and data verification. Member checking is good practice and may have added to the reliability of the study so it may be useful to consider this in future research.

Whilst the current study may be narrow in its focus, it does provide an insight into the experiences of families as they try to negotiate the social care and housing systems when

seeking out-of-home accommodation for their adult son or daughter with an intellectual disability. Further, larger scale research is needed to explore the extent to which families experience difficulties in acquiring appropriate out-of-home accommodation for an adult son or daughter with IDs, and how difficulties within the housing and social care system in Wales and beyond can be addressed.

Implications for policy and practice

In terms of implications for practice, parents are a key part of the process of identifying suitable housing and they would like to see a more collaborative approach adopted by services. Services need to demonstrate greater openness and transparency when providing information and offering accommodation to families, as withholding information does not lead to the progression of achieving either families' or services' goal of acquiring a placement for service users. It does, however, result in families distrusting services. Adopting a more family centred approach with families of adults with ID may help develop partnerships between families and housing service providers (Bigby & Fyffe, 2012). This may in turn, help to address families' dissatisfaction with the current system and reduce the stress experienced by families undertaking the process of seeking accommodation for their adult offspring. A further simple improvement would be greater clarity for families in terms of expectations about the time taken to identify suitable accommodation and the way in which the process will work. Adopting a national register for adults with ID, similar to that established in the Republic of Ireland (The National Intellectual Disability Database, Health Research Board, 2014) may also aid planning of services for people with ID and assist with the strategic targeting of resources. Further research on the supply of residential accommodation for adults with ID would also seem expedient to address future housing needs and avoid unsuitable, crisis placements.

Chapter 3: Living at home: health and well-being of adults with an intellectual disability

Orientation chapter

The findings from study 1 suggest that families experience seeking housing for their adult relative with ID within the housing system in Wales as protracted, frustrating and stressful. These findings also suggest that there exists a severe shortage of appropriate housing for adults with ID in Wales. On the whole, the system is currently only best operating to address the needs of families in crisis and neglects the needs of families who undertake longer term plans for the future of their son or daughter with ID.

In the light of these findings we wished to examine the role of living circumstances in the perception of subjective health and well-being of adults with ID. Relatively few studies have sought the views of adults with ID about subjective phenomena.

Exploring data from a large national survey of adults with ID in England (Emerson, Malam, Davies, & Spencer, 2005), a secondary data analysis of subjective health and well-being of adults with varying levels of ID was undertaken. Potential confounding factors such as level of ID and reporting mode (i.e. independently or assisted by a carer), were accounted for in multiple regression models. Whilst Emerson and Hatton (2007, 2008), undertook two studies exploring factors associated with health and well-being their studies only reflect the views of people with mild or moderate ID who could self-report. The aim of this study was to include those with more severe ID.

Analysis of secondary data enabled the use of a large data set whilst overcoming the practicalities of having a limited budget and limited research personnel.

Abstract

Little is known about the role of living circumstances to the subjective health and well-being (SWB) of adults with intellectual disability (ID). The aim of the present study was to examine whether adults who live with family and those who live out of family homes perceive their health and well-being differently, and whether potential differences persist after accounting for other variables (e.g. participants' ability levels and reporting method).

Methods: Secondary data analysis was undertaken of a large national survey of adults with an ID in England, aged 16 years and over. Participants were identified as living with family (N = 1,528) or living out-of-home (N = 874).

Results: t-test and chi-square results revealed that people living with family reported higher levels of SWB and better health than those living in out-of-home settings. Multiple linear regression analyses, fitted to explore factors associated with these reported differences revealed that, when controlling for other variables, living with family was highly positively associated with reports of SWB. Multiple logistic regression revealed that whilst people living with family were more likely to report better health status than those living out-of-home, this was only true when their support needs were low. Poorest health outcomes were found for people with highest support needs who lived with family.

Conclusion: On the whole adults with ID living with family perceive their health and well-being more positively than those living out-of-home. However, potential health disparities exist for those with high support needs who live with family. Further longitudinal research is needed to explore causes and potential solution to these inequalities.

Key Words: Family homes, adults, intellectual disabilities, subjective health, subjective well-being

There are a variety of theoretical approaches to the conceptualisation of well-being (Bradburn, 1969; Kahneman, Diener, & Schwarz, 1999; Michalos, Zumbo, & Hubley, 2000; Diener & Lucas, 1999; Rogers, 1961; Ryan & Deci, 2001; Ryff & Keyes, 1995; Waterman, 1990). In common to most theories is that well-being is a core subjective phenomenon in the overall assessment of quality of life (Diener, 1984; Kahneman, Diener, & Schwarz, 1999, Rogers, 1961; Ryan & Deci, 2001; Ryff & Keyes, 1995; Schalock et al., 2005; Waterman, 1990) that cannot be measured as an outcome of an accumulation of social or material indicators alone (Diener & Suh, 1997). Individual perception and subjective evaluation of life circumstances, both past and present, are essential aspects to this conceptualization (Bradburn, 1969; Kahneman, Krueger, Schkade, Schwarz, & Stone, 2006).

The subjective assessment of health generally also relies on self-evaluative processes based on how people feel (Kaplan & Baron-Epel, 2003). Comparisons of past and present health states and comparisons with the health of other reference groups (Fienberg, Loftus, & Tanur, 1985), together with the degree to which disease impacts on daily functioning, are integral to this evaluation (Angner, Ghandhi, Purvis, Amante, & Allison, 2013; Deeming, 2013; Hunt et al., 1980). For example, Johnston, Propper and Shields (2007) explored correlations between the objective and subjective health status of people with hypertension and found that people with known physical health problems showed a greater propensity to subjectively report poor health status than those whose health problems were undiagnosed. Therefore, a person's perception of their own health status may impact on subjective well-being (SWB). In a study addressing determinants of SWB, people with very poor health were ten times more likely to report being unhappy than those with very good health (Deeming, 2013). However, high levels of quality of life have also been reported by

people with disabilities, even though their life conditions would be judged as undesirable using objective criteria and social conventions (Albrecht & Devlieger, 1999).

Characteristics of living environments as potential determinants of subjective health and SWB became increasingly important during, and subsequent to, the deinstitutionalisation of adults with ID (Cummins, Eckersley, Pallant, Van Vugt, & Misajon, 2003; Emerson, Llewellyn, Honey, & Kariuki, 2012; Heller, Miller, & Hsieh, 2002; Perry, Felce, Allen, & Meek, 2011; Stancliffe et al., 2007). Emerson and Hatton (1996) reviewed a large body of literature on the effects of deinstitutionalisation and concluded that living in the community was mostly associated with improved outcomes. Improved outcomes were evident when reviewing evidence from objective indicators, such as leisure or activity participation and social networks (Badia, Orgaz, Verdugo, Ullán, & Martínez, 2013; Duvdevany, 2008; Felce, Perry, & Kerr, 2011), but also using subjective assessments of life satisfaction (e.g., Schwartz & Rainovitz, 2003).

Whilst health and SWB have received research attention within the field of ID (Emerson & Hatton, 2007, 2008; Kozma, Mansell, & Beadle-Brown, 2009; Schalock et al., 2002; Seltzer & Krauss, 2001) relatively few studies have focused on adults living in family homes. Much of the interest in health and well-being of adults with ID stems from concerns with outcomes of health and social care expenditure and, therefore, has focused on community care provision (e.g., Mansell, Knapp, Beadle-Brown, & Beecham, 2007). Until fairly recently, much of the health and well-being research in the field of ID has focused on the well-being of family carers (Chou, Chiao, & Fu, 2011; Rowbotham, Cuskelly, & Carroll, 2011; Seltzer, Floyd, Song, Greenberg, & Hong, 2011; Yamaki, Hsieh, & Heller, 2009). Whilst still in the

relatively early stages, researchers have recently begun to adopt inclusive methodologies to engage people with ID as respondents about their own self-reported health, well-being (Emerson & Hatton, 2007, 2008) and quality of life (Meule et al., 2013).

Emerson and Hatton (2007, 2008) reported on a large scale study examining self-rated health and well-being of adults with IDs living in a variety of settings (i.e. private homes, residential care homes and supported living). Emerson and Hatton (2008) explored the correlates of five indicators of SWB, three of negative affect (feeling sad/worried, feeling left out and feeling helpless) and two of positive affect (happiness with life and feeling confident). They found an association between living in private households (mostly with family) and one negative indicator of well-being (feeling helpless). Living in residential care homes and supported living were associated with two indicators of increased positive well-being (happiness with life and feeling confident). However, associations with living context were not present after controlling for personal characteristics (age, gender, support needs, marital status), socio-economic position, social interactions and between-variable interactions. Differences in self-reported health status and well-being for people with different levels of support need were also evidenced (Emerson & Hatton, 2007). Having lower support needs was associated with feeling less helpless, whilst having higher support needs was associated with poor health status. Importantly, however, the Emerson and Hatton (2007, 2008) findings reflected only the views of people with mild or moderate ID who could self-report, because those who were unable to self-report and required the support of a proxy respondent were excluded from the data analyses. Therefore, the identified pattern of findings may not apply to people with more severe ID.

People tend to place value on the same things irrespective of whether they have ID or not (Cummins, 2001; Schalock et al., 2002). Accessing activities and support which promote positive health and well-being may, however, be significantly more difficult when living with an ID (Pinquart & Sörensen, 2000; Schalock et al., 2002). People with ID tend to be at greater risk of exposure to negative events such as discrimination, unemployment, ill health, lower socio-economic status (SES), than people without disabilities and may face greater challenges in maintaining well-being (Cummins, 2001; Emerson, 2011; Emerson & Hatton, 2007). Socio-economic status has proven a strong determinant of health and well-being both in the general population and for people with ID (Cummins, 2001; Emerson, 2011; Emerson & Hatton, 2007, 2008; Pearlin, Menaghan, Lieberman, & Mullan; 1981; Pinquart & Sorensen, 2000).

Differences in well-being between people with ID living with family and those living out-of-home (staffed homes or independent living) have been found using objective indicators of well-being such as participation and activity indices (Felce, Perry, & Kerr, 2011). Felce et al., (2011) found, after controlling for differences in personal characteristics, that living in staffed accommodation was significantly associated with greater participation in household activities, and greater variety and frequency of social and community activities. However, the Felce et al., (2011) study reported data provided by carers and not adults with ID themselves.

In the present study our main aim was to enhance our understanding of subjective health and well-being among people with an ID who do and do not live with their families. We used data from a large national survey of adults with an ID in England (Emerson, Malam, Davies, & Spencer, 2005). Our primary research questions were: (a) whether adults who live in the family home and those who live out

of the family home perceive their health and well-being differently, and (b) whether potential differences persist after accounting for participants' ability levels and reporting method (i.e. assisted/proxy or independent responding). The latter was deemed important as evidence suggests that reports of subjective well-being differ between proxy informants and individuals themselves (e.g. Perry & Felce, 2002). While the present study drew on the same database as Emerson and Hatton (2007, 2008), these earlier studies excluded participants who did not self-report. In the present study, we included information from participants of all ability levels, regardless of their reporting method (independently, or assisted by a carer).

We also paid close attention to putative control variables. Based on findings from previous studies, we expected differences in characteristics of adults with ID based on living circumstances. Adults living with family would likely be younger (e.g. Felce, Perry, & Kerr, 2011; McConkey, Kelly, Mannan, & Craig, 2011), have lower support needs (e.g. McConkey et al., 2011; Nankervis, Rosewarne, & Vassos, 2011), and experience fewer physical health problems (Martinez-Leal et al., 2011). Previous evidence indicated that these are all factors associated with better health and well-being. However, adults living in out-of-home settings may also have greater opportunity for participation in community activities and friendship networks (Kozma, Mansell, & Beadle-Brown, 2009), factors that are also associated with quality of life outcomes (Felce, Perry, & Kerr, 2011). Therefore, we made no overall directional hypothesis.

Method

The study is based on analysis of data from the English survey of adults with intellectual disabilities in England 2003-2004 (Emerson, Malam, Davies, & Spencer, 2005, obtained from UK Data Services, reference number 10.5255/UKDA-SN-5293-

1). The survey was commissioned by the UK Department of Health and is the only national survey of its kind in the UK. Participants were recruited using five sampling frames which included people living in private homes recruited using a random sampling technique, through weekly General Household Omnibus Surveys operated by a market research organisation (British Market Research Bureau Ltd) which took place between July 2003 and August 2004, and local government administrative records of adults with ID. A questionnaire was developed for researchers to assess criteria for inclusion of those not recruited via administrative records or other services (i.e., either the respondent or a household member was aged 16 or over and had a learning disability, for which an explanation was given. See user manual for full details, available from UK Data Service, link above). People living in registered residential care homes were recruited using a database provided by the National Care Standards Commission in the UK, (now known as The Care Quality Commission (CQC), an independent organisation responsible for the inspection and regulation of health and social care in England). People living in supported accommodation, funded through the Supporting People Programme (a government scheme for funding, planning and monitoring housing related support services in England), were recruited using a national database provided by the Office of the Deputy Prime Minister. Participants living in private households were initially screened for inclusion by questions asked of support persons. These questions established whether a person in the household was 16 years or older and had a diagnosis of ID during childhood (an IQ of less than 70, Schalock et al., 2010), as mentioned above. People who had dyspraxia or cerebral palsy without a concomitant ID were not included. Samples from local government social care registers, residential care and Supporting People samples were already established as having ID in that they had been assessed by these

organisations as meeting criteria to be in receipt of ID services. Initially 2,974 people recruited via the five sampling frames, were screened for entry to the original study. Initial exclusions resulted from further questioning revealing the absence of ID, being under 16 years of age, and academic achievement which was considered too high to constitute them having an ID. This yielded a final sample of 2,898 for the original dataset (Emerson et al., 2005).

Interviews were conducted by experienced staff using a Computer-Assisted Personal Interview (CAPI) method. Questions were designed at three levels of difficulty. Level one contained simply 'yes/no' questions which were accessible to the majority of respondents with ID. For example, "Do you ever feel sad or worried?". Level two questions were slightly more complex and included questions for which respondents may have required assistance. These comprised questions requiring responses at different levels. For example, "How do you feel about your life at the moment: Very happy, quite happy, sometimes happy/sometimes unhappy and mostly unhappy?". Level three questions were most complex, and were likely to be inaccessible to people with ID. For example, "Would you say X's accommodation is suitable for them given his/her needs?". Although these level 3 questions were kept to a minimum in the original interview, interviewers encouraged adults with ID to contribute to these questions where possible. Level 3 questions were not included as variables in the current study, because they were not answered by any people with an ID.

Wording on the questionnaires was flexible with pictorial prompts used to assist understanding. Response bias and acquiescence were addressed by four questions, three of which related to negative affect (feeling sad, left out and helpless) and one positive affect (feeling confident). Where answers seemed unlikely (i.e.

affirmative answers to all four questions), participants were excluded from the original study sample (final sample for the original study was 2,898 see above) (Emerson et al., 2005).

Participants

For the purposes of the present study, adults with an ID living with family included: 1) people living with parents, or 2) living with other family members. This yielded a total of *N* = 1,528 (63.4%) adults with ID living in family homes. Participants in out-of-home placements included those living: 1) in residential care homes, 2) supported accommodation, or 3) alone. This yielded a total of *N* = 879 (36.6%) adults with IDs living in out-of-home community settings. Of those, three participants stated they were living with a partner/spouse, and were thus re-allocated to 'living with partner/spouse' group and two participants were removed due to inconsistent responses across all living circumstances variables. This resulted in a final *N* = 874 (36.4%) people living in out-of-home community settings. People living out-of-home with a spouse or partner, including the three people re-allocated (*N* = 30 4.7%) and those in National Health Service-maintained long stay hospitals (*N* = 61, 2%) were not included in this study. The former were excluded because living with a spouse or partner was considered as a different stage in the family life cycle to residing in a parental or parental figure's homes (Carter & McGoldrick, 1989). The latter group was excluded due to the potentially temporary nature of this accommodation. Further exclusions included people who did not respond to accommodation questions (*N* = 5, 0.2%) and those whose answers were unclear (i.e., recorded 'unclear', *N* = 313, 11.1%). The final overall group identified for the current study was *N* = 2,403.

The sample analysed here included 1,423 (59.2%) men and 981 (40.8%) women. Participants' ages ranged from 16 years to 89 years (M = 33.47, SD = 15.03). Twenty six (1.1%) reported having Down syndrome, 36 (1.5%) cerebral palsy, 124 (5.2%) autism, 340 (14.1%) epilepsy and 281 (11.7%) sensory difficulties. Other physical health problems included physical disabilities, heart problems, bowel problems, diabetes and other physical health problems (N = 755, 31.4%). Table 3.1 shows a breakdown of participant characteristics according to whether the people with ID lived or did not live in a family setting.

The primary respondents were adults with ID. Respondents answered questions either entirely unassisted (N = 1,186, 49.4%) or with support (N = 1,217, 50.6%). Just over a quarter of respondents were interviewed alone (N = 611, 25.6%), with the remaining 75% interviewed in the presence of a support person (N = 1,792, 74.6%).

Table 3.1: The demographic characteristics of adults with ID who lived with their family and those who lived out-of-home

		Lives with family *N* (%), or mean (*SD*)	Lives outside family home *N* (%), or mean (*SD*)
		1,528 (63.6%)	874 (36.4%)
Gender	Male	943 (61.7%)	480 (54.9%)
	Female	586 (38.3%)	395 (45.1%)
Age:	16-25	774 (50.7%)	81 (9.2%)
	25-54	638 (41.8%)	502 (57.4%)
	55+	78 (5.1%)	182 (20.8%)
Has friends outside of family		1,186 (77.6%)	675 (77.1%)
Response mode:	Unassisted	711 (46.5%)	475 (54.3%)
	Assisted or proxy reported	817 (53.5%)	400 (45.7%)
Epilepsy		232 (15.2%)	108 (12.4%)
Autism		84 (5.5%)	40 (4.6%)
Down Syndrome		18 (1.2%)	8 (0.9%)
Cerebral Palsy		29 (1.9%)	7 (0.8%)
Sensory difficulties (hearing, sight, or both)		199 (13.0%)	82 (9.3%)
At least one health problem (e.g. physical impairment, diabetes, heart or bowel problems, other physical problems)		505 (33.0%)	251 (28.6%)
Support needs score (higher scores represent higher ability)		32.44 (8.11)	32.35 (8.16)
Hardship (No. of items goes without due to lack of money)		1.34 (2.21)	0.94 (1.97)
Frequency of community activities		4.77 (1.86)	4.89 (1.90)

Measures

Subjective well-being. Five indicators of subjective well-being, two of positive affect (rating of happiness and frequency feels confident) and three of negative affect (frequency feels sad or worried, feels left out, and feels helpless) were

identified as outcome variables. For uniformity with the four other well-being variables which were coded at three levels, 'happiness with life', which was originally coded at four levels (i.e. '1 = very happy, '2 = quite happy', '3 = sometimes happy/sometimes unhappy' and '4 = mostly unhappy') was converted into a three level variable by combining levels 1 and 2. Both the new 'happiness with life' variable and the variable for 'frequency feels confident' was reverse coded so that, in line with the remaining three well-being variables, the higher score of 3 ('very happy/confident') indicated more positive affect and 1 ('mostly unhappy/ unconfident') indicated more negative affect. The five indicators of well-being were then summed to create a composite well-being variable with scores ranging from 5 (low well-being) to 15 (high well-being). This composite measure had adequate internal consistency (Cronbach's $\alpha = .69$).

Subjective health status. Respondents were asked to rate their health on a three level scale '1 = very good', '2 = fairly good' and '3 = not good'. By combining levels 1 and 2, the original three level variable was collapsed into a binary coded dichotomous variable. This was then coded 0 = poor health and 1 = good health. Single-item questions on perceived health status have been shown to have good construct validity and reliability (DeSalvo et al., 2006).

Response mode (independently or with assistance/proxy). At the end of each interview section interviewers recorded whether questions were answered by the person with ID alone (coded 1 = mainly person with ID), by the person with ID with support (coded 2 = mixed), or by a proxy informant (coded 3 = mainly proxy). For the purpose of the present study, this three level variable was collapsed by combining levels 2 and 3 into a dichotomous variable coded '0 = mainly proxy and assisted interviews' and '1 = mainly person with ID (unassisted)'.

Support needs. The support needs of each participant were measured by 11 items which assessed how much help individuals needed to accomplish daily living tasks: 1) getting dressed in the morning, 2) putting on a pair of shoes, 3) having a shower or bath, 4) ordering something to eat or drink in a café, 5) drinking a cup of tea, 6) washing own clothes, 7) making a sandwich, 8) completing a form (e.g., for a job application), 9) finding out what's on TV that night, 10) paying money into a bank or Post Office, and 11) making an appointment (e.g., to see the doctor). Each item was measured on a 4-point scale originally coded '1 = Can do it on your own', '2 = Need a bit of help', '3 = Need a lot of help', '4 = Someone to do it for you'. Items were reversed coded and summed to create an index of support needs (possible score range 11 to 44), with higher scores indicating more ability or lower support needs. This index showed good levels of internal consistency for the study sample (Cronbach's $\alpha = .89$).

Socio-economic hardship. Hardship was measured by nine items derived from the Millennium Poverty and Social Exclusion Survey (Pantazis, Gorden, & Levitas, 2006). Items on this scale assessed the number of everyday items (e.g. food, new clothes and shoes, heating, telephoning friends and family, visits to the pub, cinema or a club, hobby or sport and holiday) individuals had to go without in the past year due to a lack of money. A single variable was created from a count of the number of items individuals had to do without. This variable achieved a range 0 (indicating people did not have to go without items) to 9 (maximum number of items had to go without during the past year).

Frequency of community activities. A nine-item scale assessed individuals' level of participation in community-based activities during the preceding month. Activities included: 1) going shopping, 2) going to the pub, 3) going for a meal in a

restaurant, pub or café, 4) visiting a public library, 5) playing sport or going swimming, 6) visiting friends and family, 7) going to the hairdressers, 8) watching sport (not on TV), and 9) going to the cinema, or to plays or concerts. A single variable was created from a count of the number of activities in which a person had participated during the previous month. This variable achieved a range of 0 (no activities) to 9 (maximum number of activities participated in during preceding month).

Social networks. Two variables indicating whether an individual had friends outside of the family (friends with an ID and without) were transformed into a single variable indicating whether or not the person had any friends outside of his/her own family ('yes/no').

Physical health conditions. In the survey, participants were asked whether they had a specific health problem or physical disability: 1) physical impairment, 2) heart problem, 3) bowel problem, 4) diabetes, and 5) other physical problems. Participants could respond 'yes' or 'no' to each of these five items. These five items were combined into a single variable indicating, '0 = no physical problems' and '1 = yes, at least one specific physical health problem'. Similarly, two separate variables indicating hearing and sight problems were combined into a single variable indicating: 0) 'no, does not have a sensory problem and 1) 'yes, has at least one sensory problem'.

Results

To address our first research question, we compared subjective health and well-being between people with an ID living in family homes and those living out-of-home. A significant *t*-test result ($t_{(1415)} = -4.94, p < .001$) indicated that people living with family reported higher levels of well-being ($M = 11.44$, $SD = 2.50$) than those

living in out-of-home settings (M = 10.79, SD = 3.38). The effect size for this difference was estimated as a standardised mean difference (using the pooled standard deviation, SD_{pooled} = 2.85) and was 0.23 (95% CI:0.14 to 0.31), indicating a small effect size. It should be noted that no significant between group differences were found for support needs between those living with family (M = 32.44, SD = 8.10) and those living in out-of-home settings (M = 32.35, SD = 8.15), ($t_{(1678)}$ = -0.26, p = .796).

Potential differences in subjective health status were examined in a chi-square association. A significant chi-square ($\chi^2_{(1, N = 2379)}$ = 8.15, p = .004) indicated that more people living in out-of-home settings reported poor health (just over 16%) compared to people living with family (12%; see Table 3.2). As a measure of effect size for this comparison, we estimated an odds ratio. This was 1.41 (95% CI 1.11 to 1.79) indicating that the odds of reporting poorer health are significantly higher when living out of the family home.

Table 3.2: Well-being and physical health status in the two groups of participants

	Total N	*Mean score for support needs (SD)*	*Mean score for well-being (SD)*	*Health*	
				Good	*Poor*
Living with family	1,528	32.44 (8.15)	11.44 (2.50)	88.0%	12.0%
Living in out-of-home	874	32.35 (8.10)	10.79 (3.38)	83.8%	16.2%

As a first step in addressing the second research question, we needed to identify potential covariates among the remaining demographic information. We initially focused on factors identified as important from previous research (e.g., Deeming, 2013, Emerson & Hatton, 2007, 2008), and subsequently narrowed down

the list by examining the bivariate associations between the study outcomes and personal characteristics (gender, age, socio-economic hardship), community participation, and health conditions. Where variables were both at interval level, Pearson's *r* correlations were fitted. Where variables were interval and categorical, point biserial correlations were fitted, and where both variables were categorical phi coefficients were estimated. Table 3.3 presents the correlation coefficients between the outcomes and potential covariates.

Table 3.3: Bivariate associations between participant demographic characteristics, physical health status and well-being

	Health	Well-being
Support Needs	**.069**[2]	**.177**[1]
	***p* = .001**	***p* < .001**
Unassisted interview response	**-.047**[3]	.039[2]
	***p* = .022**	*p* = .057
Age	**-.088**[2]	.002[1]
(16-89)	***p* < .001**	*p* = .918
Gender	-.037[3]	.032[2]
	p = .068	*p* = .123
Number of community activities	**.158**[2]	**.130**[1]
	***p* < .001**	***p* < .001**
Hardship	**-.174**[2]	**-.159**[1]
(Count of items goes without)	***p* < .001**	***p* < .001**
Has friends outside of family	**.103**[3]	**.163**[2]
(Yes/No)	***p* < .001**	***p* < .001**
Has illness/physical disability	**-.258**[3]	**-.123**[2]
(Yes/No)	***p* < .001**	***p* < .001**
Has sensory problems	**-.118**[3]	.004[2]
(Yes/No)	***p* < .001**	*p* = .832
Epilepsy	**-.108**[3]	.003[2]
(Yes/No)	***p* < .001**	*p* = .892
Autism	**-.046**[3]	-.034[2]
(Yes/No)	***p* = .025**	*p* = .101
Down syndrome	.030[3]	-.026[2]
(Yes/No)	*p* = .146	*p* = .206

[1] Pearson's r correlation coefficient , [2] r_{pb} correlation coefficient, [3] Φ correlation coefficient

There was a significant correlation between support needs and response mode (r_{pb} = .55, p < .001), suggesting that people with lower support needs (i.e. people with higher levels of general ability), would be more likely to report independently. This finding, in addition to previous research demonstrating little relationship between proxy and self-reports of subjective phenomena (e.g., Perry & Felce, 2002), suggested we also needed to account for response mode. Research also suggests that people with a higher level of disability may be more likely to live outside the family home (e.g., Borthwick-Duffy, Eyman, & White, 1987; Lowe, Felce, Perry, Baxter, & Jones, 1998). We, therefore, accounted for the potential interaction between support needs and living circumstances, due to the propensity for support needs to guide decisions on residential status, (Blacher, 1990; Blacher & Baker, 1994; Lowe et al., 1998, Nankervis et al., 2011).

As shown in Table 3.3, support needs, community activities and having friends outside of the family were all significantly positively associated with both subjective health and well-being. This suggests that having lower support needs, taking part in a greater number of community activities, and having friends outside of the family were all significantly associated with reports of better subjective health and well-being. Hardship and having an illness/physical impairment were significantly negatively associated with both outcomes, suggesting that greater hardship and/or an illness/physical disability were associated with poorer subjective health and well-being. Interview response mode, age, sensory problems, epilepsy and autism were all significantly negatively associated with health, but not SWB. This suggested that unassisted respondents were more likely to report poorer health outcomes. Older people, those with sensory problems, epilepsy and/or autistic spectrum disorders,

were also more likely to report poorer health outcomes. Gender and having Down syndrome showed no significant associations with either outcome.

A multiple linear regression model was fitted to explore whether differences in the subjective well-being persisted between those living at home and those in out-of-home, after controlling for the variance in well-being accounted for by other variables. A multiple logistic regression model was fitted to explore these same associations with subjective health. The first step in both models involved fitting living circumstances, support needs and independent responding as predictors. In addition to main effects, the interaction between living circumstances and support needs was also fitted in Step 1. Potentially significant covariates (i.e., age, gender, community activities and friendships, hardship and physical health problems) were entered at Step 2. Where appropriate, continuous predictor variables (i.e., age, support needs, community activities, socio-economic hardship) were grand-mean centred to reduce the potential of multi-collinearity and ease interpretation (Kraemer & Blasey, 2004).

Table 3.4: Predictors of self-reported physical health (multiple logistic regression) and well-being (multiple linear regression)

Model	Predictors	Health[1] Odds Ratio	Well-being[2] beta
Step 1	Living with family	**1.53****	0.03
	Support needs	1.01	**0.08***
	Independent responding	**0.56*****	0.04
	Living circumstances x support needs interaction term	**1.05****	0.06
Step 2	Living with family	**1.65***	**0.13*****
	Support needs	0.98	**0.10****
	Independent responding	**0.70***	**0.06****
	Living circumstances x support needs interaction term	**1.05***	0.05
	Age	0.99	**0.16*****
	Female gender	0.82	-0.00
	Community activities	**1.17*****	**0.05***
	Hardship	**0.82*****	**-0.22*****
	Has friends outside of the family	**1.47***	**0.13*****
	Has generic illness/physical disability	**0.33*****	-0.04
	Has sensory problems	**0.58****	-0.02
	Epilepsy	**0.62****	0.02
	Autism	0.66	-0.03

*p<.05, **p<.01, ***P<.001

[1] Subjective physical health status was coded 0 (poor health) and 1 (good health).
[2] Subjective well-being ranged from 1-15, with higher scores indicating higher levels of well-being.

Table 3.4 presents the results of the multiple linear regression model for SWB and the logistic regression model for subjective health. In the model predicting SWB, Step 1 variables significantly accounted for a small percentage (2.6%) of subjective well-being score variance (R^2 = .026, $F_{(4,2147)}$= 14.60, p < .001). With the exception of support needs, which were significantly positively associated with SWB (ß = .081, p = .04), indicating that those with higher ability reported more positive well-being, all other variables showed no significant association with SWB (i.e. living circumstances, main respondent and the interaction term living circumstances by support needs). The additional variables (age, gender, socio-economic hardship, community activities, friendships and health variables) entered at Step 2 significantly accounted for 13% of variance in SWB (R^2 change = .103, $F_{(13,2138)}$ = 28.25, p < .001). When the effects of all other variables were controlled, living with family (ß = .129, p < .001) was highly positively associated with reports of SWB. Support needs remained independently positively associated with SWB, showing an increased Beta value (ß = .101, p = .01). Other variables positively associated with SWB at step 2 were age (ß = .157, p < .001), responding independently (ß = .06, p = .01), having friends outside the family (ß = .129, p < .001) and taking part in a greater number of community activities (ß = .05, p = .02). Hardship showed a negative association with SWB (ß = -.221, p < .001), indicating that more hardships was associated with lower SWB. No associations were found between SWB and gender, physical health problems, sensory problems, the presence of autism and epilepsy. The interaction term of living circumstances and support needs also showed no significant association with SWB (see Table 3.4).

A multiple logistic regression model was fitted to explore variables associated with subjective health status. At Step 1 the model significantly predicted perceived

health status ($\chi^2_{(4,\ N = 1965)} = 44.35$, $p < .001$), with 86.8% of cases correctly classified by the model. At this stage, living circumstances and the interaction of living circumstances by support needs were significantly positively associated with subjective health status. Independent responding was negatively associated with subjective health status. This suggests that living with family was associated that better subjective health status, however self-reporting was associated with more negative reports of health status. At Step 2, the addition of potential covariates of age, gender, socio-economic hardship, community activities, friendships and physical health problems resulted in a model that was still significant ($\chi^2_{(14,\ N = 1965)} = 244.33$, $p < .001$), with 88% of cases correctly classified by the model. Step 2 of the model showed that people with IDs living with family were over one and a half times more likely to report better health status than people living in other community settings OR = 1.65 (95% CI 1.19-2.28), p =.003. Other associates of positive health status were, taking part in a greater number of community activities (OR = 1.17, (95% CI 1.08-1.27), $p < .001$) and having friends outside of the family (OR = 1.47, (95% CI 1.06-2.03), $p = .02$). Negative associates of subjective health were independent responding (OR = 0.70, (95% CI 0.50-0.99), $p = .04$), hardship (OR = .82, (95% CI 0.78-0.87), $p < .001$), having more physical health problems (OR = 0.33 (95% CI 0.25-0.44), $p < .001$), having sensory problems (OR = 0.58 (95% CI 0.41-0.83), $p = .003$) and having epilepsy (OR = 0.61, (95% CI 0.43-0.87), $p = .01$). Support needs, age, gender, the presence of autism were not significantly associated with subjective health status.

The interaction term, living circumstances by support needs, was significantly associated with positive health status (OR = 1.04, (95% CI 1.01-1.08), p = 01). To investigate the interaction between living circumstances and support needs, the support needs variable was recoded into an ordinal variable at three levels (i.e. 0 =

high support needs, 1 = moderate support needs and 2 = low support needs), using the mean of the original interval-level support needs variable and one standard deviation around the mean. Using the predicted probability of reporting good health, we plotted the three levels of support needs, to explore whether living with family and living outside family homes were differentially related to the predicted probability of reporting poor health according to level of support need (Figure 3.1). People with moderate and low support needs who lived with family were more likely to report positive health outcomes than those living in other community settings. However, the opposite could be seen for people with higher support needs who lived with family. This group showed a greater likelihood of reporting poorer health compared to those living outside of family homes. Therefore, more able people living at home tended to report better health, whereas less able people living at home were more likely to report poorer health.

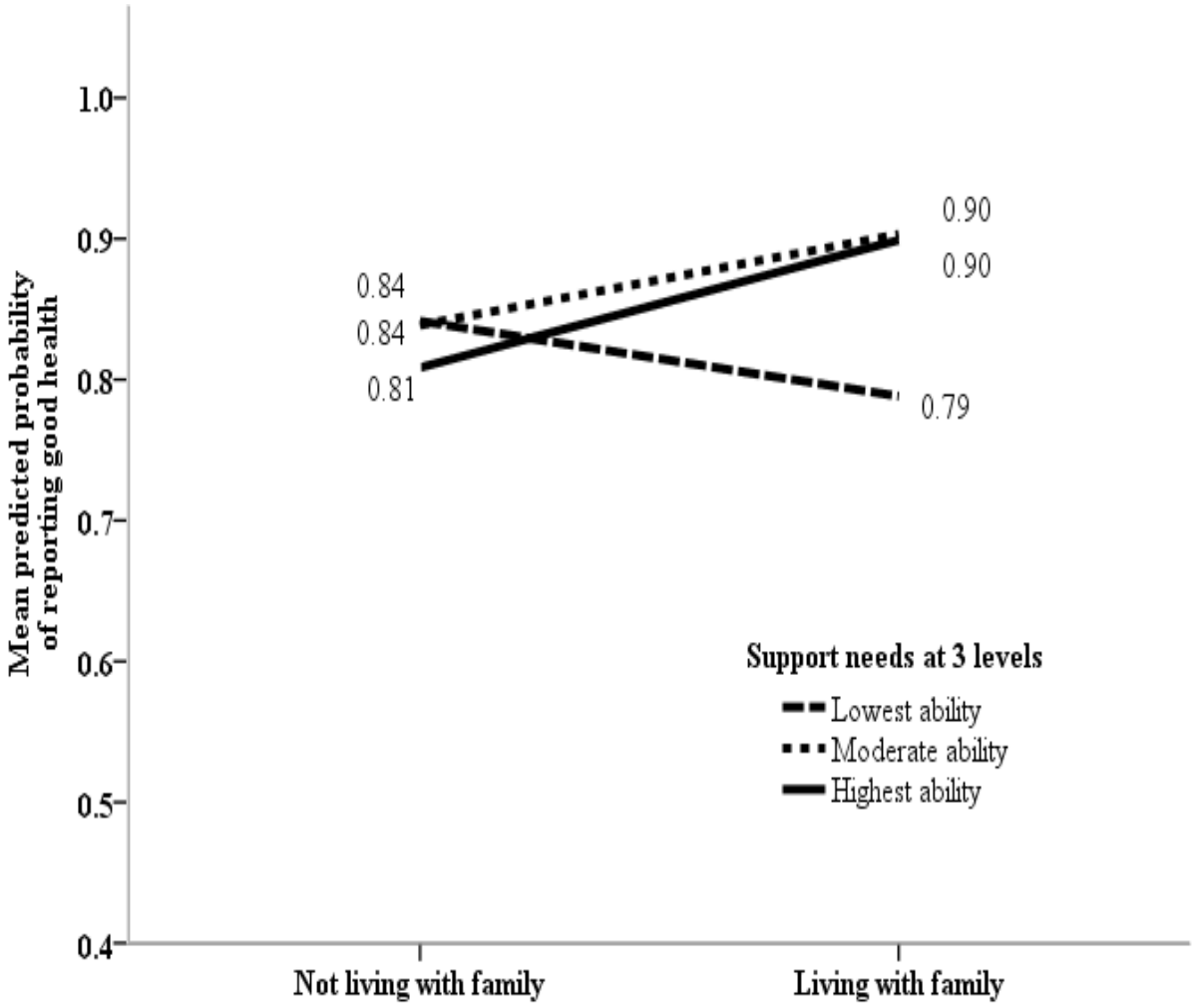

Figure 3.1: The probability of reporting good physical health among people with low, moderate and high support needs who live in family homes and those who live out-of-home.

Discussion

The present study aimed to examine levels of subjective health and well-being among adults with an ID who live in family homes and those who live out-of-home. Initial between group comparisons indicated that people living with family perceived their health and well-being more positively than those living out of the family home. Importantly, after accounting for a number of variables that are related to subjective health and well-being, living with family was still significantly associated with the two outcomes. So, after accounting for the effects of response mode (i.e. independent

responding vs proxy response/assisted interview response), level of support needs, age, gender, material hardship, frequency of community activities, friendships, the presence of physical disability/health or sensory problems and autism, living at home was still significantly associated with higher SWB ($ß = .129$, $p < .001$). Interestingly, the multivariate modelling revealed a more complex pattern of results for subjective health. After controlling for the effects of all these other factors, those who lived at home were more likely to report better health when their support needs were lower, whereas if they had higher support needs, they were more likely to report poorer health (Figure 3.1).

The current findings provide evidence of the central role families play in providing living environments conducive to the well-being of adults with ID (Scott, Foley, Bourke, Leonard, & Girdler, 2013, Seltzer & Krauss, 2001; Seltzer et al., 1995). The literature highlights the interrelated nature of roles within families, with siblings, as well as parents, providing support to their family member with ID. Many of these studies suggest that family relationships provide emotional as well as instrumental support to their family member (Seltzer, Begun, Seltzer, & Krauss, 1991; Seltzer & Krauss, 2001). Further evidence of the unique contribution families make to the well-being of their relative is provided by a study exploring the meaning of well-being from the perspective of young adults with Down syndrome (Scott et al., 2013). Themes to emerge from this study included young adults' reliance on their parents to provide a secure environment within which they felt, "loved, accepted and encouraged". The findings from the current study, together with these previous studies suggest that family homes may provide living environments conducive to emotional well-being which may be less well met in out-of-home community settings. A large proportion of friendship networks for adults living out-of-home comprise paid

support workers (Bigby, 2008; Forrester-Jones et al., 2006). However, due to the often high turnover of staff within residential settings, these friendships can be inconsistent and transient in nature. Therefore the opportunity to develop emotionally supportive relationships in out-of-home settings may be limited (Bigby, 2008). Studies have shown how families, especially mothers, play a central role in providing not only primary support, but also social support to their relative (Lunsky & Benson, 1999; Seltzer et al., 1995). Out-of-home accommodation may therefore, be less conducive to the development of emotionally rewarding relationships, thus affecting the development and maintenance of SWB. To support emotional well-being, it is, therefore, important to ensure people living in community residencies are supported to develop meaningful relationships both within and outside of the home and, where possible, maintain contact with family.

Contrary to expectation (Martinez-Leal et al., 2011) the poorest health outcomes were found for people with highest support needs who lived with family. This may be the result of disparities in accessing health care due to severity of disability making it difficult to attend primary or secondary health care facilities, especially for those reliant on public transport and/or the lack of eligibility to health promotions. Annual health checks were introduced into the UK in 2006 (initially Wales) as a way of addressing unmet health needs of adults with ID. However, a stipulation for entitlement to a health check is the registration and receipt of support from Social Services (Glover & Niggebrugge, 2013). People living in registered care homes and supported living settings are those most likely to be registered on Social Service intellectual disability registers. Evidence has shown annual health checks have increased the detection of new and often manageable morbidities for people with ID, such as obesity and high blood pressure (Baxter et al., 2006; Robertson, Roberts,

& Emerson, 2010; Robertson, Roberts, Emerson, Turner, & Greig, 2011). However, evidence has shown that less than 50% of eligible adults with ID in England received a health check in 2010/11 (Emerson, Copeland, & Gyles, 2011). Whilst, the uptake of health checks shows an increasing trend (Emerson et al., 2011), current levels of uptake may reflect problems in accessing primary health care services, especially for those with more severe disabilities. Increasing awareness and extending the criteria for access to health checks and health screening to all adults with ID, may go some way to addressing disparities and unmet health needs, especially for those more marginalised 'hidden' populations who are less likely to be in receipt of service support (Emerson, 2011). Family carers have an integral role in the support and identification of their relative's health needs (Emerson & Baines, 2010). This needs to be acknowledged by health and social care providers through adopting a whole family centred approach to service provision. Primary health care professionals should consider more flexible ways of offering appointments, through extending home visits. Specialist training is also needed for primary health care personnel in understanding the needs of people with ID and their families (Melville et al., 2006; Mencap, 2007).

The final regression models also identified seven predictor variables independently associated with health (independent responding, community activities, having friends outside of the family, hardship, epilepsy, health problems and sensory problems) and five with well-being (support needs, age, having friends outside of the family, hardship and health problems). The negative associations between having a physical health problem/impairment (i.e., physical disability/health condition, epilepsy, sensory impairment) and subjective health and well-being have mixed support from previous research. Negative associations were found by Johnston, Propper and Sheilds (2007) who reported that people with a diagnosed health problem

showed a greater propensity to report poorer subjective health, and Deeming (2013), who reported that people with poorer health were ten times more likely to report being unhappy than those with good health. However, other studies have shown people with physical impairments and life conditions which objective criteria and social convention would deem undesirable, to report high levels of quality of life (Albrecht & Devlieger, 1999). Self-perception of health status, together with the degree to which disease or impairment impacts upon daily functioning appear to be regulating factors in the evaluation of subjective outcomes of health and well-being and offer an explanation to differences in reported outcomes (Anger et al., 2013; Deeming, 2013; Hunt et al., 1980).

On the other hand, our findings were consistent with previous evidence on the association between having friends, hardship and better subjective health and well-being (Emerson, 2003, 2007; Emerson & Hatton, 2007, 2008; Felce, 1997; Hertzman & Boyce, 2010; Lynch, Kaplan, & Shema, 1997; Myers, 1999), participation in community activities and better health (Felce et al., 2011), independent responding and poorer health and older age and better well-being (Emerson & Hatton, 2007, 2008). Overall the findings from the current study suggest that despite reporting better levels of subjective health and well-being, adults living in family homes were experiencing greater material hardship (Table 3.1). Long term implications to both physical and mental health of material hardship and potential health inequalities should raise concerns for policy makers.

When considering the present findings in light of previous evidence, it is important to note that the present study used data from participants who were identified as not being in receipt of service support (including housing, welfare benefits and employment support, attending a day centre and not recruited through

administrative records). Of the study sample identified as not receiving service support (*N* = 880), the majority (*N* = 836) lived with family. Much of what is known about the health and well-being of adults with ID derives from studies focusing on people living in out-of-home community settings (e.g., Sutherland, Couch, & Iacono, 2002) and those more likely to be in receipt of service support (e.g., Janicki et al., 2002). Therefore the inclusion here of participants traditionally less likely to take part in research ensures a wider representation of adults with ID and adds to the strength of the present findings. Previous research suggests that people with ID who are not in receipt of service support have a greater propensity of experiencing material hardship, social isolation and are less likely to participate in community activities, factors associated with poorer outcomes of health and well-being (Emerson, 2011; Emerson & Hatton, 2007, 2008).

A further strength of the present study was the inclusion of data from participants of all ability levels. Whereas studies typically exclude from their design those who cannot respond independently (e.g., Emerson & Hatton, 2007, 2008) or rely solely on proxy respondents (Nota, Ferrari, Soresi, & Wehmeyer, 2007; Nota, Soresi, & Perry, 2006), the present study sought to include everyone whilst accounting for the mode of responding. Proxy/assisted interviews made up a greater part of responses for adults living with family in the current study (53.5% vs 45.7%). At the moment however, there is not a clear understanding of the effect of proxy reporting for subjective outcomes. Research has shown varying results with correlations between proxy and self-reports, with proxy reports from family members appearing more reliable than those of paid support staff (Schwartz & Rabinovitz, 2003). Proxy reports of objective ratings of health and well-being have proven more reliable than proxy reports of subjective measures. Some researchers have argued for

the use of proxy reporting with objective measures only (Perry & Felce, 2002). However, this potentially leaves a gap in the knowledge of subjective phenomena for people with severe or profound IDs. Fujiura et al., (2012) suggest that gaining a better understanding of the cognitive processes underlying responses on subjective health and well-being may go some way to addressing the problems of response validity when including people with more severe IDs in research.

When considering the limitations of the present study, the cross-sectional correlational nature of the data suggests that the relationships observed are concurrent. Cross-sectional designs only reveal associations and not causal relationships of subjective health and well-being. Further longitudinal research is needed to verify associations and potentially enable predictions of outcomes of subjective health and well-being for adults with ID living with family.

The current study suggests that adults with ID who live with family are more likely to report greater well-being and better health compared to those living out-of-home. In terms of health, this is especially the case for those with fewer support needs. Importantly, this positive effect of living with family persisted having accounted for whether the response was provided independently or via a proxy respondent, a factor known to alter the direction of subjective indicators. Subjective evaluations of health and well-being do not necessarily mirror the objective realities of people's lives. As family homes are the dominant residency model for the majority of people with ID into their mid-life, potential health inequalities which may have long term health implications should raise concerns for policy makers. Further research is needed to strengthen evidence and address the limitations of the current study.

Implications for research, policy and practice

Despite the limitation of the current study, a number of implications for future research, policy and practice can be made. From a policy and practice perspective, strategies to raise awareness of the benefits of receiving an annual health check not only amongst adults with ID, families and support workers but also GPs and primary health care personnel, along with increasing potential uptake of health checks and health promotion through implementing alternative, more flexible ways of delivering these interventions should be considered. This may help address the needs of people with more severe and profound disabilities and/or those less able to attend primary health care services. Better training for all primary health care personnel in the needs of people with ID is also needed. Strategies for supporting and enabling adults with ID living in out-of-home settings to develop peer friendships and maintain contact with family should also be considered.

From a research perspective, further research needs to be undertaken to explore the first-hand perspectives of family carers and adults with ID of the health check process with an aim of improving the experience and ensuring a service which is fit for all people with ID. Further longitudinal research is also needed to explore causes and potential solutions to inequalities (e.g., socio-economic hardship and access to health interventions) experienced by adults with ID living with families and assess the long term impact of these inequalities upon health and well-being.

Chapter 4: Physical and psychological health of family carers co-residing with an adult relative with intellectual disability

Orientation Chapter

The findings from study 2 highlight the important role families play in supporting the well-being of their adult relative with ID. Whilst the current policy aim in most Western cultures is on normalisation principles which aim at providing parity with the live of non-disabled adults and afford the same rights for adults with ID to live independent of their families. The apparent lack of available and appropriate out-of-home accommodation (Department of Health, 2011; Mansell, Beadle-Brown, Skidmore, Whelton & Hutchinson, 2006; Mansell & Wilson, 2010) suggests the reliance on family home support will continue for some time. The lack of appropriate out-of-home accommodation was a factor put forward as delaying the success of an out-of-home placement occurring in study 1 (chapter 2) of this thesis.

The literature suggests that caring for an adult family member with an ID long term can have an adverse effect upon carers' physical and psychological health (Chou, Chiao & Fu, 2011; Chou, Fu, Lin & Lee, 2011; Rowbotham, et al., 2011; Seltzer, et al., 2011; Yamaki, et al., 2009). However, much of what is known about the health of family carergivers' of adults with ID has taken place in international contexts. It was therefore considered important to gain a better understanding of the impact of providing care to an adult relative in family homes in the UK. An examination of how carers' health compares to that of national population norms was also considered important as was the role of adaption upon caregiving outcomes.

Few studies have examined both positive and negative aspects of caring for an adult with ID. It was therefore considered important to adopt a multi-dimensional focus to examine factors influencing both positive and negative outcomes of caregiving.

Abstract

Caring for a relative with an ID long term within family homes can have a negative impact on caregivers' health and well-being. Much of what is known about this care dynamic is derived from international studies. The aim of the present study is to examine how self-reported health of carers co-residing with an adult relative with an ID in homes across the UK compares to population data. Correlates of carers' physical and psychological health are also explored, taking account of both positive and negative aspects of caregiving.

Methods: Data was collected via on-line and postal questionnaires on 110 family carers' physical health (EQ-5D and EQ-VAS), psychological health (Kessler 6 and the Zarit Burden Index), family stress (Questionnaire on Resources and Stress) and positive gains from caring (Positive Gains Scale). In line with adaptive theories on family stress, psychological adaption (Family Crisis Oriented Personal Scale) and carers' satisfaction with available support (Family Support Scale) were also examined.

Results: Binominal tests indicated that a significantly higher percentage of physical and psychological health problems were reported by the study population than were evident in general population data from the UK and US. Multiple linear regression analyses revealed that being older was associated with lower psychological distress, caregiver burden and family stress. Primary carer being female was associated with lower levels of family stress. However, adult relative having higher support needs was associated with higher levels of family stress. Higher level of family socio-economic position was associated with lower caregiver distress and better subjective health. However, the latter was no longer significant when accounting for psychological adaption. Adopting more active coping strategies was

associated with positive psychological health outcomes and more positive gains from caring. Support which was perceived as helpful was associated with lower caregiver burden and more positive gains.

Conclusion: Family carers of adults with ID do appear to experience poorer health outcomes when compared to general population norms. However, factors influencing physical and psychological health appear to differ. Adaption to the caregiving role appeared to buffer negative outcomes and result in more positive gains from caregiving. More large scale longitudinal studies with comparative data from UK populations are needed. An exploration of the long term impact of psychological stress upon physiological outcomes is also needed.

Key Words: Family carers, family homes, adults, intellectual disabilities, subjective health, subjective well-being, positive gains

In Western economies, research suggests that approximately 60% of adults with an intellectual disability (ID) known to services typically live with their families (McConkey, Mulvany, & Barron, 2006; Seltzer, Floyd, Song, Greenberg, & Hong, 2011). Co-residency often continues well into an adult son or daughter's mid-life (Yamaki, Hsieh, & Heller, 2009; Rowbotham, Cuskelly, & Carroll, 2011; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Seltzer et al., 2011) and may only cease as a result of carers' inability to continue providing care (Chiu & Hung, 2006; Nankervis, Rosewarne, & Vassos, 2011).

A body of evidence exists internationally to suggest that caring for an adult family member with an ID within the family home can have an adverse effect upon carers' physical and psychological health (Chou, Chiao, & Fu, 2011; Chou, Fu, Lin, & Lee, 2011; Hill & Rose, 2009; Rowbotham et al., 2011; Seltzer et al., 2011; Yamaki et al., 2009). Primary carers of adults with ID are more likely to experience higher levels of stress, anxiety, depressive symptoms (Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsi, 2009; Seltzer et al., 2011) and physical health problems (Seltzer et al., 2011; Yamaki et al., 2009) than their non-caregiving peers. Older carers (aged 65 and above) co-residing with an adult child with ID are at particular risk of experiencing higher levels of depressive symptoms and functional impairments (Seltzer et al., 2011). In a large-scale study comparing health outcomes of carers of adults with ID with age matched non-caregiving peers (Yamaki et al., 2009), carers were significantly more likely to report experiencing higher rates of arthritis, diabetes, high blood pressure, osteoporosis, cardiovascular diseases, obesity and activity limitation than their non-caregiving peers.

Differing theoretical approaches to family stress and caregiving have been applied in the field of ID research. For example, the 'wear and tear' approach

(Johnson & Catalano, 1983) suggests that caregiving for an extended period has a detrimental and eroding impact upon health outcomes. More recently, adaptive theories of family stress (McCubbin & Patterson, 1983; Townsend, Noelker, Deimling, & Bass, 1989) have been adopted. These theories propose that carers exposed to long-term challenges develop strategies which, combined with available resources, act as potential buffers against the negative impact of providing care. McCubbin and Patterson's (1983) Double ABCX model of family stress characterises the family as a dynamic and changing system. Families who face a pile-up of stressors which challenge available resources (e.g. support, finances and health) may find their ability to manage an ongoing stressful situation reduced. An ongoing imbalance between stressors and available resources poses a threat to carers' well-being.

Partly informed by these theoretical perspectives, in terms of correlates of health and well-being, studies have evidenced that increased support and resources available to families are associated with lower levels of stress, anxiety and depressive symptoms (Chou, Pu, Fu, & Kröger, 2010; Walden, Pistrang, & Joyce, 2000), better health status (Llewellyn, McConnell, Gething, Cant, & Kendig, 2010) and quality of life for family carers (Walden et al., 2000). For example, when exploring health outcomes for older carers of adults with ID, Llewellyn et al., (2010) found that having a partner, a large support network, and caring for a person with lower support needs, were all positively associated with carers' better health.

Factors associated with negative outcomes for carer well-being include lower daily living skills of individuals with ID (Chou et al., 2010; Llewellyn et al., 2010), challenging behaviours (Minnes, Woodford, & Passey, 2007; Walden et al., 2000), having a son or daughter with profound or severe ID (Chou et al., 2011), the presence of epilepsy (Esbensen, Seltzer, & Greenberg, 2007; Kerr, Turky, & Huber, 2009),

socio-economic hardship (Chou, Pu, Kröger, & Fu, 2010; Eisenhower & Blacher, 2006; Lynch, Kaplan, & Shema, 1997), and co-residency (Seltzer et al., 2011). Seltzer et al., (2011) compared outcomes for two groups of parents (1) with a co-resident adult son or daughter with ID, and a non-co-resident group of parents of adults with ID) with a group of age matched non-caregiving peers. They found co-residency to be associated with lower levels of income, less frequent social contact with family and friends, and more physical and psychological problems for carers by mid and later life. Another study exploring health status, social support and quality of life among family carers of adults with profound and multiple disabilities in Taiwan, (Chou et al., 2011) found positive health outcomes to be associated with a higher education level, being in employment, and higher levels of social support.

Although caregiving is multi-faceted and studies have shown heterogeneity in carers' responses to the demands of providing care (Grant & Whittell, 2000; Hayden & Heller, 1997; Kim, Greenberg, Seltzer, & Krauss, 2003; Minnes et al., 2007), evaluations of the negative impact of caregiving have remained the focus of much of the literature on caring for adults with ID (Burton-Smith et al., 2009; Chen, Ryan-Henry, Heller, & Chen, 2001; Chou et al., 2011; Chou et at., 2010; Minnes et al., 2007; Yamaki et al., 2009). However, the caregiving environment may also afford families the opportunity for growth and development of skills (Ha, Hong, Seltzer, & Greenberg, 2008; Rowbotham et al., 2011; Townsend et al., 1989). Evidence suggests that coping strategies adopted by carers (Hayden & Heller, 1997; Kim et al., 2003; Seltzer, Greenberg, Floyd, & Hong, 2004), and cognitive appraisals of the caregiving situation (Rowbothom et al., 2011) are important factors in moderating the impact of caregiving demands.

Although researchers recently have been more inclined to adopt a multiple dimensional approach to include both positive and negative aspects of the caregiving experience (Ha et al., 2008; Kim et al., 2003; Llewellyn et al., 2010; Rowbothom et al., 2011; Seltzer et al., 2011; Walden et al., 2000), much of what is currently known within a UK context is derived from studies conducted with parents of children with ID or developmental disorders such as autism (Hastings, Beck, & Hill, 2005; Hastings, Allen, McDermott, & Still, 2002; Hastings & Taunt, 2002; Jones, Hastings, Totsika, Keane, & Rhule, 2014). To date, there remains a paucity of evidence on the multi-dimensional aspects of providing care to an adult with ID within family homes in the UK.

Whilst strong evidence exists to suggest support and resources moderate the negative effects of caregiving, the reality for families is that resources such as financial support, respite and day care services are finite. Therefore, resources are not always available to families, especially in difficult fiscal climates (Cummins, 2001). With the recent reforms to the Welfare system within the UK, the rising cost of living and the extra costs associated with providing care, family carers are currently caught in what has been described as 'the perfect storm' (Carers UK, 2014). Many older carers continue to provide support, within a changing context. They may be faced with their own age-related decline in health (Bowey & McGlaughlin, 2007; McConkey, Kelly, Mannan, & Craig, 2011; Prosser, 1997; Seltzer & Krauss, 1989; Seltzer et al., 2011; Shaw, Cartwright, & Craig 2011; Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012), and changing household composition. Adult children without ID leave home and, as carers' age, they are faced with the potential loss of a spouse (Seltzer et al., 2011; Seltzer & Krauss, 1989; Kim, Greenberg, Seltzer, &

Krauss, 2003) and decline in their family support network (Carter & McGoldrick, 1989).

The aims of this study were, therefore, to:

1) examine how the self-reported health of carers co-residing with an adult relative with ID in homes across the UK compares to UK national population norms;

2) examine correlates of carers' physical and psychological health, taking account of positive and negative aspects of caregiving.

Method

The study reported in this paper is a cross-sectional survey of family carers of adults with an ID. Potential participants were informed about the study through statutory or voluntary organisations for individuals with ID and/or their carers. Information was collected through either a postal or an online survey. For inclusion in this study, participants needed to be the main carer for an adult relative aged 18 years or over who was, at the time of the study, living in the family home.

Participants

Carer characteristics. In total, 115 family carers agreed to take part in the study. Of those, 79 completed the internet version of the survey and 36 completed the postal survey. Five participants were excluded due to missing data that did not permit us to establish the person was indeed caring for a relative in their own home, or a large amount of missing data, rendering the questionnaire unusable. The final number of participants was $N = 110$, of whom 18 (16.2%) were male and 92 (82.9%) were female (see Table 4.1 for demographic information). Family carers' ages ranged from 24 to 91 years ($M = 59.81$ years; $SD = 12.00$). The majority of carers were mothers/step-mothers (73.0%), with only 14.4% being fathers/step-fathers. Other family carers were siblings, cousins, aunts, uncles, spouses and adult children (see

Table 4.1 for full details). Fifty three carers (47.7%) had no to low levels of education and 51 (45.9%) were educated to advanced school level and above. The majority of family carers did not have paid work (*N* = 73, 65.8%). Over half of carers (*N* = 60, 54.1%) were married or living with a partner and 48 (43.2%) were single/divorced/ separated or widowed. With the inclusion of adult relatives with ID, the average number of people resident in each household was 3 (range 2-6 individuals, *SD* = 0.91).

Adult relative characteristics. The age of participants' adult relatives with ID ranged from 18-67 years (*M* = 34.88, *SD* = 11.57) with 65 people (58.6%) being male and 43 (38.7%) being female. Five variables indicated whether adult relatives had additional support needs i.e. 1) 'is able to speak/sign 30 words or more', 2) 'has visual or hearing impairment', 3) 'is continent during the day time and/or night time', 4) 'currently has epileptic seizure' and 5) 'needs support at meal times'. Positively phrased variables (i.e. speak/sign 30 words, continent during daytime/night time or both') were reverse coded. A composite support needs variable was created with scores ranging from 0-5, with higher scores representing higher support needs.

Table 4.1: Characteristics of participating family carers and their adult relatives with ID

		Number and percentage
Family carers' gender :	Male	18 (16.4%)
	Female	92 (83.6%)
Country of residency	England	66 (59.5%)
	Wales	40 (36.0%)
	Other (Northern Ireland & Scotland)	3 (2.7%)
Relationship to adult with ID:		
- Mother/step-mother		81 (73.0%)
- Father/step-father		16 (14.4%)
- Sister/step-sister/sister-in-law		5 (4.5%)
- Brother/step-brother/brother-in-law		1 (0.9%)
- Spouse/partner		2 (1.8%)
- Other relatives (including aunt/uncle, cousin, daughter)		4 (3.6%)
Marital status:	Living with spouse/partner	60 (54.1%)
	Not living with spouse/partner	48 (43.2%)
Number of people living in family home:		
- Two (carer and adult with ID)		34 (30.6%)
- Three		58 (52.3%)
- Four or more		18 (16.2%)
Family carers' highest level of educational attainment:		
- No formal qualifications		14 (12.6%)
- O Level/GCSE		28 (25.2%)
- Vocational qualification/FE (Apprenticeship, NVQ)		11 (9.9%)
- A Level/BTECH		11 (9.9%)
- Professional qualifications (Engineering, Accountancy)		13 (11.7%)
- Higher education (BA/BSc)		18 (16.2%)
- Post-graduate education (Masters/Doctoral Degree)		9 (8.1%)
Has a job:	Yes (full or part time)	36 (32.4%)
	No	73 (65.8%)
Income poverty		
Weekly net income of below poverty line		51(46.4%)
Weekly net income of above poverty line		59 (53.6%)
Gender of adult relative with ID:	Male	65 (58.6%)
	Female	43 (38.7%)
Adult with ID able to speak/sign 30 words or more:	Yes	79 (71.2%)
	No	27 (24.3%)
Visual impairment		13 (11.7%)
Hearing impairment		17 (15.3%)
Needs support to eat		37 (33.3%)
Incontinent during the	Daytime	25 (22.5%)
	Night time	11 (9.9%)
Has epileptic seizures		19 (17.1%)
Adult relative with ID attends a day time activity (including paid work, workshop, voluntary work, day centre, respite)		83 (74.8%)

Measures

All measures included in this study were carefully chosen for their ease of completion and suitability for inclusion in an online or postal survey. Questionnaires were available in English and, where possible, Welsh languages. Participants completed a demographic questionnaire (Appendix 10a and 10b), specifically designed for the current study to collect data on carer, care recipient and family characteristics.

Socio-economic position. The household composition variable from the demographic questionnaire was weighted in accordance with the OECD-modified equivalence scale (Office for National Statistics, 2013) to create a new single variable weighted to account for household composition. Equivalisation scales are used to adjust household income in a way that accounts for household size, composition, and income (Office for National Statistics, 2013). The scale is used to allocate different weights to each member of a household depending on role (i.e. head of the household) and age (i.e. under or over 14 years of age). This variable was then summed to get a total value which represents equivalised household composition. A second single variable was calculated from the mean of the weekly household income for the year 2013 (when data were collected). Equivalised net or disposable household income for families ranged between £80 and £567 per week (mean £240.78, SD 126.04). Median weekly net UK household income for 2013 was £406 (Office for National Statistics, 2013). This new weekly income variable was then divided by the equivalised household composition variable to create a new single household income variable which has been adjusted to take account of household size and composition. A dichotomous variable was subsequently derived using the equivalised household income variable, to represent families who would be considered as earning a weekly

income which was above or below the poverty line. The poverty line was a weekly net household income of 60% below the median for 2013, which was £243.59 and below for the present sample.

Postal code information was linked to geographical lower layer super output areas (LSOA) for each of the UK countries and used to estimate area deprivation using the Index of Multiple Deprivation. The Index of Multiple Deprivation (IMD) is an official, country specific measure which identifies relative deprivation for small areas. Each of the four UK constituent countries have unique indices comprising domains which target specific within country policies (Department of Communities and Local Government, 2011; Northern Ireland Statistics Research Agency, 2010; Scottish Government, 2012; Welsh Government, 2011).Common to all indices are the domains of income, education, employment, health, crime and living environment/housing. Quintile ranking is used to order scores for each of the indices. The IMD variables for Scotland (SIMD, 2012) and Northern Ireland (NIMDM, 2010) are both ranked 1 = most deprived and 5 = least deprived, whereas the indices for England (IMD, 2010) and Wales (WIMD, 2011) are ranked in the opposite order. Therefore the indices for Scotland and Northern Ireland were reverse ranked for conformity with the English and Welsh IMD variables. All IMD scores were then transformed into a single IMD variable for the UK. A dichotomous variable was created indicating whether carers were living in one of the 20% most deprived neighbourhoods. This dichotomous variable was used as an indicator of deprivation likely to be experienced by each household only and not as a between country comparator.

Family resources. Family Resources Scale (FRS, Dunst, & Leet, 1986, 1987) (Appendix 11) comprises 30 items rated on a six point Likert scale, measuring the

extent to which resources for families are adequately met (e.g., basic necessities such as food and shelter, and less essential resources such as family holidays). Two of the subscales which indicated material hardship ('necessities and health' and 'physical necessities and shelter') were summed to create a single interval 'material resources' variable with scores ranging from 0 to 60. These sub-scales demonstrated a high level of internal consistency with the current study sample ('necessities and health' Cronbach's $\alpha = .87$ and 'physical necessities and shelter' $\alpha = .89$). They comprise questions relating to whether families have enough money to buy food, heat their homes, for health care and for necessities for their relative with ID. The summed scores of the 'material resources' variable were subsequently split at the median (median score = 45), to form a single dichotomous 'hardship' variable indicating whether 'resources were less adequately met' or 'resources were more adequately met' for families.

Finally, a composite variable indicating families' socio-economic position (SEP) was created using five indicators: small area deprivation (IMD), hardship, carers' employment status, educational status (coded '0 = no/low education' and '1 = advanced school level and above') and income poverty. The SEP composite scores ranged from zero to five, with higher scores representing a higher socio-economic position.

Health related quality of life. Health related quality of life of family carers was measured by the EQ-5D-3L (EuroQol Group, 1990) (Appendix 12a and 12b) EQ-5D-3L is a generic measure of health-related quality of life which includes a descriptive system (EQ-5D) and a visual analogue scale (EQ VAS). The descriptive scale enables participants to self-classify health states along five dimensions (mobility, self-care, usual activities, pain/ discomfort and anxiety/depression). The

descriptive system is measured at ordinal level with each dimension being at 3 levels, 'no problems', 'some problems' and 'extreme problems'. Participants respond according to how they perceive their own health status at the time of completion. Higher scores indicate a lower level of health in a particular dimension of health. The descriptive system has the potential of defining a total of 243 health states. Weighting scores have been generated, based on values obtained from a national survey of the general population (Kind, Dolan, Gudex, & Williams, 1998) where members of the public were asked to give a value to hypothetical health states using the visual analogue scale (EQ-VAS rating scale). These preference weights can be applied to the descriptive system to generate an objectively rated single index health score based on country-specific preferences for health states, i.e. weights generated which indicate a society's preference to experience one health state (indicated by a lower score), over another health state (indicated by a higher score). For example, a society may have judged that experiencing sight impairment for one year was preferable to experiencing paraplegia for a year (Prüss-Ustün, Mathers, Corvalán, & Woodward, 2003). Therefore the latter would be allocated a higher weighting. Scores on the $EQ\text{-}5D_{(Index)}$ run from 1.0 representing no health difficulties to 0 representing extreme health difficulties or the state of being dead. Weights are deducted from 1.00 (perfect health) to indicate respondents' preference or objectively rated index scores. In the current study, participants' raw response scores from the descriptive system were converted into a single index value ($EQ\text{-}5D_{Index}$) by applying the UK specific VAS index-weighting scores available from EuroQol (www.euroqol.org/about-eq-5d/valuation-of-eq-5d/eq-5d-3l-value-sets.html).

The EQ-VAS is a 20 cm visual analogue scale on which respondents rate their subjective general health state on the date of completion. The scale ranges from 0

(worst imaginable health state) to 100 (best imaginable health state). The EQ-VAS measures provides an indication of participants' unadjusted subjective health status.

Family stress. The Questionnaire on Resources and Stress – short form (QRS-F: Friedrich, Greenburg, & Crnic, 1983), Parent and Family Problem Sub-scale-7 item version (Griffith et al., 2011) (Appendix 13) was used. The QRS-F is a self-report questionnaire which measures general stress related to caring for a family member with a disability or chronic illness. Respondents answer 'true' or 'false' to statements (e.g., 'caring for my relative with ID puts a strain on me', 'other members of the family have to do without things because of relative with ID'). The original wording of item 3 ('In future our family's social life will suffer because of the increased responsibilities and financial stress') was amended to reflect the situation for families with adult relatives with ID (i.e., 'Our family's social life has suffered because of caregiving responsibilities and financial stress'). The total score for this measure is 7, with lower scores reflecting lower levels of family stress. The 7-item measure has shown good internal consistency for psychological distress in mothers (KR-20 coefficient = .78) and fathers (KR-20 coefficient = .89) of children with rare genetic conditions (Griffith et al., 2011). The composite measure showed a high level of internal consistency for the current study population (KR-20 coefficient = .81).

Family support. The Family Support Scale (FSS; Dunst, Jenkins, & Trivette, 1984) (Appendix 14) is a self-report measure comprising 19 items designed to assess potential sources of support available to family carers and the degree of perceived helpfulness. Responses were coded on a 5 point Likert scale where 0 = not available, 1 = not at all helpful, 2 = sometimes helpful, 3 = generally helpful, 4 = very helpful and 5 = extremely helpful. The FSS has demonstrated excellent internal consistency in studies of older and younger carers of adults with ID (Cronbach's α = .88, Chou,

Lee, Lin, Kröger, & Chang, 2009). The composite measure of all 19 items also showed a good level of internal consistency for the current study participants (Cronbach's α = .75). A total score for ratings of helpfulness was calculated together with a count of the number of support services available to each family. The overall helpfulness scores were then divided by the count of the number of supports available to each family, to create a single weighted score of mean helpfulness of available supports.

Family coping. The Family Crisis Oriented Personal Scale (F-Copes; McCubbin, Olson & Larsen, 1981) (Appendix 15) consists of 30 statements designed to assess coping strategies and effective problem solving behaviour adopted by families in response to problems or difficulties. The questions are presented on a 5-point Likert-scale, scored 1) strongly disagree, 2) moderately disagree, 3) neither agree nor disagree, 4) moderately agree and 5) strongly agree. The scale was designed to measure problem focused and passive coping strategies used by families in times of crisis. The F-Copes has yielded excellent levels of internal consistency and reliability in large scale studies of older and younger family carers of adults with ID (e.g., Hayden & Heller, 1997, Cronbach's α = .86). The subscales of acquiring social support (Cronbach's α = 87), reframing problems (Cronbach's α = .83) and seeking spiritual support (Cronbach's α = .83), all showed excellent levels of internal consistency for the study sample. These three sub-scales were summed to create a single variable for active coping strategies. Total active coping strategies scale had excellent internal consistency (Cronbach's α = .87), scores ranged from 23-115.

Carer distress. The Kessler 6 (K6, Kessler et. al., 2002) (Appendix 16) is a six item scale measuring non-specific psychological distress over a past 30 day period. The K6 was developed to measure psychological distress levels in general

community populations. Respondents rate each of the 6 items a) so sad nothing could cheer you up, b) nervous, c) restless or fidgety, d) hopeless, e) everything was an effort, f) worthless) on a 5 point Likert scale scored to reflect how often carers experienced negative feelings: 1) none of the time, 2) a little of the time, 3) some of the time, 4) most of the time and 5) all of the time. The maximum score is 30, where higher scores indicate greater levels of carer distress. The K6 has very good predictive validity for psychiatric disorders as it has been shown to predict reliably serious mental illness (SMI) in general population samples in the USA (Kessler, 2002; Kessler et al., 2003). The K6 is not gender, age, nor education biased (Kessler et al., 2002). The measure showed excellent levels of internal consistency for the study sample (Cronbach's $\alpha = .90$).

Carer burden. The Zarit Burden Index -12-items (ZBI; Bédard, Molloy, Squire, Dubois, Lever, & O'Donnell, 2001) (Appendix 17). The abridged 12-item, self-report index has been developed from the original 29 item scale (Zarit, Reever, & Bach-Peterson, 1980) designed to measure subjective caregiving burden. Example questions are 'Do you feel stressed between caring for your relative and trying to meet other responsibilities to your family or work?' and 'Do you feel your health has suffered because of your involvement with your relative?' Each item is rated on a 5-point scale: 0) never, 1) rarely, 2) sometimes, 3) quite frequently, 4) nearly always. Question 9 ('Do you feel you have lost control of your life since x's condition?) was omitted from the current study, as this related to the onset of a condition in later life such as Alzheimer's disease. The maximum score of the 11 questions was therefore, 44 with higher scores indicating higher levels of burden. Although the original 29-item measure was designed to measure burden in carers of dementia patients, it has shown excellent internal consistency in previous studies assessing burden in family

carers of adults with ID (Essex, Seltzer, & Krauss, 1999; Kim, Greenberg, Seltzer, & Krauss, 2003, Cronbach's α = .86 and between α = .82-.84 respectively). The total measure showed excellent internal consistency for the study population (Cronbach's α = .86).

Measures of positive perceptions. The Positive Gains Scale (PGS: Pit-ten Cate, 2003) (Appendix 18) is a 7-item scale designed to assess perceived positive aspects of having a relative with a disability. Carers were asked to respond to statements along a 5-point Likert scale such as "having a relative with an intellectual disability has helped me grow as a person" or "having a relative with an intellectual disability has brought my family closer to one another". Responses were coded 1) strongly agree, 2) agree, 3) not sure, 4) disagree and 5) strongly disagree. Maximum score for the measure is 35, with higher scores indicating fewer perceived gains. The measure has shown good levels of internal consistency in studies of family carers of children with ID (Griffith et al., 2011; MacDonald, Hasting, & Fitzsimons, 2010; Cronbach's α between .71-.80). Although the measure has not been used previously in studies of family carers of adults with ID, it showed excellent internal consistency for the current study population (Cronbach's α = .91).

Procedure

The study protocol was approved by the Research Ethics and Governance Committee at Bangor University in the UK. Study participants were invited to complete a battery of questionnaires either posted by mail or as an online survey. Recruitment of participants was facilitated through statutory and voluntary organisations that circulated a recruitment advertisement to their members and service users via email, websites and newsletters. Social media (e.g., Twitter and Facebook, on-line fora) were also used to distribute information about the study. The recruitment

advertisement (Appendix 7a and 7b) contained a brief description of the project, summary of eligibility criteria, what participation involved, together with a link to the on-line survey questionnaires. Contact details of the principal researcher were included for those requiring further information or those preferring to complete paper copies of questionnaires. The online link gave participants access to online versions of the participant information sheet (Appendix 8a and 8b), consent form (Appendix 9a and 9b) and all project questionnaires (Appendices 10 to 18). Participants opting to complete paper copies of questionnaires received the same information as those participating online. The first author also attended carers' group meetings and social groups for adults with ID, to promote the project and deliver paper questionnaires and address any queries or concerns of potential participants. Batches of questionnaires were sent to carers' and disability support organisations who had agreed to advertise the project to their members. A stamped addressed envelope was enclosed with the postal survey for return of the questionnaires. The number of postal questionnaires sent out via statutory or voluntary organisations or requested directly by family carers totalled 150 of which, 36 (24%) were returned completed. The exact overall response rate is difficult to assess as it was not clear how many people would have been reached through online advertising methods.

Results

The first aim of this study was to describe characteristics of family carers' physical and psychological health as compared to general population norms within the UK. To address this question, the percentage of problems (some or extreme problems combined) reported for each of the five domains of health on the EQ-5D descriptive system were plotted on a bar chart against national population norms (Kind et al.,

1998; Janssen, Cabases, & Ramos Goñi, 2014), (Fig. 4.1). Percentages are relative to study population sample (*N* = 110) and UK population sample (*N* = 3,395).

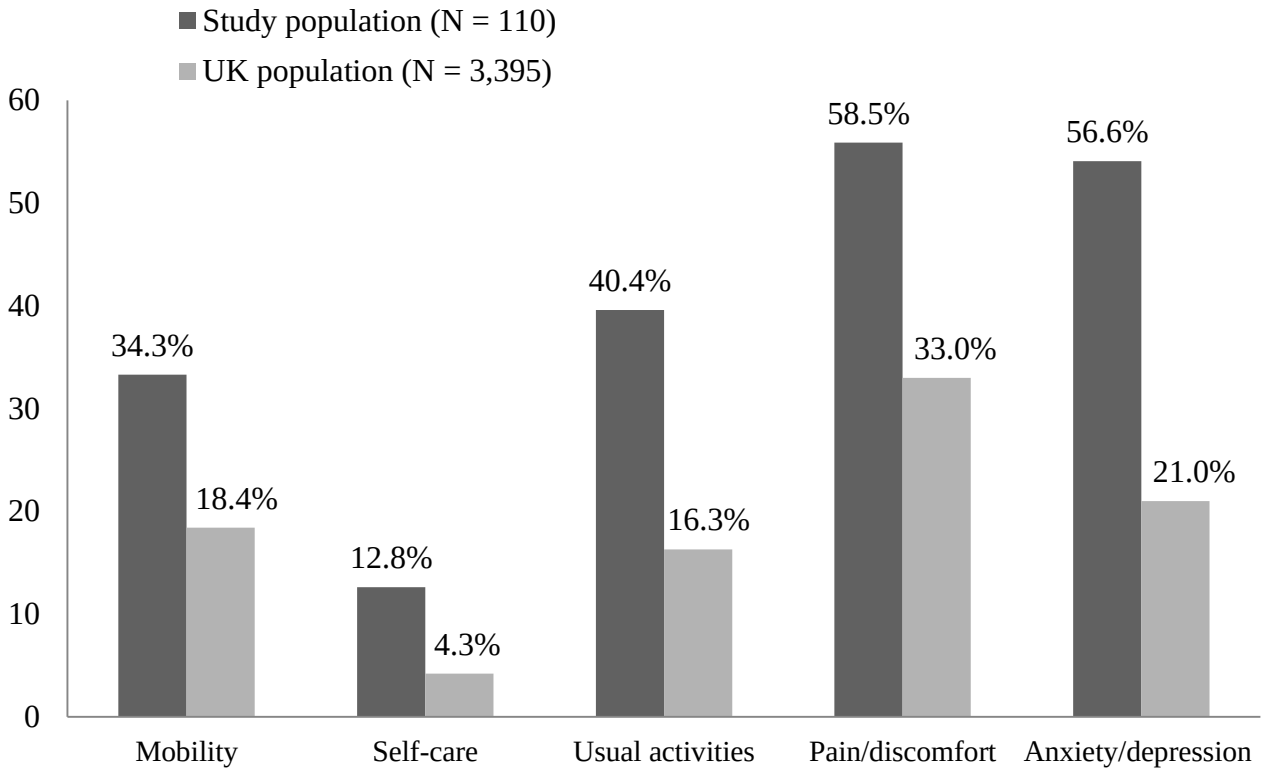

Fig 4.1: EQ-5D descriptive system: Percentage reporting health problems in the study population and the general population across five domains of health

Binominal tests indicated that the proportion of family carers from the study population experiencing problems across all five domains of physical and psychological health was significantly higher (p <. 001) than those reporting problems in UK general population norms (Kind, et al., 1998; Janssen, Cabases, & Ramos Goñi, 2014). (Table 4.2). A *t*-test was conducted to compare subjective general health scores (EQ-VAS) and objectively rated health states ($EQ\text{-}5D_{(Index)}$) between the study sample and UK national norms. Similarly, *t*-tests were also conducted to compare psychological distress scores (Kessler 6) with normative population data. Meanscores,

standard deviations (bracketed) and results for the *t*-tests are presented in Table 4.2. Comparisons for the K6 data were obtained from the Centers of Disease Control and Prevention (CDC; 2013) which was designed to collect population data from non-institutionalised adults aged 18 and over across 50 states in the USA (available at: http://www.cdc.gov/brfss/annual_data/ 2012/pdf/Overview_2012.pdf). To our knowledge, general population datasets which have included a direct measure of psychological distress using the K6 for families with adult children are currently not available in the UK.

Table 4.2: Mean, standard deviations and *t*-test results for health outcomes for study population and population normative data

	Study population (N = 110)	Normative data for adults	*t*-test results	Mean difference	95% CI of the difference
EQ-VAS	66 (18.4)	82.8 (17.0)	-9.55*	-16.95	-20.46 to -13.43
EQ-5D$_{(Index)}$	0.62 (0.24)	0.86 (0.17)	-10.44*	-0.24	-0.28 to -0.19
Kessler 6	13.6 (5.6)	8.89 (3.82)	8.79*	4.74	3.67 to 5.81

*p <. 001 Higher scores on EQ-VAS and EQ-5D$_{(Index)}$ indicate better health, higher scores on the K6 indicate poorer psychological health.

Significant *t*-test results for total means scores suggested that participants perceived their subjective health (EQ-VAS) as significantly worse than the rest of the population; they reported having more objectively rated health problems (EQ-5D$_{(index)}$); and they were significantly more distressed than the rest of the population (K6 scores). Effect sizes for the differences for each outcome measure were estimated as a standardised mean difference using pooled standard deviations (SDs). These were

EQ-VAS (SD_{pooled} = 17.04) 0.98 (95% CI: 0.78 to 1.18), and K6 (SD_{pooled} = 3.81) 1.25 (95% CI: 1.05 to 1.45), EQ-$5D_{(Index)}$ (SD_{pooled} = 17.25) 1.39 (95% CI 1.37 to 1.41), indicating large effect sizes.

Using the suggested clinical cut off score of 13 or above to indicate risk of serious mental illness (SMI) (Kessler et al., 2003), binominal tests indicated that differences in the proportion of family carers from the study population reporting levels of distress above the clinical cut-off point on the Kessler 6 was significantly higher than that found in the US national population data (17.5% vs 3.6%, p<.001). Best worldwide estimates of the proportion of the general population likely to experience depression during their lifetime are somewhere between 4-10% for major depression and 2.5-5% for dysthymia or low grade chronic depressive symptoms (NICE, 2010; Waraich, Goldner, Somers, & Hsu, 2004).

For the second research question we aimed to explore factors associated with carers' health. Six multiple linear regression models were fitted to explore the associations between predictor variables and carer health outcomes. To decide on potential predictors for entering into the regression models, we explored bivariate associations between carers' socio-demographic characteristics and outcomes. Where the bivariate association was significant, the variable was entered in the regression model. Whilst carers' age did not reach statistical significance with any of the outcome variables in the bivariate analysis, it was included in the regression models due to previous research findings of associations with outcomes of carers' health (e.g., Seltzer et al., 2011). The results of the associations are available in Appendix 20. Table 4.3 presents the standardised coefficients from the regression models. Hierarchical forced entry models were fitted for each of the outcomes (distress, burden, family stress, positive gains and subjective and objectively rated health

status). At step 1, predictors entered were carer characteristics, adult relative characteristics and family SEP, to examine the relationships between the socio-demographic profile of carers and their well-being. At step 2, two further predictors were entered: active coping strategies and satisfaction with available support. Empirical evidence suggests that active coping strategies and appropriate support can act to transcend daily stressors (Folkman, Lazarus, Gruen, & Delongis, 1986; Seltzer, Greenberg, & Krauss, 1995) and impact positively on health outcomes. With this step, the aim was to examine how the association between socio-demographic characteristics and carer well-being might change after accounting for the effect of coping and support on well-being.

Table 4.3: Regression analysis of physical and psychological health of carers

Model	Predictor Variables	K6: Distress	ZBI: Burden	PGS: Positive gains	QRS-F: Family stress	EQ-VAS: Subjective health	EQ-5D$_{(Index)}$
1	Carer gender (Female)	.019	-.041	-.073	**-.204**[1]	-.058	-.032
	Carer's age	**-.409**[3]	**-.332**[2]	.079	**-.328**[2]	.160	.012
	Carer's marital status (Co-residing)	.051	.156	-.003	.045	.206	.040
	Adult relative's age	.016	-.058	.073	-.115	-.012	-.152
	Adult relative's gender	-.049	.106	-.016	.095	.035	-.005
	Adult relative's support needs	.138	.146	.016	**.277**[2]	-.047	-.158
	Family SEP	**-.250**[2]	-.031	.005	-.066	**.222**[1]	.040
2	Carer gender (Female)	.019	-.046	-080	**-.205**[1]	-.053	-.026
	Carer's age	**-.387**[3]	**-.303**[2]	.110	**-.294**[2]	.153	.000
	Carer's marital status (Co-residing)	.029	.128	-.031	.011	.220	.049
	Adult relative's age	-.012	-.089	.041	-.156	-.002	-.143
	Adult relative's gender (Male)	-.081	.063	-.064	.046	.056	.014
	Adult relative's support needs	.150	.170	.045	**.295**[3]	-.064	-.174
	Family SEP	**-.227**[2]	.001	.042	-.034	.206	.023
	FSS: Satisfaction with support	-.093	**-.202**[1]	**-.241**[1]	-.150	.118	.138
	F-Copes: Active coping	**-.222**[1]	**-.243**[2]	**-.247**[1]	**-.328**[3]	.081	.062

[1] p=.05, [2] p=.01, [3] p= .001

Model 1: Carer psychological distress (Kessler 6). Carer characteristics, adult relatives' characteristics and SEP entered as predictor variables at step 1 of the model accounted for a significant percentage of the variance in carer's psychological distress scores (R^2 = .247, $F_{(7,91)}$ = 4.27, p < .001). Carer's age (ß = -.409, p < .001) and SEP (ß = -.250, p = .01) were both independently negatively associated with distress, suggesting that being older and of higher SEP is associated with reduced psychological distress. The addition of carers' satisfaction with available support and active coping strategies at step 2, accounted for additional score variance for psychological distress (R^2 change = .073, $F_{(9,89)}$ = 4.84, p = .01). Carers' age (ß = -.387, p = .001) and SEP (ß = -.229, p = .02) both remained significantly negatively associated with distress. Additionally, at step 2, active coping strategies was also independently negatively associated with carer's psychological distress (ß = -.222, p = .03), suggesting that the utilisation of more active coping strategies is associated with reduced psychological distress. Carer's gender (ß = .019, p = .841), marital status (ß = .029, p = .762), adult relative's age (ß = -.012, p = .911), gender (ß = -.081, p = .379) and support needs (ß = .150, p = .105), and satisfaction with available support (ß = -.093, p = .346) were not independently associated with psychological distress.

Model 2: Carer burden (Zarit Burden Index). At step 1, the model predicting carer burden was significant (R^2 = .206, $F_{(7,91)}$ = 3.38, p = .003). Carer's age was the only variable significantly independently associated with carer burden, which was in a negative direction (ß = -.332, p = .01), suggesting older age was associated with lower levels of carer burden. The addition of satisfaction with available support and active coping strategies at step 2 accounted for additional significance in carer burden score variance (R^2 change = .138, $F_{(9,89)}$ = 9.33, p <.001).

Carer's age (ß = -.303, *p* = .01), satisfaction with available help (ß = -.202, *p* = .04) and active coping strategies (ß = -.243, *p* = .01) were independently significantly negatively associated with carer burden. This suggests that older age, greater satisfaction with available support and the adoption of more coping strategies was associated with lower levels of carer burden. Carer's gender (ß = -.046, *p* = .618), marital status (ß = .128, *p* = .169), adult relative's age (ß = -.0895, *p* = .392), gender (ß = .063, *p* = .490), support needs (ß = .170, *p* = .061) and SEP (ß = -.001, *p* = .989) were not significantly associated with burden.

Model 3: Positive gains from providing care (Positive Gains Scale). Step 1 led to a non-significant model (R^2 = .028, $F_{(7,91)}$ = 0.37, p = .917), suggesting that none of the variables in the model were associated with positive gains from caring. The addition of satisfaction with available support and active coping strategies accounted for a significant part of the variance in positive gains scores at step 2 (R^2 change = .165, $F_{(9,88)}$ = 9.11, *p* < .001). Satisfaction with available support (ß = -.241, *p* = .03) and active coping (ß = -.247, *p* = .02) were both independently significantly negatively associated with carer's perception of positive gains from providing care in a negative direction. Lower scores for the positive gains scale indicate greater levels of perceived satisfaction derived from providing care. As with carer burden, these associations suggests that greater satisfaction with available support and adopting more active coping strategies was associated more positive gains from caring. Carer's gender (ß = -.080, *p* = .428), age (ß = .110, *p* = .353), marital status (ß = -.031 *p* = .762), adult relative's age (ß = .041, *p* = .720), gender (ß = -.064, *p* = .528), support needs (ß = .045, *p* = .653) and SEP (ß = .042, *p* = .684) were not significantly associated with positive gains.

Model 4: Family Stress (QRS-F). Regression models at both step 1 (R^2 = .277, $F_{(7,91)}$ = 4.99, p < .001) and step 2 (R^2 change = .167, $F_{(9,89)}$ = 13.37, p < .001) were significant. Carer's gender (ß = -.204, p = .03) and age (ß = -.328, p = .004) were both negatively associated with family stress, whilst adult relative's support needs (ß = .277, p = .003) were positively associated with family stress at step 1. With the addition of the variables of satisfaction with available support and active coping strategies at step 2, carer's gender (ß = -.202, p = .02), age (ß = -.294, p = .003) and adult relative's support needs (ß = .295, p = .001) remained independently associated with family stress. This suggests that being female and older were associated with lower levels of family stress. However, adult relatives having higher support needs were associated with higher levels of family stress. Additionally, active coping strategies were independently negatively associated with family stress at step two (ß = -.328, p < .001). This suggested that carers' adoption of more active coping strategies were associated with reduced family stress. Marital status (ß = .011, p = .894), adult relative's age (ß = -.156, p = .107), gender (ß = .046, p = .581), SEP (ß = -.034, p = .691) and the additional satisfaction with available support (ß = -.150, p = .095) all failed to account for significance in family stress score variance.

Models 5 Subjective health (EQ-VAS). At step 1, the regression model predicting EQ-VAS (general health) was significant (R^2 = .149, $F_{(7,91)}$ = 2.25, p = .04). Only SEP was independently positively associated with subjective health scores, suggesting higher SEP to be associated with better health status. With the addition of satisfaction with available support and active coping strategies at step 2, the model became non-significant (R^2 change = .027, $F_{(9, 89)}$ = 1.47, p = .236). This suggests that when accounting for active coping strategies and satisfaction with available support, SEP was no longer independently associated with general health, neither were the

remaining variables of carers' demographic profile and characteristics of care recipient.

Model 6 Objectively rated health states (EQ-5D$_{(Index)}$). The regression models predicting physical health problems as measured by the EQ-5D$_{(Index)}$ scores were not significant (Step 1 R^2 = .052, $F_{(7, 91)}$ = .708, p = .665 and Step 2 R^2change = .029, $F_{(9,89)}$ = 1.42, p = .248), suggesting that health difficulties weighted to reflect socially preferred health states in this group of carers, were not associated with carers' demographic profile, the characteristics of the care recipient, or coping and satisfaction with available support.

Discussion

The present study adopted a cross-sectional design to examine the well-being of family carers of co-residing adults with an ID. To address the first aim of the study, outcomes of self-reported physical and psychological health states were examined against population data. Comparative analysis indicated significant differences in health status across five domains of health (mobility, self-care, ability to carry out usual daily activities, pain/discomfort and anxiety/depression), with a greater percentage of study participants appearing to experience poorer health outcomes when compared to UK general population data (Kind et al., 1998). Further comparative analyses indicated carers in the study population were experiencing significantly poorer subjective health (EQ-VAS), objectively rated health states (EQ-5D$_{(Index)}$) and psychological distress (K6). Due to the lack of comparative UK data for the latter measure, comparisons were carried out with US population data (The Behavioral Risk Factor Surveillance System, CDC, 2012).

To our knowledge, this is the first study to explore differences in the self-reported health status of UK family carers living with an adult relative with ID with

general population data. The findings are consistent with previous research conducted outside of the UK (Burton-Smith et al., 2009; Seltzer et al., 2011; Yamaki et al., 2009), and trans-Atlantic comparisons (Walden et al., 2000) which also found carers to report poorer health outcomes than non-caregiving peers. Whilst the findings provide further evidence of health disparities between caregiving and non-caregiving families, caution is needed in interpreting the results. Differences may be the result of the time period (Kind et al., 1998) or cultural context (CDC, 2012) within which the comparison studies were conducted. Previous research which has highlighted cross-national differences in quality of life of caregivers (Seltzer et al., 1995; Walden et al., 2000) supports the need for further research with UK samples.

The self-selection of study participants also cannot be ruled out as influencing the results of this study (Bethlehem, 2008; Søgaard, Selmer, Bjertness, & Thelle, 2004). The current study did, however, aim to address the problem of selection bias and under coverage of non-computer users by including the option of a paper copy questionnaire and adopting a mixed recruitment strategy (i.e. via a widely distributed advertisement and face-to-face attendance at carer support and social groups). The offer of Welsh language questionnaires also addressed language equity for Welsh speaking participants. However, the inclusion of other languages and easy read information/questionnaires may have increased participation by families from BME and marginalised communities. Applying methods more commonly used in economics research to address selection bias such as statistical modelling, may also help to identify and address selection bias. Statistical methods such as logistic regression models are used to detect differences in characteristics of participants and those of the target population. Sample selection bias can subsequently be corrected by

weighting the data appropriately to address any potential differences (Bethlehem, 2008; Braver & Bay, 1992; Cuddeback, Wilson, Orme, & Combs-Orme, 2004).

The results of multivariate analyses revealed mixed support for previous research. Carer age was negatively associated with psychological outcomes (carer distress, burden and family related stress), indicating, that being older was associated with better psychological health. This finding is in line with previous research which has shown family carers of adults with ID to self-report improvements in mental health status as they get older (Ben-Zur, Duvdevany, & Lury, 2005; Ha et al., 2008; Llewellyn et al., 2010; Minnes et al., 2007). Lending some support and possible explanation to this age-related phenomenon, Grant, Nolan, & Keady, (2003), propose that caregiving is a stage-based process which involves key transitional stages of skills development. They suggest that, over time, carers develop an expertise of the "art and craft" of caregiving. Grant et al., (2003) further propose that long term caregiving relationships may evolve into increasingly reciprocal arrangements, leading to greater parity within these relationships. Further support for this finding is offered by Llewellyn et al., (2010) who found that younger carers were more likely to report experiencing stress related difficulties such as "feeling helpless" or "not able to relax" as a result of their caregiving role. Whilst older age is associated with a greater propensity to somatic health problems (Llewellyn et al., 2010; Seltzer et al., 2011; Yamaki et al., 2009), Minnes et al., (2007) propose that self-evaluative processes such as carers' perception of aging, as opposed to chronological age or age-related health problems, mediate the relationship between health and depression. The differences in reported health status between older and younger carers may, however, result from survivor effect i.e. the greater propensity for healthier people to survive into older

age. The tendency for cross-sectional studies to be susceptible to this effect (Zigman, Seltzer, & Silverman, 1994), supports the need for more longitudinal research.

Minnes' et al., (2007) mediation theory may also offer some explanation for further results of the current study such as the lack of association between physical health outcomes. Interestingly, subjective health status (EQ-VAS) and objectively rated health states ($EQ\text{-}5D_{(Index)}$) were not associated with any characteristics of the carer or the care recipient. One possibility for this lack of associations is that none of the socio-demographic characteristics we measured was related to the perceived physical health of participants in the current study, even though overall they reported worse physical health status than national norms. With the exception of age (see above), that could suggest that self-perceived physical health in this population is related to the presence of other, unmeasured, characteristics of the carers, for example the presence of physical health problems. Future studies would benefit from including objective evaluations of physical health (for example, the presence of specific diseases). Another possibility relates to the sampling method and suggests that the lack of associations may be specific to the present group of participants only. Finally a further possibility is that the measure used to evaluate physical health status (ED-5D) was not specific enough to capture any associations between carers and care recipients' profiles with specific physical health conditions.

Consistent with a plethora of evidence and social role expectation (Burton-Smith et al., 2009; Chou et al., 2011; Llewellyn et al., 2010; Minnes et al., 2007; Werner & Shulman, 2013), the majority of carers in the current study were female (83%). The mean age of study participants was just under 60 years of age. Inconsistent with the literature which suggests that mothers experience poorer health outcomes than fathers (Olsson & Hwang, 2001; Samadi, McConkey, & Bunting,

2014), the current study found that being female was associated with more positive outcomes of family related stress. No significant relationships were found with the remaining outcomes (i.e. psychological distress, burden, positive gains or general health). Much of the evidence which contradicts this finding is, however, derived from studies of families providing care to children and/or individuals with developmental disabilities such as ASD (Jones, Totsika, Hastings, & Petalas, 2013; Olsson & Hwang, 2001; Samadi, McConkey, & Bunting, 2014). Little is known about gender related difference in well-being when the care recipient is an adult. One US study comparing the impacts of life long caring found no differences in health outcomes for mothers and fathers providing care for a co-resident adult child with ID (Seltzer et al., 2011). A further study exploring outcomes for families providing care for co-resident adults with profound and multiple ID in Taiwan, also found no significant between gender differences in health status (Chou et al., 2011). An explanation for the results found in the current study may relate to gender related differences in cognitive appraisal of stressful events. Theories propose that psychological outcomes occur as a processing response to stressful stimuli and not simply due to experiencing the stimuli alone (Grant & Whittell, 2000; Lazarus & Folkman, 1984). Whilst relatively few studies have examined this phenomenon within ID populations, those which have, explored coping strategies in families of individuals with ID (Grant & Whittell, 2000) and children with autistic spectrum disorders (Hastings, Kovshoff, Brown, Ward, Espinosa, & Remington, 2005). These studies suggest that women have a greater propensity to adopt more positive coping strategies than their male counterparts. More research examining potential difference in caregiving outcomes and adaptive coping strategies of mothers and fathers of co-resident adults with ID is needed to gain a better understanding of potential gender

related health outcomes. This would have practical implications for more informed and better targeted support services.

Psychological resources (i.e. active coping and satisfaction with available support) explained a significant amount of variance in the multiple regression analyses and may provide support for the above finding. The adoption of a greater number of active coping strategies was associated with lower psychological distress, caregiver burden, family stress and more positive gains. Satisfaction with support was associated with lower burden and more positive gains. Previous research provides support for these findings, which have demonstrated that the adoption of active or problem-focused coping and appropriate support can act to buffer the effects of daily stressors (Grant et al., 2003; Grant & Whittell, 2000; Llewellyn et al., 2010; Peer & Hillman, 2012).

Consistent with previous research, higher levels of SEP was associated with lower psychological distress and better subjective general health (Chen et al., 2001; Chou, Lin, Chang, & Schalock, 2007; Chou et al., 2010; Eisenhower & Blacher, 2006). However, when accounting for psychological resources (active coping and satisfaction with available support), SEP was no longer associated with physical health status. Although we should be cautious with this finding, it suggests that any adverse effects on physical health might be buffered by active coping mechanisms and the availability of helpful supports. However, in the current study associations were not large enough to reach statistical significance.

Consistent with previous research (Egan & Walsh, 2001; Walden et al., 2000), adult relatives' support needs was positively associated with family related stress, even after accounting for factors relating to caregivers' psychological resources (coping and support). Overall, however the characteristics of the care recipient were

not associated with carer outcomes. This was most puzzling in the case of support needs, as higher support needs would have been expected to be associated with more negative outcomes. One possibility is that our broad measure of support needs was not robust enough to capture care recipients' adaptive skill levels. Another possibility is that unlike childhood where children's adaptive skills are related to carer well-being (McCarthy, Cuskelly, van Kraayenoord, & Cohen, 2006; Plant & Sanders, 2007), in adulthood carers' well-being becomes less sensitive to the characteristics of the person with an ID, and more dependent on the quality and availability of supports, or potential changes in these supports. Future replications with care recipients of varying ages are needed to examine whether this is a phenomenon related to the life phase each family is going through or limited to our current sample only.

Throughout the discussion, we have mentioned that one potential limitation in the interpretation of the findings is the sampling method, as those who selected to take part might have been better or poorly adjusted. A further limitation was the reliance on carer informants for collecting data on care recipient characteristics. Current UK legislation (Department for Constitutional Affairs, 2007) indicates that care recipient information such as support or adaptive skills levels may be collected by direct data collection following assessments of capacity to participate in research and data collection. In our attempt to balance the need for such information with the need to capture information from as many UK families as possible, we opted for data collection methods that were only accessible to carers. Whilst aimed at reaching a wide population of family carers, this prevented us collecting in-depth data about care recipients' adaptive behaviours and additional support needs. The cross-sectional, correlational design can also only provide a 'snap-shot' of the health of family carers of adults with ID within the UK. Further, large scale, longitudinal research is needed

to gain a more long term view of carers' health and overcome some of the methodological problems of the current study.

The present study provides evidence that family carers co-residing with an adult relative with ID within the UK appear to experience poorer physical and psychological health outcomes than non-caregivers. When examining the factors potentially associated with their well-being, findings from the present study indicated that carer well-being - especially psychological health and positive gains - was largely unrelated to characteristics of the care recipient or material resources. In fact, with the exception of age, it was mostly unrelated to characteristics of the carer. Findings indicated that older carers tended to report less psychological distress, less perceived burden from caregiving, and less family stress. In contrast, psychological resources (coping and support) were systematically related to psychological health and positive gains, highlighting thus the importance of coping strategies that carers use, and the helpfulness of the available support. Finally, findings from the present study also highlighted the lack of associations between carer or care recipient characteristics and physical health. The relationship between physical health and caregiving is a complex one, where the relationship between poorer physical health and caregiving remains unclear (Pinquart & Sörensen, 2007). Findings from the present study seem to suggest that associates of physical health might be different to associates of psychological health. Further large scale, longitudinal research is needed which not only includes an examination of objective indicators of health but also biomarkers such as cortisol levels, to better our understanding of both associates of physical health and the long term impact of psychological stress upon carers' physical health.

Implications for research, policy and practice

Despite the limitations outlined above, the present study does provide further support of the health disparities experienced by caregiving families when compared to non-caregiving peers. The findings suggest that older carers who continue providing long term care to their adult relative report experiencing fewer negative psychological outcomes. Also carers who adopt more active or problem-focused coping strategies and receive more helpful support appear less prone to negative health outcomes. Results from the present study build on previous evidence which suggests that family carers acquire a wealth of skills and expert knowledge through providing care to their family member. Policy makers and service practitioners may, therefore, wish to collaborate with family carers to instigate carer-led, peer support groups to utilise this expert knowledge and help teach active coping strategies. An exploration of service support which is of most help and value to carers is also needed to ensure services are better targeted and fit for purpose. This may also help local government and social care providers when evaluating which services to continue funding.

Overall, findings from the present study do not identify a particular socio-demographic group of carers as more susceptible to poorer well-being. Rather, they indicate that over time and with the appropriate support and coping, psychological well-being, at least, may benefit. More large scale, longitudinal research is needed to both examine and better predicate factors associated with carers' physical health, together with an examination of the implications and impact of experiencing long durations of psychological stress upon carers' physiological outcomes. Future research on other aspects of the caregiving experience may also help us understand what is important for good physical health status or why caregivers report lower well-being compared to the rest of the population.

Chapter 5: Placement decisions of families co-residing with an adult relative with an intellectual disability

Orientation Chapter

The final study is a prospective study, which tracks the placement tendencies of a cohort of families who took part in study 3. Having explored the experiences of families seeking out-of-home accommodation in study 1, the role of family homes in the subjective evaluation of the health and well-being of adults with ID (study 2) and the impact upon carers' subjective health and well-being of providing long term care to their relative with ID (study 3), it was decided to explore the dynamics of placement tendencies of families and factors influencing change in these tendencies and behaviours.

The current social and policy context for seeking an out-of-home placement for an adult relative with ID is starkly different from that of a child. It has now become a normalised aspiration for families and adults with ID to consider living out-of-home. However, much of what is known about families' placement tendencies comes from studies of families of children with ID (Blacher, 1990; Blacher & Hanneman, 1993; Hanneman & Blacher, 1998; Llewellyn, Dunn, Fante, Turnbull, & Grace, 1999; Llewellyn, McConnell, Thompson, & Whybrow, 2005). To our knowledge no studies have explored the dynamics of placement tendencies of families of adults with a wide spectrum of ID and no studies examining placement tendencies have been undertaken in a UK context.

Abstract

Little is known about the placement tendencies of family carers of adults with ID. The aim of the study was to explore the placement tendencies of family carers who co-reside with an adult relative with ID over a 12 month period. Factors associated with changes in families' placement tendency scores over this period have also been explored.

Methods: A longitudinal prospective design was adopted to collect data from 75 family carers at two time points separated by 12 months. At time 1 data were collected via an on-line or postal questionnaire. Twelve months subsequent to completion of the original questionnaires, carers were again asked to complete the PTI only. Scores at the two time points were examined for change. Carer and care recipients' characteristics were examined as covariates of change.

Results: In a 12 month period thirty families had moved forward on the scale, towards increased consideration of an out-of-home placement. Of these families 14 had placed their relative out-of-home. An exploration of single indicators of carer, care recipient and family characteristics revealed only coping as significantly associated with relatives remaining at home at time 2, suggesting that carers who adopt more active coping strategies were less likely to favour an out-of-home placement for their relative by time 2.

Conclusion: Changes in the placement tendencies of family carers of adults with ID demonstrated similar patterns found in previous studies with children with ID/ASD, supporting the predictive properties of the PTI. Placement of adult relatives in out-of-home accommodation did occur more rapidly than an out-of-home placement of children. This may reflect current social policy and societal attitudes to a move out-of-home as more normative for adults with ID than children with ID. The

lack of association with all but one of the carer characteristics and care recipient and family characteristics suggest that changes in placement tendencies may be more affected by factors external to the family. Further large scale research exploring factors not included in the current study need to be undertaken. The implications for practice are also discussed.

Keywords: Family carers, adults, intellectual disability, family homes, placement tendencies

A growing body of empirical evidence exists that explores factors associated with the relinquishment of care of a relative with an intellectual disability (ID) by family carers (Chiu & Hung, 2006; McConkey, Kelly, Mannan, & Graig, 2011; Nankervis, Rosewarne, & Vassos, 2011; Seltzer, Greenburg, Krauss, & Hong, 1997; Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012). These factors include both carer and family characteristics such as age (e.g., being older), physical and mental health problems, family socio-economic status, single carer status, family stress, lack of support and resources, caregiver burden, decline in caregiving capacity and poor coping strategies. Care recipient characteristics include: high support needs, poor health, functional skills and maladaptive/challenging behaviour and the impact of care recipient upon other family members (Chiu & Hung, 2006; McConkey et al., 2011; Nankervis et al., 2011; Seltzer et al., 1997; Taggart et al., 2012).

In more recent years, out-of-home moving for an adult relative with ID has gained momentum as an aspiration associated with equality of rights and not merely as the result of families' inability to continue providing care (Department of Health, 2001, 2009; United Nations, 2006; Welsh Assembly Government, 2007). The guiding philosophy underlying the 'normalisation movement', which has attempted to give parity to the whole lifecycle of people with ID with that of non-disabled people, is human rights (Nirje, 1970). A major development of the 'normalisation movement' was the deinstitutionalisation of people with ID in many Western societies. This aimed to improve the quality of life of people with an ID, and their inclusion in 'mainstream' society. Normalisation principles and relevant policy placed emphasis on the right of people with ID to make choices and decisions in matters which affect their own lives (King's Fund Centre, 1980; Department of Health and Social Security, 1971). Included in these is the right to choose where and with whom to live. These

principles were translated into policy and practice in the UK (e.g., Department of Health, 2001, 2009). It has, therefore, become a more normalised aspiration for families and adults with ID to consider living out-of-home. In reality, however, the relinquishment of the care of a relative with ID is complex and fraught with a number of considerations. A severe lack of appropriate community housing (Department of Health, 2011; Mansell, Beadle-Brown, Skidmore, Whelton, & Hutchinson, 2006; Mansell & Wilson, 2010), together with families' concerns about inappropriate placements, security of tenure, the future well-being of their relative and the belief that better care can be provided at home (Bibby, 2012; Chiu & Hung, 2006; Grey, Griffith, Totsika, & Hastings, in press; Prosser, 1997; Weeks, Nilsson, Bryanton, & Kozma, 2009) all have an impact on families' attitudes towards seeking an out-of-home placement for their relative with ID.

Over two decades ago, Blacher (1990) developed a theory to explain the processes which families pass through prior to placing their child out-of-home. Blacher (1990) proposed that placement decisions do not occur as a one-off discrete event, but as the result of protracted, stage based cognitive and behavioural processes. These processes involve periods of decision-making and deliberation prior to the act of placement. Each stage of the decision making process is sequential. Theoretically, no family could achieve a higher stage of the placement process without having first passed through earlier stages. Blacher (1990) empirically tested this theory, by adopting a prospective design to examine the ongoing cognitive and behavioural processes of 84 families of children aged 3 to 8 years with severe ID over a three year period. Blacher's (1990) placement tendency theory is characterised by six hierarchical decision making and behavioural stages. These stages not only characterise the processes involved in placement tendencies but are also reflective of

families' beliefs about care provision which intrinsically influence these decisions. The six placement decision making stages progress from 1) 'never having thought about it', through to 6) 'son or daughter has moved out of the family home' (see table 2 for full scale). Blacher's (1990) study demonstrated, over a series of three interviews, that families, who were committed to the continued care of their child (stages 1-3 of the PTI) at interview 1, demonstrated little or no change in their placement thinking during subsequent interviews. Strong relationships were also found between families who had initially reached higher or further stages of the placement process at the beginning of the study period (4 = making enquiries or 5 = initiating paperwork) and subsequent occurrence of out-of-home placement. Blacher (1990) called these latter stages "the point of no return", due to the seemingly inevitable move towards a placement, once families had reached these stages of decision making.

Support for Blacher's (1990) placement tendency theory and the predictive properties of the Placement Tendency Index, (PTI), come from both retrospective (Blacher & Baker, 1994; Llewellyn, Dunn, Fante, Turnbull, & Grace, 1999) and prospective, longitudinal studies of families with young children (Blacher & Hanneman, 1993; Hanneman & Blacher; 1998; Llewellyn et al., 2003; Llewellyn, McConnell, Thompson, & Whybrow, 2005) and adolescents/young adults (McIntyre, Blacher, & Baker, 2002) with severe or profound ID and children with autistic spectrum disorders (ASD)/pervasive developmental disorders (PDD, Perry & Black, 2006). In a prospective study spanning approximately six years, Blacher and Hanneman (1993) examined behavioural-intentional dynamics of placement decisions as predictors of the duration until placement of 100 families of children and adolescents with severe ID. Mean placement tendency scores showed a steady

increase over the duration of the study, with 20 families having placed their children out-of-home by the end of the study.

In the same study Blacher and Hanneman (1993) went on to examine the connection between intent and subsequent placement behaviour. Results showed a variable pattern of parental attitudes and placement intentions which was influenced by, not only the dynamics of child and family characteristics, but personal and prevailing societal attitudes to out-of-home placement of a child with ID. Whilst these variable patterns of parental attitudes/intentions made it difficult to predict subsequent behaviour from intention, significant, albeit, modest associations were found between initial PTI scores and actual placement. Families scoring lowest on the PTI at time 1 (between 1 and 3) of the study were most likely to show greater stability in scores and record a similar score by the end of the study. These lower scores were reflective of families who demonstrated a firm commitment to the continued home care of their child throughout the study. Consistent with subsequent studies, the presence of a child exhibiting maladaptive behaviours which impacted negatively upon other family members was associated with higher scores on the PTI and a move closer to an out-of-home placement (Hanneman & Blacher, 1998; Lewellyn et al., 1999; Llewellyn et al., 2003; Llewellyn et al., 2005; McIntyre et al., 2002) or the relinquishment of care by families (Alborz, 2003; Nankervis et al., 2011). This study also demonstrated that the predictive validity of the PTI was strongest over shorter periods (e.g., 18 months) but demonstrated weaker associations over longer periods of time.

A further longitudinal study examined not only the effects of child characteristics and home environment upon families' behavioural intentions, but ways in which behavioural intentions (placement tendencies) mediate the effects of these variables on the probability of placement occurring (Hanneman & Blacher, 1998). To

account for the increased weakness in predictability of placement tendencies over time, data were collected on both predictor and outcome variables over five time points (separated by approximately 18 months). This allowed for monitoring changes in both predictor and outcome variables. Whilst not highly predictable, prior behavioural intentions did appear to exert an influence on actual placement independent of other predictor variables. Factors independently associated with probability of placement included child appearance (families whose child had fewer physical impairments and stereotypical behaviours were less likely to favour placement) burden of care and the negative impact of the child upon the family were significant factors. Other notable predictors of attitudes which favoured out-of-home placement were mothers' higher levels of education and greater occupational prestige and a larger number of siblings. Caregiver stress was found to be predictive of both placement intentions and actual placements. Llewellyn et al., (2003) however, found no significant associations between placement intentions and income or number of siblings in household. A significant association was found between number of adults living in the household and placement intentions.

Previous studies exploring families' placement tendencies to date have been extensive in their breadth and depth, with longitudinal studies focusing on the on-going dynamics between factors influencing families' attitudes, behavioural intentions and subsequent placement behaviours (Blacher, 1990; Blacher & Hanneman, 1993; Hanneman & Blacher, 1998). Other studies have adopted comparative designs to examine factors influencing between group differences in families' placement tendencies and behaviours (Llewellyn et al., 2003; McIntyre et al., 2002). In common all these studies have focused on the placement tendencies of families of children with severe to profound ID (Blacher, 1990; Blacher & Hanneman, 1993; Hanneman &

Blacher, 1998; Llewellyn et al., 2003; 2005) or ASD (Perry & Black, 2006). To our knowledge, no studies have explored the dynamics of placement tendencies and factors associated with changes in these tendencies of families of adults with a wide spectrum of IDs. Whilst McIntyre et al., (2002) explored placement tendencies of parents of young adults with ID, their focus was on the transitional period between adolescence and adulthood (16 and 25 year of age). Many of their study sample were still attending educational institutions. Adolescence is a time of change, which is characterised by issues specific to this developmental period such as biological change and a striving for greater autonomy (Crockett & Crouter, 2014). Families' placement decision may therefore have been influenced by different factors to those of families of older relatives. Whilst factors influencing the relinquishment of care of a child with ID (Llewellyn et al., 1999, 2003, 2005) and adults with ID (McIntyre et al., 2011; Nankervis et al., 2011) do not appear to differ considerably, the contemporary social and policy context within which care is provided in Western societies does differ. Families and adults with ID are now afforded greater aspirations towards independence which, in principle, are increasingly gaining normative status (Department of Health, 2001, 2009; United Nations, 2006; Welsh Assembly Government, 2007). The placement of a child either with or without a disability out-of-home is considered less usual and is often prompted by adverse family circumstances (Beeman, Kim & Bullerdick, 2000; Ehrle & Green, 2002). Therefore these factors may relate differently to placement tendencies and behaviours of families with adults with ID. Therefore the aims of the study are to

a) examine changes in the placement tendencies of families of adults with ID over a 12 month period using the PTI (Blacher, 1990; Blacher & Hanneman, 1993).

b) identify whether earlier social, demographic, or psychological characteristics of the family or the adult with ID are associated with changes in the placement index.

Method

The study reported in this paper is a longitudinal prospective study exploring placement decision of family carers who co-reside with an adult relative with ID over a 12 month period. This study is a follow up on an original cross-sectional study examining the health and well-being of 110 family carers of adults with ID. Participants from the original study were asked to indicate their agreement to be contacted by researchers for potential inclusion in the follow up study 12 months subsequent to completion of a batch of questionnaires at Time 1. Placement Tendency scores were measured at Time 1 and Time 2. The criteria for inclusion in this study required participants to be English or Welsh speaking and the main carer for an adult relative aged 18 years or over who was, at time 1 of the study, living in the family home.

Participants

All measures included in this study were carefully chosen for their ease of completion and suitability in an online or postal survey. At Time 1, participants completed a demographic questionnaire specifically designed for the current study, together with a batch of other measures which included the PTI (see measures section).

Carer characteristics. Of 110 family carers at Time 1, 105 families agree to be contacted at Time 2. The final number of participants who completed and returned PTI questionnaires at Time 2 was $N = 75$, of who 11 (14.7%) were male and 64

(85.3%) were female (see Table 5.1 for demographic information). Although the majority of carers answered all questions, percentages are shown based on the total number of people who responded to each question. The majority of carers were mothers/step-mothers (80%), with only 10 (13.0%) being fathers/step-fathers. Other family carers were siblings, cousins, aunts, uncles, spouses and adult children (see Table 5.1 for full details). Family carers' ages ranged from 36 to 86 years (M = 61.36 years; SD = 10.15), with 35 (46.7%) being within the working age range (aged 20-60 years) and 40 (53.3%) being over 61 years of age. Thirty five (48.6%) carers had no to low levels of education and 37 (51.4%) were educated to advanced school level and above. The majority of family carers did not have paid work (N = 50, 66.7%). Over half of carers (N = 42, 56.0%) were co-residing with a partner or spouse and 33 (44.0%) were single, divorced or widowed and not co-residing with a partner. With the inclusion of adult relatives with ID, the average number of people resident in each household was 3 (range 2-6 individuals, SD = 0.98).

Adult relative characteristics. The age of adults with ID ranged from 18-67 years (M = 36.18, SD = 11.99) with 46 people (61.3%) being male and 29 (38.7%) being female. Five variables indicated whether adult relatives had additional support needs i.e. 1) 'is able to speak/sign 30 words or more' (reverse scored), 2) 'has visual or hearing impairment', 3) 'is continent during the day time and/or night time' (reverse scored), 4) 'currently has epileptic seizure' and 5) 'needs support at meal times'. A composite support needs variable was created with scores ranging from 0-5, with higher scores representing higher support needs. The separate variables making up the composite support needs variable are presented in Table 5.1. About 27% (N = 28) of care recipients had no additional support needs, whilst 28% (N = 21) had one

impairment, 17.3% (*N* = 13) had two. Four percent (*N* = 3) of care recipients were reported as having all five of the listed impairments.

Table 5.1 Demographic characteristics for participating carers and their adult relatives with ID

		Number and percentage
Family carer's gender :	Male	11 (14.7%)
	Female	64 (85.3%)
Country of residency	England	46 (61.3%)
	Wales	27 (36.0%)
	Other (Northern Ireland & Scotland)	2 (2.7%)
Relationship to adult with ID:		
Mother/step-mother		60 (80.0%)
Father/step-father		10 (13.3%)
Sister/step-sister/sister-in-law		3 (4.0%)
Spouse/partner		1 (1.3%)
Other relatives (including aunt/uncle, cousin, daughter)		1 (1.3%)
Carer marital status:	Living with spouse/partner	42 (56.0%)
Not living with spouse/partner		33 (44.0%)
Number of people living in family home (incl. adult with ID):		
Two		23 (30.7%)
Three		40 (53.3%)
Four or more		12 (16.0%)
No/low level of education		35 (48.6%)
Advanced school education or above		37 (51.4%)
Carer employment status	Yes (full or part time)	25 (33.3%)
	No	50 (66.7%)
Income poverty		
Families with a weekly net income at/or below poverty line		33(44.0%)
Families with a weekly net income above poverty line		42 (56.0%)
Gender of adult relative with ID:	Male	46 (61.3%)
	Female	29 (38.7%)
Adult with ID able to speak/sign 30 words or more:	Yes	56 (74.7%)
	No	18 (24.0%)
Visual impairment		7 (9.5%)
Hearing impairment		13 (15.6%)
Needs support to eat		24 (32.0%)
Communication difficulties		18 (24.3%)
Incontinent during the	Daytime	17 (23.0%)
	Night time	7 (11.7%)
Has epileptic seizures		12 (16.7%)
Adult relative with ID attends a day time activity (including paid work, workshop, voluntary work, day centre, respite provision)		63 (86.3%)

Measures

All measures including the PTI were completed at Time 1 of the study (Appendices 10 to 17). The PTI was subsequently re-administered at Time 2 for the prospective follow-up study. All predictor variables used in the current study were created from data collected at Time 1. Apart from the follow-up PTI data, no other additional data was collected from carers at Time 2.

Placement tendency of families. The Placement Tendency Index (Blacher, 1990) (Appendix 6) is a single item measured on a 6-point scale that assesses thoughts and actions regarding out-of-home placement of a relative (Blacher, 1990). The scale is hierarchical and ranges from 1 = "never thought about it [placement]", through to 6 = "our son/daughter has moved out of the family home" (see Table 5.2 for full scale). Each stage of the scale is sequential therefore, theoretically carers cannot achieve a stage without having previously passed through an earlier stage. Placement tendency or decisions are assessed on stages 1 to 5, with 6 indicating an actual out-of-home placement has occurred. The original wording was changed to reflect a UK context with the word 'placement' being substituted by the word 'accommodation' and stage 6 'we have placed our child' being substituted for 'our son/daughter has moved out of our home'. This measure was specifically developed to assess attitudes or intentions to seek out-of-home accommodation and subsequent actions of parents of children with ID (Blacher, 1990) and has also been used with young adult populations (McIntyre, Blacher & Baker, 2002). Inter-rater reliability (parental agreement) is reasonably high at $r = .78$, $p < .0001$ (Blacher & Hanneman, 1993).

Socio-economic position. The household composition variable was weighted in accordance with the OECD-modified equivalence scale (Office for National

Statistics, 2013) to create a new single variable weighted to account for household composition. Equivalisation scales are used to adjust household income in a way that accounts for household size, composition, and income (Office for National Statistics, 2013). The scale is used to allocate different weights to each member of a household depending on role (i.e. head of the household) and age (i.e. under or over 14 years of age). This variable was then summed to get a total value which represents equivalised household composition. A second single variable was calculated from the mean of the weekly family household income. Equivalised net or disposable household income for families ranged between £83 and £567 per week (M = £252.13, SD = 127.71). Median weekly net UK household income for 2013 was £406 (Office for National Statistics, 2013). This new weekly income variable was then divided by the equivalised household composition variable to create a new single household income variable which has been adjusted to take account of household size and composition. A dichotomous variable was subsequently derived using the equivalised household income variable, to represent families who would be considered as earning a weekly income which was above or below the poverty line. The poverty line was a weekly net household income of 60% below the median for 2013, which was £243.59 and below for the present sample. Fifty six percent (N = 42) families' weekly income was below the poverty line.

Postal code information was linked to geographical lower layer super output areas (LSOA) for each of the UK countries and used to estimate area deprivation using the Index of Multiple Deprivation. The Index of Multiple Deprivation (IMD) is an official, country specific measure which identifies relative deprivation for small areas. Each of the four UK constituent countries has unique indices comprising domains which target specific within country policies (Department of Communities

and Local Government, 2011; Northern Ireland Statistics Research, 2010; Scottish Government, 2012; Welsh Government, 2011). Common to all indices are the domains of income, education, employment, health, crime and living environment/housing. Quintile ranking is used to order scores for each of the indices. The IMD variables for Scotland (SIMD, 2012) and Northern Ireland (NIMDM, 2010) are both ranked 1 = most deprived and 5 = least deprived, whereas the indices for England (IMD, 2010) and Wales (WIMD, 2011) are ranked in the opposite order. Therefore the indices for Scotland and Northern Ireland were reverse ranked for conformity with the English and Welsh IMD variables. All IMD scores were then transformed into a single IMD variable for the UK. A dichotomous variable was created indicating whether carers were living in one of the 20% most deprived neighbourhoods. This dichotomous variable was used as an indicator of deprivation likely to be experienced by each household only and not as a between country comparator. Fifteen (21.4%) families reported living in areas which would be classified as within the top 20% most deprived areas of the UK.

Family resources. The Family Resources Scales (FRS, Dunst & Leet, 1986, 1987) (Appendix 11) comprises 30 items rated on a six point Likert scale, measuring the extent to which resources for families are adequately met (e.g., basic necessities such as food and shelter, and less essential resources such as family holidays). This scale was analysed both as a total score and, separately, included as part of the family socio-economic position (SEP) composite variables, to indicate family hardship. Two of the subscales which indicated material hardship ('necessities and health' and 'physical necessities and shelter') were summed to create a single interval 'material resources' variable with scores ranging from 0 to 60. These total score and the sub-scales demonstrated a high level of internal consistency with the current study sample

(total score Cronbach's α = .93, 'necessities and health Cronbach's α = .83 and 'physical necessities and shelter' α = .89). They comprise questions relating to whether families have enough money to buy food, heat their homes, for health care and for necessities for their relative with ID. The summed scores of the 'material resources' variable were subsequently split at the median (median score = 49), to form a single dichotomous 'hardship' variable indicating whether 'resources were less adequately met' or 'resources were more adequately met' for families. Thirty five (46.7%) families felt that access to resources were not adequate to meet their families' needs.

A composite variable indicating families' socio-economic position (SEP) was created using five indicators: small area deprivation (IMD), hardship, carers' employment status, educational status (coded '0 = no/low education' and '1 = advanced school level and above') and income poverty. The SEP composite scores ranged from zero to five, with higher scores representing a higher socio-economic position.

Carer's health related quality of life. Health related quality of life of family carers was measured by the EQ-5D-3L (EuroQol Group, 1990) (Appendix 12a and 12b) (EQ-5D-3L is a generic measure of health-related quality of life which includes a descriptive system (EQ-5D) and a visual analogue scale (EQ VAS). The descriptive scale enables participants to self-classify health states along five dimensions (mobility, self-care, usual activities, pain/ discomfort and anxiety/depression). The descriptive system is measured at ordinal level with each dimension being at 3 levels, 'no problems', 'some problems' and 'extreme problems'. Participants respond according to how they perceive their own health status at time of completion. Higher scores indicate lower level of health in a particular dimension of health. The

descriptive system has the potential of defining a total of 243 health states. The scale can either be used to generate individual health states or, by applying weights to the descriptive system, can be converted into an objectively rated single index health score.

The EQ-VAS is a 20 cm visual analogue scale on which respondents rate their subjective general health state on the date of completion. The scale ranges from 0 (worst imaginable health state) to 100 (best imaginable health state). The EQ-VAS measure provides an indication of participants' unadjusted subjective health status.

Care recipient's health related quality of life. Health related quality of life of adult relatives was measured by the EQ-5D-3L, Proxy version 2 (EuroQol Group, 1990) (Appendix 21). This measure is made up of the same two page measure as the self-completed EQ-5D, with both the descriptive and VAS measures included. The proxy version requires 'the proxy' to rate how he/she thinks the care recipient would rate his/her own health related quality of life.

Family stress. The Questionnaire on Resources and Stress – short form (QRS-F: Friedrich, Greenburg & Crnic, 1983), Parent and Family Problem Sub-scale-7 item version (Griffith, et al., 2011) was used (Appendix 13). The QRS-F is a self-report questionnaire which measures general stress related to caring for a family member with a disability or chronic illness. Respondents answer 'true' or 'false' to statements (e.g. 'caring for my relative with ID puts a strain on me', 'other member of the family have to do without things because of relative with ID'). Four of the questions are negatively worded, whilst 3 are positively worded. Therefore the latter 3 questions were reverse coded for consistency with the negatively worded statements. The original wording of item 3 ('In future our family's social life will suffer because of the increased responsibilities and financial stress') was amended to reflect the

situation for families with adult relatives with ID (i.e. 'Our family's social life has suffered because of caregiving responsibilities and financial stress'). The total score for this measure is 7, with lower scores reflecting lower levels of family stress. The 7-item measure has shown good internal consistency for psychological distress in parents (KR-20 coefficients = .78 to .89) of children with rare genetic conditions (Griffith et al., 2011). The composite measure showed a high level of internal consistency for the current study population (KR-20 coefficient = .81).

Family support. The Family Support Scale (FSS; Dunst, Jenkins & Trivette, 1984) (Appendix 14) is a self-report measure comprising 19 items designed to assess potential sources of support available to family carers and the degree of perceived helpfulness. Responses were coded on a 5 point Likert scale where 0 = not available, 1 = not at all helpful, 2 = sometimes helpful, 3 = generally helpful, 4 = very helpful and 5 = extremely helpful. The FSS has demonstrated excellent internal consistency in studies of older and younger carers of adults with ID (Cronbach's α = .88, Chou, Lee, Lin, Kröger & Chang, 2009). The composite measure of all 19 items also showed an acceptable level of internal consistency for the current study participants (Cronbach's α = .69).

Family coping. The Family Crisis Oriented Personal Scale (F-Copes; McCubbin, Olson & Larsen, 1981) (Appendix 15) consists of 30 statements designed to assess coping strategies and effective problem solving behaviour adopted by families in response to problems or difficulties. The questions are presented on a 5-point Likert-scale, scored 1) strongly disagree, 2) moderately disagree, 3) neither agree nor disagree, 4) moderately agree and 5) strongly agree. The scale was designed to measure problem focused and passive coping strategies used by families in times of crisis. The F-Copes has yielded excellent levels of internal consistency and reliability

in large scale studies of older and younger family carers of adults with ID (e.g. Hayden & Heller, 1997, Cronbach's α = .86). Four variables which indicate passive appraisal (i.e. 'watching television', 'knowing luck plays a big part in how well we are able to solve family problems', 'feeling that no matter what we do to prepare, we will have difficulty handling problems' and 'believing if we wait long enough, the problem will go away') were reverse coded. All variables were subsequently summed to create a single variable for coping strategies with scores ranging from 30-150. Higher scores indicate more active coping strategies. Total active coping strategies scale showed excellent internal consistency (Cronbach's α = .87).

Carer distress. The Kessler 6 (K6, Kessler et. al., 2002) (Appendix 16) is a six item scale measuring non-specific psychological distress over a past 30 day period. The K6 was developed to measure psychological distress levels in general community populations. Respondents rate each of the 6 items (a) so sad nothing could cheer you up, b) nervous, c) restless or fidgety, d) hopeless, e) everything was an effort, f) worthless) on a 5 point Likert scale scored to reflect how often carers' experienced negative feelings: 0) none of the time, 1) a little of the time, 2) some of the time, 3) most of the time and 4) all of the time. The maximum score is 24, where higher scores indicate greater levels of carer distress. The K6 has very good predictive validity for psychiatric disorders as it has been shown to predict reliably serious mental illness (SMI) in general population samples in the USA (Kessler, 2002; Kessler et al., 2003). The K6 is not gender, age, nor education biased (Kessler et al., 2002). The measure showed excellent levels of internal consistency for the study sample (Cronbach's α = .90). The K6 was also transformed into a dichotomous variable using the score of 13 or above to categorise carers who were at risk of serious mental illness (SMI). Scores 1-12 indicated carers' who were not at risk of SMI.

Carer burden. The Zarit Burden Index -12-items (ZBI; Bédard, Molloy, Squire, Dubois, Lever, & O'Donnell, 2001) (Appendix 17). The abridged 12-item, self-report index has been developed from the original 29 item scale (Zarit, Reever, & Bach-Peterson, 1980) designed to measure subjective caregiving burden. Example questions are 'Do you feel stressed between caring for your relative and trying to meet other responsibilities to your family or work?' and 'Do you feel your health has suffered because of your involvement with your relative?' Each item is rated on a 5-point scale: 0) never, 1) rarely, 2) sometimes, 3) quite frequently, 4) nearly always. Question 9 ('Do you feel you have lost control of your life since x's condition?) was omitted from the current study, as this related to the onset of a condition in later life such as Alzheimer's disease. The maximum score of the 11 questions was therefore, 44 with higher scores indicating higher levels of burden. Although the original 29-item measure was designed to measure burden in carers of dementia patients, it has shown excellent internal consistency in previous studies assessing burden in family carers of adults with ID (Essex, Seltzer, & Krauss, 1999; Kim, Greenberg, Seltzer, & Krauss, 2003, Cronbach's α .86 and between α .82-.84 respectively). The total measure showed excellent internal consistency for the study population (Cronbach's α = .85).

Procedure

The study protocol was approved by the Research Ethics and Governance Committee at Bangor University in the UK. Recruitment of participants was facilitated through statutory and voluntary organisations who circulated a recruitment advertisement to their members and service users via email, websites and newsletters. Social media (e.g., Twitter and Facebook, on-line fora) were also used to distribute information about the study. Of the 110 participants at Time 1, 105 consented to be

followed up 12 months later. Eighty participants were contacted by post (43 returned data) and 21 were contacted by telephone (11 returned data). Four families were not contactable or not available at Time 2. Overall participant retention rate was approximately 71%.

Results

To answer the first question of whether changes occurred in families' placement decision between Time 1 and Time 2 of the study, an initial examination of scores at both time points was undertaken (Tables 5.2 and 5.3).

Table 5.2: Overall placement tendency scores for participants at Times 1 and 2.

Placement Tendency Index	Time 1	Time 2
1) No, we have never thought about it	11 (14.7%)	12 (16.0%)
2) Occasionally we have given it a thought	20 (26.7%)	14 (18.7%)
3) Yes, we have thought a lot about it, but we have done nothing about it	10 (13.3%)	9 (12.0%)
4) We have thought about it and made enquiries	16 (21.3%)	20 (26.7%)
5) We have started to put into action the process of finding accommodation	18 (24.0%)	6 (8.0%)
6) Our son/daughter has moved out of our home	-	14 (18.7%)

In a period of 12 months, families' placement tendency scores did change. Table 5.3 shows the changes in families' placement decisions from Time 1 to Time 2, in terms of stages on the Placement Tendency Index.

Table 5.3: Changes in families' PTI Scores from Time 1 to Time 2 in terms of stages on the PTI

PTI Scores at Time 1	0-point change N (%)	1-point change N (%)	2-point change N (%)	3-point change N(%)	4-point change N (%)	5-point change N (%)
Forward movement and static scores on PTI						
1	8 (10.7)	2 (2.7)	-	-	-	-
2	8 (10.7)	5 (6.7)	2 (2.7)	-	2 (2.7)	-
3	2 (2.7)	5 (6.7)	-	-	-	-
4	9 (12.0)	2 (2.7)	1 (1.3)	-	-	-
5	4 (5.3)	10 (13.3)	-	-	-	1 (1.3)
Backward movement on PTI						
1	-	-	-	-	-	-
2	-	3 (4.0)	-	-	-	-
3	-	3 (4.0)	-	-	-	-
4	-	2 (4.0)	1 (1.3)	1 (1.3)	-	-
5	-	4 (5.3)	-	-	-	-

Whilst 31 families' (approximately 41% of the total number of participants) decisions to consider out-of-home placement for their relative at both time points remained unchanged, 30 families (40%) demonstrated movement in a forward direction, reflecting increased consideration of out-of-home placement. Fourteen families (almost 19%) showed a backwards move, further away from considering placement. Unexpectedly, eight of these families were at the later stages of placement thinking at Time 1 (a move from 4 or 5 on the PTI to the previous or earlier stage on the Index). Of the families whose scores had remained unchanged, 13 (17%) were at the later stages of placement decisions at both Times 1 and 2 (PTI scores 4 or 5). Out of the 30 families (40%) who had moved forward, closer to considering a placement, including 10 families who had placed their relative out-of-home at Time 2, 24 families (almost 32%) had moved forwards only one step on the PTI. Nine families (12%), which

included seven of those who had progressed only one step forwards, had progressed to the more serious stages of considering an out-of-home placement, (i.e., stage 4, making enquiries or stage 5, initiating paperwork). Fourteen families (almost 19%) had placed their family member out-of-home at Time 2 (score 6). Of the 14 families who had placed, the majority (11, almost 79%) were at stage 4 or 5 on the PTI at Time 1. Three of the remaining families who had placed were, however, only in the early stages (1 and 2) of placement thinking at Time 1.These families made the leap from score 1 (Never having considered a placement) and 2 (Occasionally giving placement a thought) to having placed their off-spring out-of-home by Time 2. This finding is inconsistent with Blacher's original placement tendency theory which poports that placement decisions are hierarchical and that theoretically no person could achieve any step on the PTI without having first passed through a previous sequential stage. This is also inconsistent with Blacher's finding of strong relationships between families recording lower scores on the PTI (scores 1 and 2) and a lack of placement (score 6) or risk of placement (score 4) occurring at a subsequent 18 to 24 month period (Blacher, 1990). The finding of the current study may, however, be the result of families' responding to a sudden change of circumstances such as a 'crisis' situation where continued home care was no longer feasible (Blacher & Hanneman, 1993) or had undertaken an unexpected opportunity for their son or daughter to live more independently (Llewellyn et al., 2003). Whilst these seemingly abrupt placement behaviours do not follow the predicted behavioural patterns of placement tendency theory and may appear to bear little relationship to carers' initial placement intentions as captured by the PTI, Blacher (1990) does make the point that the decision to look for out-of-home accommodation is complex. Initial intentions recorded by families of 'never having thought about out-of-home accommodation',

may not necessarily rule out some less tangible thoughts towards placement which have not been explicitly expressed or recorded on the PTI by families.

To answer the second research question exploring factors associated with changes in families placement decisions occurring between Times 1 and 2, we created two new dichotomous outcome variables using the PTI scores from Time 1 and Time 2, as below:

1) No change/moved backwards (*N* 45, 60%) vs moved forwards (*N* 30, 40%) on the PTI.
2) Living at home (*N* 61, 81.3%) versus moved out of home (*N* 14, 18.7%) at Time 2.

In order to examine independent factors which may increase the likelihood of the observed events occurring (i.e., a move forwards on the PTI, closer to more serious consideration of an out-of-home placement and a move out of home) without the presence of other possible confounding factors, we first regressed the two outcome variables in logistic regression models on single indicators of carer characteristics, adult relatives' characteristics and family characteristics (see Tables 5.3, 5.4 and 5.5).

Table 5.4: The association between change on the PTI and carer socio-demographic and psychological characteristics. Unadjusted odds ratios (OR) with 95% confidence intervals (CI) are reported and were obtained from simple logistic regression models.

	No change/backward vs forward move Unadjusted OR (95% CI)	Living at home vs moved out Unadjusted OR (95% CI)
Age	0.98 (0.94-1.03)	1.0 (0.94-1.06)
Gender (0 = male, 1 = female)	0.50 (0.14-1.82)	0.32 (0.08-1.32)
Marital Status (0 = not co-residing, 1 = co-residing)	1.65 (0.64-4.25)	3.55 (0.90-13.99)
Relationship to relative (0 = other relative, 1 = parent carer)	0.42 (0.07-2.67)	0.91 (0.94-8.85)
Carer's education (0 = no/low education, 1 = advanced school and above)	0.81 (0.32-2.08)	0.45 (0.14-1.51)
Paid work (0 = no, 1 = yes)	2.10 (0.79-5.60)	2.39 (0.73-7.80)
EQ-5D (0 = no problems, 1 = problems)		
- Mobility	0.55 (0.19-1.57)	0.56 (0.14-2.23)
- Self-care	0.72 (0.17-3.14)	0.00 (0.00- .)
- Usual activities	1.26 (0.49-3.23)	0.54 (0.15-1.91)
- Pain/discomfort	2.0 (0.76-5.48)	1.01 (0.31-3.29)
- Anxiety/depression	2.08 (0.79-5.48)	1.40 (0.41-4.78)
EQ-VAS	0.99 (0.96-1.01)	1.03 (0.99-1.07)
Kessler 6 total scale	1.05 (0.96-1.14)	1.06 (0.95-1.18)
Kessler 6 (0 = no SMI; 1 = SMI)	1.23 (0.30-5.01)	2.50 (0.54-11.54)
ZBI total scale	1.05 (0.99-1.12)	1.04 (0.97-1.23)
Coping – total scale	0.97 (0.95-1.00)	**0.95 (0.91-0.98)***
QRS-F total scale	1.18 (0.93–1.49)	1.35 (0.96-1.89)

*p = .05

Table 5.5: Unadjusted odds ratios for adult relative's characteristics

	No change/backwards vs forwards move Unadjusted OR (95% CI)	Living at home vs moved out Unadjusted OR (95% CI)
Age	101(0.96–1.05)	0.99 (0.94-1.04)
Gender	0.87 (0.34-2.25)	1.24 (0.38-4.03)
Has a hearing or visual impairment (0 = no, 1 = yes)	0.48 (0.16-1.44)	0.64 (0.16-2.56)
Needs support to eat (0 = no, 1 = yes)	0.38 (0.13-1.40)	0.13 (0.02-1.04)
Continent during day time (0 = no, 1 = yes)	1.24 (0.40-3.83)	1.79 (0.36-9.02)
Continent during night time (0 = no, 1 = yes)	1.64 (0.29-9.25)	1.40 (0.15-12.93)
Epilepsy (0 = no, 1 = yes)	1.07 (0.30-3.77)	1.67 (0.38-7.27)
Does a daytime activity (0 = no, 1 = yes)	0.66 (0.17-2.51)	0.94 (0.18-5.01)
EQ-5D (0 = no problems, 1 = problems)		
- Mobility	2.20 (0.81-5.88)	1.62 (0.46-5.76)
- Self-care	0.77 (0.16-1.18)	0.36 (0.10-1.30)
- Usual activities	4.00 (0.81-19.76)	1.18 (0.23-6.09)
- Pain/discomfort	1.34 (0.52-3.43)	0.71 (0.21-2.36)
- Anxiety/depression	2.26 (0.79-3.33)	0.48 (0.15-1.52)
EQ-VAS	0.99 (0.97-1.01)	1.00 (0.97-1.02)

$^{*}p = .05$

Table 5.6: Unadjusted odds ratios for family characteristics

	No change/backward vs forward move Unadjusted OR (95% CI)	Living at home vs moved out Unadjusted OR (95% CI)
Income Poverty (0 = below poverty line, 1 = above poverty line)	1.20 (0.47-3.03)	0.66 (0.20-2.18)
Composite SEP	1.23 (0.86-1.76)	1.48 (0.92-2.37)
Resources adequately met (0 = no, 1 = yes)	1.57 (0.62-4.00)	1.74 (0.52-5.80)
Number of people living in household	1.29 (0.80-2.08)	1.41 (0.82-2.43)
Number of people over 14 years	1.09 (0.65-1.83)	0.95 (0.49-1.84)
Satisfaction with available support (0 = no, 1 = yes)	0.91 (0.49-1.70)	0.60 (0.25-1.41)
Family Resources Scale – total scores	1.0 (0.56-1.31)	1.01 (0.99-1.04)
Family Support Scale – total scale	1.00 (0.96-1.05)	0.98 (0.93-1.04)

*p = .05

The total coping score was the only variable which was significantly negatively associated with relatives remaining at home at Time 2 of the study (OR = 0.95, (95% CI 0.91-0.98), p = .01). This indicates that carers who adopt more active coping strategies were more likely to continue providing home care to their relative at Time 2. No other predictor variables were significantly associated with either outcome variable at Time 2. It was intended to explore these associations further in multivariate models. However, given the lack of significant findings in univariate analyses, together with the wide CI for most of the ORs, this was not considered viable.

Discussion

The present study adopted a prospective design to examine potential changes in the placement tendencies of family carers of adults with ID over a 12 month period and assess factors associated with these changes. To our knowledge, this is the first

study to explore the placement tendencies of family carers of adults with ID. To address the first aim of the study, we examined families' PTI score between Time 1, when all adult relatives were living in family homes, and at a subsequent 12 month period. Descriptive data showed that changes in the placement tendencies of families' of adults with ID, on the whole, showed similarities in patterns found in previous studies with children with severe ID and/or autism (Blacher, 1990; Blacher & Hanneman, 1993; Hanneman & Blacher, 1998; Llewellyn et al., 2005; McIntyre et al., 2002; Perry & Black, 2006)..

Consistent with previous evidence and lending some support to the predictive capacity of the PTI (Blacher, 1990; Blacher & Hanneman, 1993; Perry & Black 2006), the majority of families who had placed their relative out-of-home by Time 2 (11 out of 14) were, at Time 1, at the later or 'concrete' stages of placement thinking, having recorded scores of 4 (made enquiries) or 5 (initiated paperwork) on the PTI. The small inconsistencies found for three families who, having placed their relative out-of-home at the end of the study, although initially in the earliest stages of placement thinking at Time 1 (PTI scores of 1 and 2), were consistent with the occurrence of a 'crisis' (Blacher & Hanneman, 1993; Perry & Black, 2006) or 'opportunity' placement (Llewellyn et al., 2003). The accelerated placement may, therefore, have occurred more as a result of unforeseen circumstances such as a carer's inability to continue providing care or the sudden availability of out-of-home accommodation arising, as opposed to planned actions or previous placement intentions. Whilst obvious caution is needed in interpreting the results for such a small number of families, it may, however, suggest that not all placement decisions occur as the result of families' passing through sequential behavioural stages as suggested in Blacher's placement tendency theory (1990). Also that factors

influencing accelerated placement may fail to be picked up when administering the PTI over a time period of 12 months.

Interestingly, four families who were at the 'concrete' stages of placement thinking (stage 4) at Time 1 subsequently demonstrated a decline in favouring an out-of-home placement for their relative by Time 2. Two of these carers recorded dramatic changes in their placement scores, moving back from stage 4 to stages 1 or 2, indicating a considerable decreased inclination towards placement. This finding is again inconsistent with Blacher's placement tendency theory which proposes that the latter stages of placement thinking (stage 4 and above) represents the 'point of no return' in families' placement intensions. Subsequent studies have, however, evidenced a trend for a small minority of families who have reached the latter stages of seeking an out-of-home placement for their relative (stage 4 of the PTI) to subsequently move away from intending to place out of home (Blacher & Hanneman, 1993; Hanneman & Blacher, 1998). Blacher & Hanneman, (1993) suggest this may result from families, who have initially reached the moderate or later stages of considering an out-of-home placement for their relative, subsequently finding some form of adaptation that causes them to move away from seeking a placement. Another possible reason for this declining pattern of placement seeking behaviours may also be due to a lack of appropriate out-of-home accommodation for adults with ID (Department of Health, 2011; Grey et al., 2015; Mansell, Beadle-Brown, Skidmore, Whelton, & Hutchinson, 2006; Perry & Black, 2006); a factor previously reported by families of children with autism as delaying the occurrence of an out-of-home placement (Perry & Black, 2006). Families may therefore have reconsidered their placement decisions, after having made enquiries about out-of-home accommodation for their relative. Inter-family disagreement or ambivalence towards an out-of-home

placement for a relative has also been found to influence this changing pattern of behaviour, a factor which was not measured in the current research (Blacher & Hanneman, 1993). Future research with families of adults with ID should therefore, consider the inclusion of whole family attitudes towards placement as an influence on subsequent placement behaviours.

A strength of the current study was the exploration of changes in families' placement tendency scores across the 12 month period at an individual level. Previous studies which have examined changes in PTI scores over time have tended to focus on changes in group mean PTI scores (Blacher, 1990; Blacher & Hanneman, 1993; Hanneman & Blacher, 1998). This may have resulted in change which occurred at the individual level being less evident. Whilst the above findings show relatively minor inconsistencies with the findings of previous studies exploring placement tendencies of families of children with ID (Blacher, 1990; Blacher & Hanneman, 1993; Hanneman & Blacher, 1998), it may however suggest that not all families pass through a sequence of hierarchical stages prior to the act of an out-of-home placement. The current findings also suggest that the placement tendency model does not necessarily account for changes in external factors (e.g. the availability of suitable out-of-home housing) that may accelerate or change the course of parental behaviour. The model may be more applicable in a context of stable external factors. However, in reality, variation in external circumstances (e.g. housing availability, changes in services) are likely to impact on families' placement tendencies which are likely to lead to non-linear change in behaviour.

The rate of out-of-home placement for adults with ID in the current study appeared to occur more rapidly than demonstrated in previous longitudinal studies of children with severe ID (Blacher, 1990, Blacher & Hanneman, 1993; Hanneman, &

Blacher, 1998). For example, 14 adults (approximately 19%) in the current study were placed out-of-home in a relatively short period of 12 months compared to previous studies where 8 children (9.5%) over 3 years (Blacher, 1990) and 20 children (20%) over a 6 year period were placed (Blacher & Hanneman 1993). Perry and Black (2006) found a similar discrepancy in rate of placement of a sample which included a small number of young adults with autism. The difference in the rate of placement of an adult relative may be reflective of differences in current social policy, care and societal attitudes to placing an adult as opposed to a child, out-of-home (Department of Health, 2001, 2009; United Nation, 2006; Welsh Assembly Government, 2007).

An exploration of unadjusted ORs as predictors of the likelihood of families moving closer to a placement and an out-of-home placement occurring at Time 2, revealed only coping as a significant predictor of the latter outcome. This finding is consistent with previous evidence which suggests that carers who are better adapted to coping with providing care for a relative with ID, are less likely to favour out-of-home placement (Hanneman & Blacher, 1998). Coping strategies have consistently been associated with better adjustment to the caregiving role, which, in turn buffers negative impacts upon carer's and family well-being (Grant, Nolan, & Keady, 2003; Grant & Whittell, 2000; Llewellyn, McConnell, Gething, Cant, & Kendig, 2010; Peer & Hillman, 2012). The lack of significant associations for the remaining predictors may be a result of the small sample size which may have reduced measurement precision and inflated some of the CIs. Alternatively, this may be due to natural variability in the predictor variables. Recruitment of larger samples may go some way to addressing these problems.

The lack of significant associations of characteristics of carer, care recipient or family with change in families' placement tendencies or increased likelihood to place

in the current study, may be reflective of the complexities of placement dynamics. Evidence from previous studies of placement tendencies of families of children with ID suggest that the initial decision to seek an out-of-home placement for a relative with ID is influenced by factors intrinsic to families (Blacher & Hanneman, 1993; Hanneman & Blacher, 1998; Llewellyn et al., 1999; Llewellyn et al., 2005). Evidence from these studies indicated that family stress, burden of care, level of child's impairments and/or challenging behaviours, concerns about the quality of life of the child with ID and other family members and families' SEP relate to family carers considering an out-of-home placement for their child or an actual placement taking place. Initial attitudes to placement have, in turn, been found to influence subsequent placement tendencies (Blacher, 1990; Blacher & Hanneman, 1993; Hannerman & Blacher, 1998). Evidence from the present study indicates that the likelihood that variables intrinsic to the family may not be associated with changes in placement tendency or actual out-of-home placement of adult relatives with an ID. Changes may be more affected by external factors, such as availability of appropriate out-of-home accommodation (Grey et al., in press; Perry & Black, 2006), or the provision of family support services. These were factors that were not included in the present study. It is possible, however, that other intrinsic factors are related, such as major life events and/or the nature of the support relationship between carer and care recipient (i.e., adults with ID are more likely than children with an ID to have reciprocal care to their ageing carers (Bowey & McGlaughlin, 2005; Williams & Robinson, 2001). Future research should, therefore, consider how more complex systemic relationships and external factors, over which families have little or no control, impact on changes in these placement tendencies.

Cautious interpretation of these results is needed, which may be study population specific. Further large scale longitudinal studies are, therefore, needed to gain a better idea of rate of placement of adults with ID, based on families' previous placement intentions and factors which facilitate or delay an out-of-home placement. This may help assist with service planning for out-of-home accommodation for adults with ID and enable service providers to identify those families moving closer to seeking a placement. The influence of survivor effect or the self-selection of study participants can also not be ruled out as influencing the results. These factors may result in a greater likelihood of those families who continue home care of a relative into their adult years being families who have experienced fewer challenges from the caregiving role or had greater access to resources and were, therefore, better equipped to adapt to those challenges (McCubbin & Patterson, 1983).

Implications for policy and practice

A body of evidence is developing which provides an empirical understanding of the stage based, cognitive processes which underlie families' placement decisions (Blacher, 1990; Blacher & Hanneman, 1993; Hanneman & Blacher, 1998; Llewellyn et al., 2005; Perry & Black, 2006). Whilst there are obvious limitations on the generalisability of the findings of the present study due, in part to the small sample size and self-selected nature of participants, gaining a better understanding of the patterns of placement behaviours of families' of adults with ID and early indicators of the number of families who may be moving closer to seeking an out-of-home placement, could have the potential to assist with future service planning for both housing and support service providers. More large scale, longitudinal research is, however, needed exploring variables which may be more relevant to families' co-

residing with adult relatives with ID including external factors such as availability of out-of-home accommodation.

Whilst we still do not know what factors are associated with families being more or less likely to place their adult relative out-of-home, the suggested association in the current study of carer adaption and continued home care highlight the need to make widely available family support services that can support families in their ongoing role as carers. What is clear from the pattern of findings is that such decision-making is more complex than the design of the current study. An implication for future research is to consider the views of adults with ID themselves. To our knowledge no studies have explored the dynamics of placement thinking of adults in ID research.

Chapter 6. General Discussion

Broad Overview

Family carers of individuals with ID are unique amongst informal carers as they often provide care to their relative across the duration of their childhood and a vast proportion of their adult lives. Family carers contribute greatly to the social care economy. The total economic value informal carers in general contribute to the UK economy is estimated at £119 billion per annum (Buckner & Yeandle, 2011). A value far in excess of the annual spent on the entire NHS, which has been estimated as £98 billion per annum. The contribution of support provided by each individual carer is almost £18,500 for care provision alone (Buckner & Yeandle, 2011). Out-of-home accommodation costs are estimated to be around £1,278 to £1689.60 per week (Perry et al., 2013). Whilst the provision of care given by families is clearly a huge asset to a country's economy, evidence suggests that providing long term care is not without consequence to family carers. A wealth of evidence exists to suggest that providing long term care to a relative with ID can have a negative impact upon carers' health outcomes (Chou, Chiao, & Fu, 2011; Chou, Fu, Lin, & Lee, 2011; Hill & Rose, 2009; Rowbotham, Cuskelly, & Carroll 2011; Seltzer, Floyd, Song, Greenberg, & Hong, 2011; Yamaki, Hsieh, & Heller, 2009). Primary carers of adults with ID are more likely to experience higher levels of stress, anxiety, depressive symptoms (Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsi, 2009; Seltzer et al., 2011) and physical health problems (Seltzer et al., 2011; Yamaki, et al., 2009) than non-caregivers.

The aim of this thesis was to contribute to our knowledge of issues relating to informal care provision of adults with ID by family carers. Much of what we currently know about the impact of providing care is derived from studies conducted outside of the UK. Therefore, the aim of the thesis was to contribute further knowledge within

the field of family ID research within a UK context. Adopting a mixed methods approach using both qualitative and quantitative methods, an examination of the impact of providing long term care upon family carers' health and well-being, the role of family homes in the health and well-being of adults with ID, exploration of the experiences of families seeking out-of-home accommodation and the dynamics of families' placement tendencies has been undertaken.

Whilst the main overarching theme of the thesis is family care of adults with ID, the structure of the thesis can be viewed under two broad sub-themes of, 1) health and well-being and 2) accommodation. Chapter 2 (study 1) adopted a qualitative design to explore issues relating to families' experiences of seeking out-of-home accommodation for their adult relative with ID. Chapters 3 (study 2) and 4 (study 3) utilise quantitative methods to explore subjective health and well-being of adults with ID and families co-residing with an adult relative with ID respectively. Of central interest in the former study is the impact of living environments upon the perceived health and well-being of adults with ID. Finally, Chapter 5 (study 4) re-introduces the theme of out-of-home accommodation and explores the dynamics of the placement tendencies of families of adults with ID. This discussion will first summarise the findings from these four chapters and then present methodological limitations and implications for future research within the field of ID. Finally, implications for policy and practice will be discussed.

Chapter analysis

Study 1 (chapter 2). A qualitative approach was chosen to explore the experiences of nine family carers seeking out-of-home accommodation for their adult child with ID in Wales. Qualitative methods were chosen with an aim of gaining an in-depth understanding of how parents experienced the latter stages of seeking out-of-

home accommodation for their son or daughter, a process of which little is currently known. Semi-structured questionnaires were chosen to ensure coverage of the same themes with each family. However, questions were open-ended to allow an in-depth exploration of parents' experiences (e.g., "*Could you tell me about your experiences of finding housing for X?*"). Topic prompts assisted parents to open up about their experiences (Appendix 4).

The initial intention was to recruit 10 family carers who were in the process of seeking out-of-home accommodation for a co-residing adult son or daughter with ID. However, it proved difficult to recruit families who fitted the criteria who also wished to take part in the study and talk about their experiences. We were, however, contacted by a number of families who had already placed their relative out-of-home, who wanted the opportunity to retell their experiences retrospectively. The methodological aim was to recruit families from different local authority areas across Wales to ensure we captured a variety of experiences within different local authority housing systems and not just focus on families' experiences of one local authority area. Therefore for pragmatic and logistical reasons it was agreed to finish recruitment once nine suitable families had been recruited.

Interviews were recorded using a digital recorder. I transcribed all nine interviews verbatim. Whilst time consuming, transcription of scripts by researchers ensures familiarity with data prior to commencing initial analysis. Data was analysed using Thematic Analysis (Braun & Clarke, 2006). From the data two main themes and six sub-themes were identified. Theme 1: Moving on: reasons for seeking housing, sub-themes a) Parents' decreasing ability to cope at home, b) Carers' needs: parents' desire for a life outside of their care role and c) A taste of independence: perceived aspirations of offspring. Theme 2: A long road: experiences of seeking housing, sub-

theme a) Parents' expectations versus experienced reality, b) Increasing disillusion with the housing system and c) Families in stasis: obstacles to gaining suitable housing.

The study had obvious limitations in its scope and geographical breadth, which does limit the generalizability of the findings. However, it does provide further evidence and insight of the demands of providing care to an adult son or daughter who has become physically more difficult to care for and the increasing difficulties of providing care as parents themselves get older (Bowey & McGlaughlin, 2007; McConkey, Kelly, Mannan, & Craig, 2011; Prosser, 1997; Shaw, Cartwright, & Craig, 2011; Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012).

The findings also add to the literature which suggests a greater desire on the part of parents and adults with ID for parity with the lives of their siblings and other young people who do not have an ID and to have the right to move out-of-home (Essex, Seltzer, & Krauss, 1997). However, a mismatch between these aspirations, policy rights (United Nations, 2006) and reality was found.

Whilst there are methodological limitations to the study (discussed further later on in this chapter), some of which are common to qualitative studies (e.g., small study samples), it does provide some evidence of potential systematic failings within the housing system in Wales and offers an initial exploration of families' experiences within this system.

Study 2 (chapter 3). This study comprised a secondary analysis of data from the English survey of adults with ID in England 2003-2004 (Emerson, Malam, Davies & Spencer, 2005). The original survey was unique in directly interviewing adults with ID about issues which affect their lives. The use of accessible questionnaires and

pictorial prompts were specific strengths of the original study which enabled the participation of adults with ID either directly or with support.

The aim of this study was to enhance our understanding of subjective health and well-being among people with an ID, taking account of living circumstances. The primary research questions were: (a) whether adults who live in family homes (N = 1,528) and those who live out of the family home (N = 874) perceive their health and well-being differently, and (b) whether potential differences persist after accounting for participants' ability levels and reporting method (i.e. assisted/proxy or independent responding). The latter was deemed important due to the evidence which suggests that reports of subjective well-being differ between proxy informants and individuals themselves (e.g., Perry & Felce, 2002).

Results showed that, when controlling for response mode, level of support needs and other characteristics, people living with family perceived their subjective well-being more positively than those living out of family homes. However, multivariate modelling revealed a more complex pattern of results for health. People living with family perceived their health more positively but only when their support needs were lower.

Consistent with previous research, these findings provide further evidence of the central role families play in providing living environments conducive to the well-being of adults with ID (Scott, Foley, Bourke, Leonard, & Girdler, 2013, Seltzer & Krauss, 2001; Seltzer, et al., 1995). The results also suggest that out-of-home accommodation may be less conducive to the well-being of its residents. These findings have important implications for policy and services providers (discussed later in the chapter).

Whilst the findings for subjective health identify potential health inequalities between those living with family with high support needs and those living in other community settings, cautious interpretation of these results is needed. New health interventions have been introduced for adults with ID in the UK subsequent to the collection of this survey data. A major improvement in health interventions for adults with ID was the introduction of the annual health checks in 2006 (Baxter et al., 2006; Robertson, Roberts, & Emerson, 2010; Robertson, Roberts, Emerson, Turner, & Greig, 2011). Annual health checks have been effective in identifying unrecognised health needs and preventing worsening physical health for those with an entitlement to this intervention (Baxter et al., 2006; Robertson, Roberts, & Emerson, 2010; Robertson, Roberts, Emerson, Turner, & Greig, 2011). Whilst an obvious promising development in health interventions, more recent data has shown that there is a considerable way to go to achieve universal coverage of health support for adults with ID in the UK and that health disparities remain (Emerson, 2011). People living in family homes are those least likely to receive public service support, a criteria for entitlement of an annual health check, whilst people living in care homes and supported living settings are those most likely to be in receipt of public service support regardless of support needs. People living with family with high support needs may therefore have difficulties accessing health care and health promotions. Evidence has also shown a comparatively low take up of health checks even amongst those entitled to this service (Emerson, Copeland, & Glover, 2011). This may suggest problems with accessing primary health care services, especially for those with more severe disabilities. Better promotion of health interventions, together with ways of offering more flexible approaches to providing health care and widening the inclusion

criteria, especially to those more marginalised individuals, is needed to offer a universally inclusive health care system and address potential health disparities.

A major strength of the study was the use of random sampling techniques via weekly General Household Omnibus Surveys to recruit participants. This resulted in the recruitment of 880 people who reported as not being in receipt of public service support. The majority of these adults (N = 836) lived in family homes. The potential of a 'hidden' population of adults with higher support needs, living with families who are experiencing poorer health outcomes should be of concern to health and social care providers and policy makers alike. Whilst research is beginning to address ways of including these more marginalised families (Emerson, 2011), more research is needed to explore issues and potential health disparities faced by this population. Researchers need to ensure they consider more creative recruitment methods to ensure inclusion of marginalised individuals in order to better represent a wider population of people with ID and their families.

The aim and strength of the current study was the inclusion of data from participants with varying levels of ability and support needs. A design was therefore chosen which enabled us to both account for and examine the association between mode of responding and outcomes of health and well-being of all participants. Previous studies have typically excluded individuals who cannot respond independently (e.g., Emerson & Hatton, 2007, 2008) or rely solely on proxy respondents (Nota, Ferrari, Soresi, & Wehmeyer, 2007; Nota, Soresi, & Perry, 2006). The modelling also enabled identification of a previously unknown dimension. Whilst accounting for any potential effects of proxy/self-reporting and ability level, the study indicated that better health status was not reported across all those who live with family, but only those who have fewer support needs. Consistent with previous

research which has shown that adults with ID living in family homes were less likely to receive preventative health care or health care procedures than those living in other residential settings (Bershadsky et al., 2012). The results from the current study therefore suggest that a desire to move out-of-home may not only be associated with increased independence and self-determination of adults with ID (see study 1), but may also facilitate access to better health care for individuals with higher support needs.

A limitation of the study was the focus on outcomes of subjective health and well-being. Subjective evaluations of health and well-being do not necessarily mirror the objective realities of people's lives (Perry & Felce, 2002). Therefore how a person evaluates their health and well-being may not give an accurate picture of their objective realities. Whilst modes of reporting were accounted for in regression models (see above), there remains a lack of clarity of the effect of proxy reporting on subjective outcomes (Perry & Felce, 2002; Schwartz & Rabinovitz, 2003). More research is therefore needed exploring the cognitive processes which underlie responses to subjective phenomena, which may help to address problems with response validity and the exclusion of individuals with more severe ID from future research (Fujiura et al., 2012). Further limitations are discussed later in this chapter.

Study 3 (chapter 4). A cross sectional survey of 110 family carers co-residing with an adult relative with an ID in homes across the UK, was undertaken to examine how family carers' self-reported health status compares to national population norms. Comparative analysis indicated significant differences in psychological and physical health status of family carers than reported in national population data (Kind, Dolan, Gudex, & Williams 1998; The Behavioral Risk Factor Surveillance System, CDC, 2012). To our knowledge this is the first study to explore difference in health status of

UK based family carers of adults with ID with general population data. Strengths of the study are the inclusion of both positive and negative aspects of caregiving and the inclusion of indicators of coping strategies and resources, factors associated with adaption to the caregiving role (McCubbin & Patterson, 1983).

Multivariate analyses revealed age (being older), higher levels of SEP and being female to be associated with more positive psychological and subjective health outcomes. The association of gender and positive outcomes of health and well-being has mixed support from previous research with carers of children and adults (Chou, et al., 2011, Jones, Totsika, Hastings, & Petalas, 2013; Olsson & Hwang, 2001; Samadi, McConkey, & Bunting, 2014; Seltzer et al., 2011). Therefore further large scale longitudinal research is needed focusing on carers of adults with ID.

In support of adaptive models of family stress (McCubbin & Patterson, 1983), and previous research (Grant, Nolan, & Keady, 2003; Grant & Whittell, 2000; Llewellyn, McConnell, Gething, Cant, & Kendig 2010; Peer & Hillman, 2012), proactive coping and satisfaction with support received were associated with positive psychological outcomes and more positive gains derived from providing care. Whilst relatively few studies have examined the impact of cognitive appraisal upon outcomes for family carers of adults with ID. Those studies which have explored this phenomenon (Grant & Whittell, 2000; Hastings et al., 2005) suggest that women have a greater propensity to adopt more positive coping strategies than their male counterparts. More research is needed examining potential gender differences in adaptive coping strategies and outcomes for caregivers. This could have practical implications for more targeted support services.

No significant association were found with subjective physical health outcomes and any characteristics of the carer or care recipient. The results suggest

that correlates of physical health may differ from that of psychological health. Further large scale longitudinal research is needed which includes more comprehensive indicators of health, such as physical health conditions and biomarkers such as cortisol levels, in order to gain a better understanding of the impact of providing long term care and the association of psychological and physical health.

Whilst the findings provide further evidence of health disparities between caregiving and non-caregiving families, caution is needed in interpreting the results. One of the main limitations of the study was the limited external validity of the findings due to the use of a convenience sampling method. This may have resulted in the study sample being non-representative of the wider population of family carers of adults with ID. Whilst providing an initial or preliminary picture of the health and well-being of a self-selected sample of family carers, therefore there are obvious limitations on the generalisability of these findings. An interesting dimension for future research would be the comparison of well-being indicators among different groups of caregivers to examine whether the presence of an ID is associated with different psychological adaptation in caregivers.

The option of an on-line or postal survey was adopted for pragmatic reasons of limited research personnel, although this may have impacted on the quality of data. The aim was to target a wide population of carers across the UK. However, this resulted in the adoption of data collection methods that were only accessible to carers. In turn, this prevented us collecting in-depth data about care recipients' adaptive behaviours and support needs, which would have required prior consent or an assessment of the mental capacity to give consent from potential participants who have ID. Therefore a weakness of the study was that the geographical breadth may have affected the depth of data we were able to collect. Whilst recruitment was also

conducted through attendance of social and support groups and parent/carer forums, this would only have led to gaining consent from a minority of adults with ID and potentially lead to inconsistent methods of recruitment. Gaining access to social groups, parent and carers' groups and other forums was, at times, difficult, as it initially requires gaining the trust and interest of gatekeepers. Persistence and sensitive negotiating skills were required. Recruitment was also assisted by Mencap and Cartrefi Cymru who were non-academic partners who partially funded this PhD.

Study 4 (Chapter 5). This study reports on a longitudinal prospective study exploring changes in placement tendencies of 75 families who, at the beginning of the study (Time 1) were co-residing with an adult relative with ID. Using the Placement Tendency Index (PTI, Blacher, 1990, Blacher & Hanneman, 1993), carers indicated their thinking on seeking out-of-home accommodation at Time 1. At a 12 month subsequent period (Time 2), carers were again asked to indicate their placement thinking on the PTI. Factors associated with changes in families' placement thinking were also explored. To our knowledge this is the first study to explore placement tendencies of family carers of adults with ID.

During the 12 month period, 14 adult relatives were placed out-of-home. The majority of these families were at the latter stages of placement thinking at Time 1 of the study. Changes in families' placement thinking were, on the whole, consistent with previous research with families of children with ID and/or ASD. The findings support the predictive capacity of the PTI (Blacher, 1990; Blacher & Hanneman, 1993; Hanneman & Blacher, 1998; Llewellyn, McConnell, Thompson, & Whybow, 2005; McIntyre, Blacher, & Baker, 2002; Perry & Black, 2006).

An exploration of unadjusted odds ratios (ORs) as predictors of likelihood of families moving close to a placement and an out-of-home placement occurring at

Time 2 of the study, revealed only coping as a significant predictor of a move out-of-home. No other significant associations were found for the remaining predictors. Factors associated with families' initial placement decisions and the placement of children with ID (e.g. family stress, burden of care, level of relative's impairments and families' SEP), may, therefore, differ from those influencing subsequent change in the placement tendencies of families of adults with ID. The findings from study 1 indicate that re-housing decisions and the success of gaining out-of-home accommodation for an adult relative with ID are ultimately influenced by factors external to the family. Factors include decisions taken by housing service providers, the availability of appropriate accommodation and the perceived priority of the need of families for out-of-home accommodation. Future studies should consider these additional factors.

A strength of this prospective study, which had a relatively low attrition rate (N = 35, 31% of participants lost from initial study), was the ease of completion of the follow up questionnaire (PTI) and the lack of demand on participants' time. Although in terms of quantitative studies the sample size was fairly small. Another limitation may have been the use of data collected at a fixed time point to assess factors of change at a 12 month subsequent time point. Future research should take account of changes which may occur in potential covariates as well outcome variables.

Conceptual overview of thesis

Overall the topics examined within this thesis of health and well-being and out-of-home accommodation could be viewed within the framework of Blacher's (2001) conceptual model of transition to adulthood for young people with ID. Whilst the model was originally developed as a focus on the period of transition between 18

and 26 years of age for adults with ID, the basic concepts of the model could be applied across a lifetime. Blacher (2001) stated that the conceptual model is not linear but represents simultaneous processes operating over time, in different orders and may occur at different times over the life stage. In line with Chapter 4 (study 3), the main outcome of interest is family well-being. Blacher's conceptual model has some parallels with Hill's (cited in Blacher, 2001) ABCX model of family stress, which was later extended by McCubbin & Patterson, (1983) for their adaptive theory of family stress, the double ABCX model. The primary outcome domain of family well-being in Blacher's (2001) model parallels the "X" in Hill's (1949) model of well-being. The secondary outcome domain is transition, the degree to which this is viewed as positive and successful by relevant parties being important to family well-being. Factors which influence a successful transition include young adults' characteristics (the "A" in the Hill model), family resources (the "B" in the Hill and subsequent models). Included within this model are positive and negative factors and coping strategies, the latter of which parallels the "C" in Hill's model. Factors included in transition success are residential placement, vocational opportunities, socialisation and quality of life for adults with ID.

The studies which make up this thesis can loosely be mapped onto the framework of Blacher's (2001) conceptual model. As stated above, the main outcomes of interest in study 3 (Chapter 4, family carer's health and well-being) parallels the primary outcome domain of the conceptual model (family well-being) or the "X" in Hill's (1949) model. The focus of study 1 (Chapter 2, seeking out-of-home accommodation), the main outcomes of study 2 (Chapter 3, health and well-being of adults with ID and the focus of study 4 (Chapter 5, families' placement tendencies) could all be viewed as the secondary outcome domain (the transitional period), the

success or otherwise of which impacts on the outcome of family well-being. Although it is important to note here that only two of the studies which make up this thesis include a cohort of people who participated in two of the studies (i.e. the cross sectional family well-being study and the prospective family placement tendency study). No follow up of the impact of placement upon family well-being or the well-being of adult relatives was undertaken. Blacher's (2001) conceptual model of transition and family well-being does, however, offer a conceptual framework for guiding larger longitudinal prospective studies which explore the experiences of families and individuals with ID during transition through to gaining an out-of-home placement and beyond.

Methodological limitations and implication for future research

The findings within this thesis provide a unique contribution to the field of ID research and issues affecting families co-residing with an adult relative with ID. However, these studies are not without their limitations. Whilst some strengths and limitations have been discussed under each summary chapter, further limitations common to each study, together with implication for future research will be discussed below.

Study 1 (Chapter 2) adopted a qualitative design in order to gain an in-depth understanding of the latter part of the process of seeking out-of-home accommodation for an adult son or daughter with ID, of which little is currently known. However, the findings are limited to the experiences of a small group of geographically restricted parents. These experiences may, therefore, not be representative of the experiences of parents in other countries of the UK or indeed other family carers across Wales. The study also gained a view of the housing system in Wales from the perspective of

families only. An interesting piece of future research would be to explore services' perspectives on barriers and facilitators in moving out-of-home. It would also seem pertinent to map the availability of accommodation against demand in different areas of the UK.

A limitation in Chapter 5 (study 4) may have been sample size. In terms of scale of quantitative studies, the sample size of 75 participants was quite small. This may, therefore, have resulted in reduced measurement precision and inflated confidence intervals of the odds ratios (ORs). Therefore further larger longitudinal studies are needed exploring placement tendencies of family carers of adults with ID. Relatively little is currently known about the placement tendencies of families of adults with ID and factors influencing initial decisions and subsequent changes in these decisions. Future research may consider adopting mixed methodologies, as used in studies with families of children with ID (Blacher & Hanneman, 1993; Llewellyn, Dunn, Fante, Turnbull, & Grace, 1999), which may provide a more explorative, multi-dimensional, in-depth understanding of the dynamics of these families' placement tendencies. Gaining a better understanding of factors which influence families' decisions to seek a placement or move closer towards an out-of-home placement may go some way to assisting service providers with future planning and service provision.

The impact of the self-selection of participants and survivor effect cannot be ruled out as influencing the results of Chapter 4 (study 3) and Chapter 5 (study 4). The first study examined the health and well-being of families co-residing with an adult relative with ID. The second study was a prospective longitudinal study examining placement tendencies of a cohort of families who originally took part in study 3, who subsequently opted to take part in the prospective study. The self-

selection of participants may, therefore, have resulted in those selecting to take part being either better or more poorly adjusted to the caregiving role. Whilst the survivor effect may have resulted in a greater likelihood of families who continue providing care to a relative long term (a criterion for participation) being those who are healthier, have experienced fewer challenges from the caregiving role, are better adapted at providing ongoing care and/or have greater access to resources. Whilst overcoming the possible effects of self-selection is not always easy, adopting a more randomised design may help overcome this problem.

Adopting a cross-sectional design for Chapter 2 (study 1) and Chapter 4 (study 3) meant we could only examine associations and not causal relationships of subjective health and well-being. Further longitudinal research is needed to verify associations and potentially enable predictions of outcomes of subjective health and well-being for family carers and adults with ID.

Implications for policy and practice

Whilst acknowledging the limitations of the findings of the studies in this thesis, they do raise important issues of concern for policy and practice. Chapter 2 (study 1) not only highlighted reasons for seeking out-of-home accommodation as relating to difficulties associated with providing care to an adult relative and parents' own age related decline in health, but also the lack of appropriate community housing stock available to adults with ID. These findings, together with the findings in Chapter 4 (study 3) of the potential health disparities experienced by family caregivers compared to population norms, highlight issues which cannot be ignored. Findings from Chapter 4 (study 3) suggest that younger carers experience poorer psychological outcomes than older carers, however, when tied in with the findings

from Chapter 2 (study 1), it becomes apparent that older parents cannot continue providing care to their adult son or daughter indefinitely, therefore ways of both identifying and addressing the future housing need of adults with ID are urgently needed. Difficult relationships which developed during parents' dealing with housing and social service staff should also be of concern. Better training of service staff in the needs and issues faced by family carers may help overcome these negative and often stressful experiences.

Findings from Chapter 3 (study 2) highlighted potential disparities in the health and well-being of adults with ID which related to living circumstance. Whilst people living out-of-home appeared to experience lower well-being that those living with family, people living with family with higher support needs experienced poorer health outcomes. Obviously advances in health intervention for adults with ID have occurred since the data was collected for the original study (discussed above), however, there do remain concerns. It would therefore seem important to explore ways of supporting people living in community accommodation to develop and maintain meaningful relationships which are conducive to their well-being. Increasing awareness and extending the criteria for access to health checks and health screening to all adults with ID and offering more flexible ways of offering primary health care appointments and interventions may help address unmet health needs.

With the current economic climate and austerity potentially continuing for some years to come and the severe shortage of appropriate out-of-home community accommodation (identified as barriers to gaining out-of-home accommodation in Chapter 2), family homes are likely to continue as the main residencies of adults with ID. Potential health disparities between family carers and non-caregivers identified in Chapter 4 (study 3) together with age related decline in parents health identified in

Chapter 2 (study 1), should be of great concern. Whilst Carers' Assessments were introduced into the UK to identify and address some of the support needs of carers, results from this Chapter 3 suggest that carers themselves offer an effective source of expertise which policy makers and service practitioners should explore. The findings suggest that older carers and those who adopt more problem-focused coping strategies appear less prone to negative health outcomes. Therefore policy makers and service practitioners should explore ways of working collaboratively with carers to instigate carer-led peer support groups and utilise carers' expert knowledge to help teach active coping strategies. The findings from this study also suggest that helpfulness as opposed to the number of services provided to families also impacts health, well-being and the experience of providing care. In the light of severe budget cuts, policy makers and service providers should engage with family carers in identifying and evaluating those services which are of most use to families.

Whilst the findings from study 4 (Chapter 5) suggest we still need to gain a better understanding of factors which influence changes in families' placement thinking and a move towards an out-of-home placement of an adult relative with ID, addressing issues of availability of appropriate out-of-home accommodation (identified in study 1), a potential factor in families placement behaviours, is needed. The suggested association of carer adaption and continued home care not only support the findings in study 3, but also highlight the need to make widely available family support services that can support families in their ongoing role as carers.

Conclusion

Family homes are likely to remain the main residencies of adults with ID for much of their lives. Developing ways of supporting families to provide on-going care

to their relative within their homes, which buffer the negative impacts of providing care and increase the positive gains from caring, are essential to avoid family crisis and inappropriate out-of-home placements occurring. Policy makers and service professionals also need to consider ways of addressing the disparities between policy rights and realities. The contribution that family carers of individuals with ID make to the social care system must be acknowledged and respected not only in policy (e.g., Carers' Assessments) but in the practices of those providing services to these families.

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Appendices

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YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

PRIFYSGOL BANGOR UNIVERSITY

Introductory letter to parents

Dear Parent

We are writing to inform you about a research project we are conducting at Bangor University, looking at the experiences of parents who are in the process of waiting to get their adult son or daughter, who has a learning disability, accommodation outside of the family home. We are particularly interested in what it has been like for you as a parent during this time. We hope to do this by having a brief discussion with you at your home or a place of your choosing.

Please find enclosed an information sheet that gives you some detailed information about the research and why it is being carried out and what it will involve. Once you have read the information, if you are still unclear about any aspect of the study or have any queries, please do not hesitate to contact Jillian Grey by telephone 01248 388255 email j.m.grey@bangor.ac.uk or at the address below.

If you feel that you would like to share your family's experience about this, we would be grateful for your participation in this project.

I look forward to hearing from you.

Yours sincerely

Jillian Grey
School of Psychology

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Llythyr rhagarweiniol i rieni

Annwyl Riant,

Rydym yn ysgrifennu atoch i roi gwybod am broject ymchwil rydym yn ei gynnal ym Mhrifysgol Bangor, yn edrych ar brofiadau rhieni sy'n aros i gael llety tu allan i gartref y teulu ar gyfer eu mab neu ferch wedi tyfu sydd ag anabledd dysgu. Mae gennym ddiddordeb arbennig mewn dod i ddeall sut brofiad rydych wedi ei gael fel rhiant yn ystod y cyfnod hwn. Hoffwn wneud hyn trwy gael trafodaeth fer gyda chi yn eich cartref neu mewn lle o'ch dewis.

Amgaeaf daflen wybodaeth sy'n rhoi ychydig o wybodaeth fanwl am yr ymchwil a pham y mae'n cael ei wneud a'r hyn y bydd yn ei olygu. Ar ôl i chi ddarllen yr wybodaeth ac os nad ydych yn deall unrhyw agwedd ar yr astudiaeth neu os oes gennych unrhyw gwestiynau, mae pob croeso i chi gysylltu â Jillian Grey drwy ffonio 01248 388255, anfon e-bost j.m.grey@bangor.ac.uk neu anfon i'r cyfeiriad isod.

Os ydych yn teimlo yr hoffech rannu profiad eich teulu am hyn, byddem yn ddiolchgar iawn pe baech yn cymryd rhan yn y project hwn.

Edrychaf ymlaen at glywed oddi wrthych.

Yn gywir

Jillian Grey
Ysgol Seicoleg

kess
Ysgoloriaethau Sgiliau Economi Gwybodaeth
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INFORMATION SHEET FOR PARENTS AND CARERS

Study Title: Experiences of parents waiting for their adult child with an intellectual disability (learning disability) to get housing outside the family home.

We would like to invite you to take part in a new study being conducted at Bangor University, in collaboration with the Mencap Cymru and Cartrefi, providers of support to people with learning disabilities and their families.

Purpose of Study:
We would like to obtain first-hand accounts of families experiences of finding accommodation for their adult son or daughter who has a learning disability, outside of the family home across Wales. The study is part of a longer doctoral project which looks into the well-being of families with adult children with a learning disability.

We would hope that your experiences will contribute to the development of service support in Wales for families in the near future and provide adults with learning disabilities with real housing choice which would enable them to feel valued members of their own communities.

Why you have been invited to take part:
You have an adult son or daughter with a learning disability and you are currently in the process of seeking accommodation for them outside the family home. You are in contact with either the local authority, Mencap Cymru or Cartrefi who thought you may find this project interesting.

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If you decide to participate, any information you share with us will not be disclosed to either the local authority, Mencap, Cartrefi or any other organisation identifying you or your family (unless you request it). Your participation in this project is independent of any services or support you receive from Mencap, Cartrefi or any other voluntary or statutory organisation.

What does taking part involve?

Participation in the research project will involve the following:

- If you are interested in taking part, please complete the enclosed consent form and return it in the pre-paid envelope to Bangor University.

- Jillian Grey will phone you within two weeks of receiving the signed consent form to arrange a convenient time to have a discussion

- The discussion will involve asking a few background questions, such as how many people live in your household. We would then mainly talk about the process of trying to find a new home for your child and what this has been like for you, for your child and for your whole family.

- We could talk either face to face in your home or another place of your choosing, or over the telephone.

- With your permission, our discussion will be recorded. The discussion may last 10 minutes to about an hour.

- Jillian will only need to visit you on one occasion in connection with this research project.

- After speaking to all the families, Jillian will look at the interviews together to describe families' experiences overall, without identifying you or your family in any written reports.

Consent:

Taking part in this project is completely voluntary and will not affect your rights to receive services from either statutory, voluntary or private sector service providers. If you wish to take part please complete the enclosed consent form and return it to us in the enclosed pre-paid envelope.

Withdrawal:

Should you decide that you no longer wish to be involved in the study, the information that you have provided can be withdrawn at any time without you giving any reason. Even after the interview has been completed, consent can be withdrawn and any data collected will be destroyed. This will not restrict your access to services and will not affect the right to support from statutory, voluntary or private service providers.

Confidentiality:
All information collected as part of this research project will be treated in accordance with the Data Protection Act (1998)

When recordings of the interview are not being used they will be stored in a locked filing cabinet in Bangor University's School of Psychology.

Information identifying you and your son or daughter will not be stored on or with the digital recorder.

- Information collected from families will be anonymised using a coding system. All data that can identify families will not be kept with the coded data.

- The only people who will have access to identifiable information are the researchers at Bangor University's School of Psychology.

- No information identifying you or your family will be passed on to a third party outside of the research team without your prior permission.

All information collected will be kept on a confidential database that is only accessible to those working on the project. If published, information will be presented without reference to any identifying information.

At the end of the study:
We will send you information on the findings of the study. Any requests for advice concerning your son or daughter will be referred to the appropriate service provider. It is possible that you may be invited to participate in further research after the study. However, consenting to participate in this study does not mean that you are obliged to do so.

Once the study has been finalised, all identifying information collected will be suitably destroyed and not passed on to any third parties.

Any concerns or queries?
If you are unclear about any aspect of the study or have any questions, please do not hesitate to contact Jillian Grey by telephone: 01248 388255, by email j.m.grey@bangor.ac.uk or at address on the covering letter.

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Dr Gemma Griffith, Research Officer (g.m.griffith@bangor.ac.uk)
School of Psychology, Bangor University

Telephone number 01248 382211 or 07807995629

If you have any complaints about the way this research is being conducted you are welcome to address unresolved concerns to:

Mr Hefin Francis
School Manager
School of Psychology
Bangor University
Brigantia Building
Penrallt Road
Bangor,
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TAFLEN WYBODAETH I RIENI A GOFALWYR

Teitl yr astudiaeth: Profiadau rhieni sy'n aros i'w plant wedi tyfu ag anableddau dysgu gael tŷ tu allan i gartref y teulu.

Hoffem eich gwahodd i gymryd rhan mewn astudiaeth newydd a gynhelir ym Mhrifysgol Bangor, mewn cydweithrediad â Mencap Cymru a Cartrefi, darparwyr cymorth i bobl gydag anableddau dysgu a'u teuluoedd.

Pwrpas yr Astudiaeth:
Hoffem gael clywed yn uniongyrchol am brofiadau teuluoedd, ym mhob rhan o Gymru, sy'n chwilio am lety tu allan i gartref y teulu i'w mab neu ferch wedi tyfu sydd ag anableddau dysgu. Mae'r astudiaeth yn rhan o broject doethuriaeth hirach sy'n edrych ar les teuluoedd â phlant wedi tyfu ag anableddau dysgu.

Rydym yn gobeithio y bydd eich profiadau chi yn cyfrannu at ddatblygu gwasanaethau cymorth yng Nghymru i deuluoedd yn y dyfodol agos ac yn rhoi gwir ddewis o ran tai i oedolion ag anableddau dysgu a fyddai'n eu galluogi i deimlo'n aelodau gwerthfawr o'u cymunedau eu hunain.

Pam y'ch gwahoddwyd i gymryd rhan:
Mae gennych fab neu ferch wedi tyfu ag anabledd dysgu ac rydych ar hyn o bryd yn chwilio am lety iddynt tu allan i gartref y teulu. Rydych mewn cysylltiad naill ai gyda'r awdurdod lleol, Mencap Cymru neu Cartrefi a oedd yn meddwl y byddai gennych ddiddordeb yn y project hwn.

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Os ydych yn penderfynu cymryd rhan, ni fydd unrhyw wybodaeth y byddwch yn ei rhannu gyda ni yn cael ei datgelu i naill ai'r awdurdod lleol, Mencap, Cartref nac unrhyw sefydliad arall a ddynodwyd gennych chi neu eich teulu (oni bai eich bod yn gofyn i ni wneud hynny). Mae eich cyfranogiad yn y project hwn yn annibynnol o unrhyw wasanaethau neu gymorth rydych yn eu derbyn gan Mencap, Cartref neu unrhyw sefydliad gwirfoddol neu statudol arall.

Beth mae cymryd rhan yn ei olygu?
Bydd cymryd rhan yn y project ymchwil fel a ganlyn:

- Os oes gennych ddiddordeb mewn cymryd rhan, a fyddech cystal â llenwi'r ffurflen gydsynio amgaeedig a'i dychwelyd yn yr amlen radbost at Brifysgol Bangor.

- Bydd Jillian Grey yn eich ffonio o fewn pythefnos i dderbyn y ffurflen gydsynio wedi ei llofnodi, i drefnu amser cyfleus i gael trafodaeth

- Bydd y drafodaeth yn golygu gofyn ychydig o gwestiynau cefndirol, er enghraifft faint o bobl sy'n byw yn eich cartref. Byddem wedyn yn siarad yn bennaf am y broses o geisio cael cartref newydd i'ch plentyn a sut brofiad oedd hyn i chi, eich plentyn a'r teulu cyfan.

- Gallwn naill ai siarad wyneb yn wyneb yn eich cartref neu mewn lle arall o'ch dewis chi, neu dros y ffôn.

- Gyda'ch caniatâd, bydd ein trafodaeth yn cael ei recordio. Gall y drafodaeth hon bara rhwng 10 munud ac awr.

- Dim ond un waith y bydd rhaid i Jillian ymweld â chi ynglŷn â'r project ymchwil hwn.

- Ar ôl siarad gyda'r holl deuluoedd, bydd Jillian yn edrych ar y cyfweliadau gyda'i gilydd i ddisgrifio profiadau teuluoedd yn gyffredinol, heb eich enwi chi na'ch teulu mewn unrhyw adroddiad ysgrifenedig.

Cydsyniad:
Mae cymryd rhan yn y project hwn yn gwbl wirfoddol ac ni fydd yn effeithio ar eich hawl i dderbyn gwasanaethau gan naill ai darparwyr gwasanaethau statudol, gwirfoddol neu'r sector preifat. Os hoffech gymryd rhan, llenwch y ffurflen gydsynio amgaeedig a'i hanfon yn ôl atom yn yr amlen radbost a ddarperir.

Tynnu'n ôl:
Os byddwch yn penderfynu nad ydych eisiau bod yn rhan o'r astudiaeth ddim mwyach, gall yr wybodaeth a roddwyd gennych gael ei thynnu'n ôl ar unrhyw adeg heb fod angen i chi roi rheswm. Hyd yn oed ar ôl gorffen y cyfweliad, gallwch dynnu eich cydsyniad yn ôl a bydd unrhyw ddata a gasglwyd yn cael ei ddinistrio. Ni fydd hyn yn cyfyngu ar eich gallu i fynd at wasanaethau ac ni fydd yn effeithio ar yr hawl i gael cymorth gan ddarparwyr gwasanaeth statudol, gwirfoddol na phreifat.

Cyfrinachedd:
Bydd yr holl wybodaeth yr ydych yn ei darparu yn cael ei thrin yn unol â Deddf Gwarchod Data (1998).

Pan na fydd y recordiadau o'r cyfweliad yn cael eu defnyddio byddant yn cael eu storio mewn cabinetau ffeilio dan glo yn Ysgol Seicoleg, Prifysgol Bangor.

Ni fydd gwybodaeth lle gellir eich adnabod chi neu eich mab neu ferch yn cael ei storio ar neu gyda'r recordydd digidol.

- Bydd yr wybodaeth a gesglir oddi wrth deuluoedd yn ddienw gan ddefnyddio system godio. Ni fydd data lle gellir adnabod teuluoedd yn cael eu cadw gyda'r data wedi ei godio.

- Dim ond yr ymchwilwyr yn Ysgol Seicoleg Prifysgol Bangor fydd yn cael mynd at wybodaeth lle gellir adnabod rhywun.

- Ni fydd unrhyw wybodaeth y bydd modd eich adnabod chi neu eich teulu yn cael ei rhoi i drydydd parti tu allan i'r tîm ymchwil heb eich caniatâd ymlaen llaw.

Bydd yr holl wybodaeth a gesglir yn cael ei chadw ar gronfa ddata gyfrinachol a dim ond y rhai sy'n gweithio ar y project fydd yn gallu mynd at yr wybodaeth honno. Os caiff ei chyhoeddi, bydd yr wybodaeth yn cael ei chyflwyno heb unrhyw gyfeiriad at wybodaeth lle gellir adnabod rhywun.

Ar ddiwedd yr astudiaeth:
Byddwn yn anfon gwybodaeth am ganfyddiadau'r astudiaeth atoch. Bydd unrhyw geisiadau am gyngor ynglŷn â'ch mab neu ferch yn cael eu cyfeirio at y darparwr gwasanaeth priodol. Mae'n bosibl y cewch eich gwahodd i gymryd rhan mewn ymchwil pellach ar ôl yr astudiaeth. Ond nid yw cydsynio i gymryd rhan yn yr astudiaeth hon yn golygu bod rhaid i chi wneud hynny.

Unwaith bod yr astudiaeth wedi ei chwblhau, bydd yr holl wybodaeth a gasglwyd lle gellir adnabod rhywun yn cael eu dinistrio'n briodol ac ni fydd yn cael ei throsglwyddo i unrhyw drydydd parti.

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Unrhyw bryderon neu ymholiadau?
Os nad ydych yn deall unrhyw agwedd ar yr astudiaeth neu os oes gennych unrhyw gwestiynau, mae pob croeso i chi gysylltu â Jillian Grey drwy ffonio: 01248 388255, drwy e-bost j.m.grey@bangor.ac.uk neu anfon i'r cyfeiriad ar y llythyr.

Dyma rai o aelodau eraill o'r tîm ymchwil:

Dr Vasiliki Totsika, Darlithydd mewn Seicoleg a Thiwtor Ymchwil (v.totsika@bangor.ac.uk)
Yr Athro Richard Hastings, Athro Seicoleg (r.hastings@bangor.ac.uk)
Dr Gemma Griffith, Swyddog Ymchwil (g.m.griffith@bangor.ac.uk)
Ysgol Seicoleg, Prifysgol Bangor, Ffôn 01248 382211

Os oes gennych unrhyw gwynion ynglŷn â'r ffordd y mae'r ymchwil hwn yn cael ei gynnal, mae croeso i chi fynd ag unrhyw bryderon heb eu datrys at:

Mr Hefin Francis
Rheolwr yr Ysgol
Ysgol Seicoleg
Prifysgol Bangor
Adeilad Brigantia
Ffordd Penrallt
Bangor,
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YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

PRIFYSGOL BANGOR UNIVERSITY

Consent form

Study Title: **Experiences of parents waiting for their adult child with a learning disability to get housing outside the family home.**

Please take your time to read this consent form and initial the boxes if you wish to take part in the research.

Please sign one copy and return in the SAE provided and keep one copy for information.

Nature of the research project
This research project aims to explore the experiences of parents with an adult child with a learning disability as they wait for appropriate out-of-family-home housing.

Names of Investigators/Researchers

Ms Jillian Grey, Doctoral Researcher (j.m.grey@bangor.ac.uk)
Dr Vasiliki Totsika, Lecturer in Psychology and Research Tutor (v.totsika@bangor.ac.uk)
Prof. Richard Hastings, Professor of Psychology (r.hastings@bangor.ac.uk)
Dr Gemma Griffith, Research Officer (g.m.griffith@bangor.ac.uk)
School of Psychology, Bangor University

Tel: 01248 388255

I confirm that I have read and understood the attached information sheet for the above study and have had the opportunity to ask questions. ☐

I understand that participation in the study is voluntary and that I am free to end my involvement at any time, or request that the data collected in the study be destroyed, without giving a reason. ☐

I agree to the interview being recorded. ☐

I agree to participate in the above study. ☐

Please complete the information below:

Name…….Mr/Mrs/Miss/other (please circle)

Date of Birth…….....

Name of your child…….

Son/Daughter's Date of Birth……..…

Phone Number……

Best time of day to phone…..……...…

Signature……Date…….…..

Email address…….

FOR OFFICE USE ONLY

Signature of researcher……Date…….....

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Ffurflen Gydsynio

Teitl yr astudiaeth: **Profiadau rhieni sy'n disgwyl i'w plant wedi tyfu ag anableddau dysgu gael tŷ tu allan i gartref y teulu.**

Darllenwch y ffurflen gydsynio hon a rhowch eich blaenlythrennau yn y blychau os ydych yn dymuno cymryd rhan yn yr ymchwil.

Llofnodwch un copi a'i ddychwelyd yn yr amlen radbost a ddarperir a chadwch un copi er gwybodaeth.

Natur y project ymchwil
Amcan y project ymchwil hwn yw edrych ar brofiadau rhieni gyda phlant wedi tyfu ag anableddau dysgu wrth iddynt aros am dŷ priodol tu allan i gartref y teulu.

Enwau'r Archwilwyr/Ymchwilwyr:

Ms Jillian Grey, Ymchwilydd Doethurol (j.m.grey@bangor.ac.uk)
Dr Vasiliki Totsika, Darlithydd mewn Seicoleg a Thiwtor Ymchwil (v.totsika@bangor.ac.uk)
Yr Athro Richard Hastings, Athro Seicoleg (r.hastings@bangor.ac.uk)
Dr Gemma Griffith, Swyddog Ymchwil (g.m.griffith@bangor.ac.uk)
Ysgol Seicoleg, Prifysgol Bangor

Ffôn: 01248 388255

Cadarnhaf fy mod wedi darllen a deall y daflen wybodaeth sydd ynghlwm ynglŷn â'r astudiaeth uchod, ac wedi cael cyfle i ofyn cwestiynau. ☐

Deallaf fod cymryd rhan yn yr astudiaeth yn wirfoddol a fy mod yn rhydd i roi'r gorau i gymryd rhan ar unrhyw adeg, neu ofyn i'r data a gasglwyd yn yr astudiaeth gael ei ddinistrio, heb roi rheswm. ☐

Rwy'n cytuno i'r cyfweliad gael ei recordio. ☐

Rwy'n cytuno i gymryd rhan yn yr astudiaeth uchod. ☐

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Rhowch yr wybodaeth isod os gwelwch yn dda

Enw ……Mr/Mrs/Miss/arall (rhowch gylch)

Dyddiad geni…….....….....

Enw eich plentyn……

Dyddiad Geni eich Mab/Merch …….....…….…

Rhif ffôn…….

Adeg gorau'r dydd i ffonio …..…….....…

Llofnod……..……Dyddiad .....

Cyfeiriad e-bost ……...

AR GYFER Y SWYDDFA'N UNIG:

Llofnod yr ymchwilydd …….

Dyddiad:……

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DEMOGRAPHIC QUESTIONNAIRE (TO BE FILLED IN BY RESEARCHER DURING INTERVIEW, AS PART OF INTRODUCTORY PHASE)

1. Today's date: _____

2. Participant number _____

3. Gender of adult child: ☐ Male ☐ Female

4. Date of Birth: ___/___/____ Age:_____

5. What are your son's/daughter's independence skills like?

   Dependent on others ☐

   Mostly dependent on others ☐

   Partially dependent on others ☐

   Independent ☐

6. What is your son or daughter's diagnosis? _____

7. How long has your son or daughter been living with you? _____

8. Who is your son or daughter's main caregiver? _____

9. Is your son/daughter registered on the Social Services Disability Register?

10. How many people live in your household? .....adult(s)..……children

11. If not already clear, ask for marital status/make-up of household:

    Married/dual parent household ☐ Single/lone parent household ☐

12. Do you have caregiving responsibilities for other people? Yes / No

    If yes, what is the relationship of this person to you? _____

    Do they live in the household? _____

13. Details on siblings

Child 1. Sex:……. Age:… Relationship to Adult child……..….

Child 2. Sex:……. Age:… Relationship to Adult child……..

Child 3. Sex:……. Age:… Relationship to Adult child……..

14. Do you attend any support group or get support from any voluntary groups (e.g. Mencap or Cartrefi)?

_____

_____

Interview protocol

Prior to commencing interview session

- Introduce yourself, check that it is still a good time to call.
- Remind participants that the interview will be recorded, check that it is still ok to do this.
- Remind participants of confidentiality and that any use of their data will not identify them as individuals.

Introductory Questions

See Demographic questionnaire.

Experience of waiting for housing for adult son/daughter - General, setting the scene questions.

1. Could you tell me about your experiences of finding housing for X?

   Prompts: When did you start thinking about finding housing for X?
   Who did you contact first?

2. What have your experiences with service providers been like?

   Prompts: What do you think of these?
   Tell me about this support?
   How did your experiences with services make you feel?

Overview

3. Overall how would you evaluate your experiences in trying to get housing for X?
   (If relevant) What effect has these experiences had on you?
   (If relevant) What effect has these experiences had on X and your family?

Involvement

4. How do you feel services listened to what you had to say about housing options?

   Prompts: Where did X want to live?
   Was X given any options about where he/she wanted to live?
   What do you think about the options?

Future concerns

5. How do you see things changing when X moves to his/her new home?

   Prompts: Why/Why not?

6. Looking back, would anything have been helpful for you to know about the process of finding a home for X?

7. Would you have any advice to other parents looking for a home for their adult child?

Additional filler questions may be required to expand some answers.

Examples are:

> You mentioned ……. . earlier, could you tell me more about this?
> We have talked about this already but is there anything you would like to add?

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Placement Tendency Index

Please circle one of the numbers next to the statements below which indicate your current thinking on finding a place (housing) for your relative with a learning disability, to live outside of the family home.

Score	Item
1	No, we have never thought about it.
2	Occasionally we have given it a thought.
3	Yes, we have thought a lot about it, but have done nothing about it.
4	We have thought about it and made enquiries. We have talked with the Local Authority/ housing association/local voluntary organisation (or other organisation/agency) but we have not done anything yet.
5	We have started to put into action the process (including any paperwork) of finding accommodation for our son/daughter.
6	Our son/daughter has moved out of our home.
7	I would prefer not to answer.

Initial theme table for family 01

Themes/subthemes	Page of Quote	Quote demonstrating theme
1) Factors associated with decision to seek out-of-home accommodation		
Carers' needs for life outside of intensive care role	1	I actually discovered a life of my own when she was away at college and it was quite hard having her back at home. Carers do have needs as well.
a. Self-determination		
The development of independent living skills raised expectation of a future with increased independence from family.	1	Now we had always thought that when she finished college she would come back to the area to live. We never thought she would come back to live in the family home. We always thought that she would have a little flat or be in a house somewhere.
Positive appraisal of opportunity to experience independent living.	1	So really it [residential college] was a wonderful taste of independent living for X.
Increasing development of independence skills.	1	At the end of the first year she moved into one of the college bungalows which was really a step further towards independence
Dilemma of raising unrealistic expectations.	4	[Gives researcher a DVD about on-line documentary about 5 people with learning disabilities who live in a house together]. They do have care staff living in and they made documentary series. Won awards. "The Specials". I discovered it. I was in two minds, do I show X "The Specials". Is it fair to show her something that she might not be able to have. But in the end I thought it was unfair to keep it from her really. She watched it and absolutely loved it. She just totally captivated by these people.
Helping develop capacity to make choices.	4	My feeling is that it's not just about what we want for X, it's about what X wants for herself. And how can a person like X know what they want it you don't present them with the options, you know they don't really necessarily have that capacity to imagine.
Mother's expectation social services would support adult daughter enabling her to relinquish some of her own support.	6	But I think this was another misconception on my part. I thought X is an adult now and she deserves to be treated like an adult and she has a social worker who is taking responsibility for her, I will step back

Acknowledging daughter's transition to adulthood.	6	She was 20 at the time, 21 when she came back from college. It's not appropriate at 21 to have your mum sort your life out for you.
Experience of independence influencing future decision	11	If X hadn't been away to college we might not be as keen to get her out of the house and living independently. But she's had a taste of it and it's what she wants.
Experience of residential college natural progression to independence for both mother and daughter.	12	Moving away to college, handing the responsibility over to someone else was actually quite easy step and if she'd have gone straight into supported living straight from college it would have been a natural progression really.
Aspirations for 'normalised', independent future.	18	Why shouldn't she also be able to leave home and be able to live independently, like our eldest daughter is. Life's never going to be quite the same but at least let it resemble normal life.
2) Interaction with services and professionals:		
a. Transition from family home		
College review meeting prompting initial thinking about post-college placement.	1	At the end of her first year in college there was like a college review and I think we realised then that, even though we knew she had another two years to go, we needed then to start thinking what would happen for her when she left college.
Attendance at residential college influencing decision to find out-of-family home accommodation	11	If X hadn't been away to college we might not be as keen to get her out of the house and living independently. But she's had a taste of it and it's what she wants
b. Service support and provision		
Self-deprecation over misperception of extent of Social Services responsibilities.	1	I think possibly we were very naïve. Possibly we were just very optimistic. But somehow we thought that all of this would just happen. That somebody somewhere was making plans and taking care of it [post-college accommodation].
Shock realisation of lack of resources to support housing needs of adults with LDs.		I think I thought that there was designated housing for people with learning disabilities. You know I just thought these places existed. It was a rude awakening for me to discover that, no, there is no designated housing.
Re-location offering better support	19	If I'm being very cynical I'd move out of the local authority area to one with better facilities. But that's

		a nonsense because X is safer here than being in a big city.
c. Deterioration of relationships with service professionals		
Realisation of lack of support from social services.	2	I think really it dawned on us very slowly that nobody in Social Services was actually doing anything at all to prepare for X's return back to the area when she finished [residential college] in the July.
Frustration with social worker's lack of support. Difficult relationship with social services professional.	2	I think we've been unfortunate in the particular social worker who was assigned to X and I'm like this at the moment whether to make a formal complaint really. Because I think more could have been done. I think if we'd have had another social worker perhaps more would have been done.
Difficulty with social worker raising concerns about social care system as a whole.	2	I'm also concerned about the service as a whole because if one social worker isn't doing their job properly, surely there should be safeguards in place. Somebody should be checking up really.
Advised that placement at residential college made daughter ineligible to initiate process of seeking accommodation.	2	We discussed what the plans were really for accommodation and she [social worker] claimed that we could not fill in the forms for the housing association. She said we couldn't fill the application forms in while X was still at college because she was housed while she was still in college. So we couldn't fill them in until she came back to live at home. She seemed to be saying you can't even get on the waiting list until you are in need of housing.
Start of the difficult relationship with social worker.	3	And my husband remembers all too well that he asked her to put a timescale on something she was proposing and she, said, I'm sorry I can't do that I can't put a time to it. And he says to me that it was obvious in that moment that she had no real plans at all. It was all too vague, too haphazard and that she had no serious intention of doing anything at all
3) Cycle of care/resumption of care		
Parents' ability to provide accommodation resulting in lowering of priority for housing.	5	I don't think there is a special category for people like X [on housing waiting lists]. I think she is just on the list with everyone else. Maybe she gets points for her disability (laughs), if you know what I mean. But I think that any points she might get for her disability, are cancelled out by the fact she is living at

Parents' ability to provide home for daughter, negates housing need.		home. She's perfectly safe and well cared for. She's not a crisis situation by any means.
Feel abandoned by social services.	6	But to be honest I think that was a really big mistake I made [assuming support from social services], because nearly 2 years down the road, the only person who is going to achieve anything on X's behalf is me.
Negative emotions leading to desperate thoughts.	7	On a bad day we think that we'll just move her in to flat nearby and we'll tell Social Services. Just give them her address and let them sort it out really. There's a part of us that feels that's what they are there for and it's what they should jolly well do really.
Mothers' feelings that Social Services view adults with learning disabilities as children under full guardianship of parents.		But I think the local authority still view X as a child living at home with her parents. We provide all the care, we make all the arrangements.
On-going intensive support burden on family carers.		She is as totally dependent on us as she was when she was a child. Nothing in that respect has changed. And I think I expected it to change.
Mother's expectation of social services taking on role of advocate for adult daughter.		I expected Social Services to take the primary responsibility for her when she came back from college. And I've been very slow to realise that, actually, nothing has changed.
Mother feels that social services would only take over guardianship of daughter if she were made homeless.		And they are never going to take that kind of responsibility for her unless we throw her out of the house.
Carers' needs for life outside of intensive care role.		I actually discovered a life of my own when she was away at college and it was quite hard having her back at home. Carers do have needs as well.
Sole responsibility resting with parents. Universal solution needed to address all housing requirements on an equal basis.	11	Sometimes I think it's a sad inevitability that no one else is going to look after her except us. And I guess really we have to be thankful that we would eventually be in a position to do that. But where does that leave everybody else. That's not a solution to the situation nationwide. There has to be a way of providing suitable accommodation.
Carer/care recipient co-dependency upon return home.	12	I think we've missed our opportunity with X because since living back at home she's got very used to it. I've got used to it. And if that flat across the way become vacant tomorrow it

		would be a huge thing emotionally.
Regression in independence skills with a resumed reliance upon mother upon return home.	12	No disrespect to X she's does a lot in life, she's great. But she does nowhere near as much for herself as she used to when she was at college. She would need a lot more support really to gain back some of those skills she's lost.
Increased dependence on mother.		I found it hard when she came back to live. I don't think I realised what I did for her until she went away to college.
a) Parental agency		
Proactive action by parents in seeking accommodation.	6	So where we are at now, and this is really, it's from last summer that we suddenly just started thinking about two houses just over the road here. The lady who owns the house lives upstairs and the flat is downstairs.
Conclusion parents alone will have to resolve daughter's future housing requirement.		But I think it's slowly dawning on us that when the girls [daughters] have finished their studies we are going to have to look at selling the student house [bought by family after death of maternal grandmother] and buy somewhere for X. Or somewhere for us and X so that she's not living in same house with us but she is living nearby.
4) Future considerations		
Worry about future care.	11	You know there comes a point when you wonder what on earth is going to happen to your son or daughter when you are no longer able to care for them.
Examples from other families' situations raising concerns for future. Families faced with insecure future.	11	I've got a friend who's got a brother, I think he's in his late 40s. He lives with their mother who is over 90 and has had a stroke. And I said to my friend, in all honesty, who is looking after who? Is your mother caring for your brother or is he caring for her. And she said, you know it's a bit of both. It's so sad really to see the insecurity that people face.
Disillusionment with Social Services.	18	[Advice to other parents starting process] It would be don't rely in Social Services. Be prepared to have to take it upon yourself to achieve whatever it is you are looking for.
Advice against procrastinations of making future accommodation plans.	18	For a lot of people we tend to think maybe in the future. I think the future is now. You've arrived there before you realise is you can't afford to put things off really.
Future planning increasingly difficult as parents age	18	I don't think it would ever become easier, if anything harder. From time to time I remember seeing a documentary about a women in her 30s with Down Syndrome moving into a flat on

		her own her parent had become elder, they wanted to see her settled and have peace of mind before anything happen to them. If you keep putting if off you 'll end up in a position where you are forced into it and won't have luxury of time to find what you want.
Fears that lack of future planning could lead to 'crisis' re-housing and inappropriate accommodation.	19	I think in terms of advice for other parents. It can become crisis situation if you put if off. You know some parents of people with Down Syndrome are already quite old when their child is born for those people don't delay.
Facing up to the realities of the future for adult children with learning disabilities.	19	It's hard I know it's hard. But I think it's something we have to face up to we are not going to be here forever. Most of us would prefer to see our children settled and not approach end of our lives with huge anxieties

PRIFYSGOL BANGOR UNIVERSITY

Family Carers' Health

Do you care for an adult relative with a learning disability within your family home?

Bangor University, in collaboration with Mencap Cymru and Cartrefi Cymru, are starting a new research project looking at the health of family carers.

We want to find out about:

- Your experiences of being a carer.
- Your health and well-being.
- The support you get to help with your care role from friends and family.
- The support you get from social services and voluntary organisations.
- Your thoughts and plans about the future.

What does taking part involve?

You can either:

- Complete questionnaires on-line. For further information and/or to take part go to https://www.survey.bris.ac.uk/bangor/carerwellbeing for English language information.
- For Welsh language information and questionnaires https://www.survey.bris.ac.uk/bangor/iechydgofalwyr
- Or contact Jillian Grey, details below, to receive further information and/or paper copies of questionnaires.

How long will it take?

The questionnaires have been carefully chosen for ease of completion. These should not take much longer than 20 minutes in total to complete.

For further information about how to take part, please contact:

Jillian Grey
School of Psychology
Brigantia Building
Bangor University
Bangor, Gwynedd, LL57 2AS

Tel: 01248 388255
Email: j.m.grey@bangor.ac.uk

Iechyd Gofalwyr Teuluol

Ydych chi'n gofalu am berthynas sy'n oedolyn (18 oed a hŷn) gydag anabledd dysgu yn eich cartref teuluol?

PRIFYSGOL BANGOR UNIVERSITY

Mae Prifysgol Bangor, ar y cyd gyda Mencap Cymru a Chartrefi Cymru, yn dechrau project ymchwil newydd sy'n edrych ar iechyd gofalwyr teuluol.

Rydym ni eisiau gwybod y canlynol:

- Eich profiadau o fod yn ofalwr.
- Eich iechyd a'ch lles.
- Y gefnogaeth a gewch i helpu gyda'ch swyddogaeth gofalu gan ffrindiau a theulu.
- Y gefnogaeth a gewch gan y gwasanaethau cymdeithasol a sefydliadau gwirfoddol.
- Eich meddyliau a'ch cynlluniau ar gyfer y dyfodol.

Beth mae cymryd rhan yn ei olygu?

Gellwch naill ai:

- Lenwi holiaduron ar-lein. Am fwy o wybodaeth, ac/neu i gymryd rhan, ewch https://survey.psychology.bangor.ac.uk/iechydgofalwyr.
- Neu cysylltwch gyda Jillian Grey, manylion isod, i dderbyn rhagor o wybodaeth a/neu gopïau papur o holiaduron.

Faint o amser fydd yn ei gymryd?
Mae'r holiaduron wedi cael eu dewis yn ofalus er mwyn iddynt fod yn hawdd i'w llenwi. Ni ddylai'r rhain gymryd llawer mwy nag 20 munud i gyd i'w llenwi.

Am ragor o wybodaeth am sut i gymryd rhan, cysylltwch â:

Jillian Grey
Yr Ysgol Seicoleg
Adeilad Brigantia
Prifysgol Bangor
Bangor, Gwynedd, LL57 2AS

Ffôn: 01248 388255
E-bost: **j.m.grey@bangor.ac.uk**

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SCHOOL OF PSYCHOLOGY

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PARTICIPANT INFORMATION SHEET

Physical and Mental Health of Families Co-residing with an Adult Relative with a Learning Disability.

We are a group of researchers from the School of Psychology at Bangor University. We would like to invite you to take part in a new study being conducted at Bangor University, in collaboration with Mencap Cymru and Cartrefi Cymru, providers of support to people with learning disabilities and their families.

What is the purpose of the study?

We know that caring for an adult with a learning disability 24-hrs a day, is not an easy task. We would like to find out how carers' cope, how they feel, and how they plan for the future.

Why am I being invited?

Because you live with an adult with a learning disability (aged 18 years or older) and you are the main carer for this person.

What does taking part involve?

You will be asked to fill in some questionnaires. This takes about 20 to 30 minutes, and you can choose to do it online or we can post them to you. The questionnaires will ask you about yourself and your current circumstances, your health and well-being, how you are supported in your caregiving role, and whether you are thinking of alternative accommodation for your son or daughter in the future.

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EBOST/EMAIL: e.c.leek@bangor.ac.uk
www.bangor.ac.uk www.bangor.ac.uk/psychology

Registered charity number: 1141565

If you agree, we would also like to contact you again about 12 months after you have first completed the questionnaires. At that point we will only ask you whether your adult relative is still living with you. You can choose whether to respond to this question on the phone or by post. It will take about 1 minute to respond.

Why should I take part?

Through carrying out this study would hope to improve two main things:

(1) how much we know about the health and well-being of carers who have been caring for a long time for their adult relative in their own house.

(2) how families think and plan about alternative accommodation. The information you provide will help us understand how carers like you need to be supported, and how services need to plan for out of home accommodation.

Confidentiality

All information collected for this project will be treated in accordance with the Data Protection Act (1998). The only people who will have access to identifiable information are the research team at Bangor University's School of Psychology (see below). No information identifying you or your family will be passed on to a third party outside of the research team without your prior permission.

Information collected from families will be made anonymous using a coding system. All data collected will be kept in a locked drawer or anonymised on secure databases. When the study finishes, all identifying information will be safely destroyed.

We will not identify any of the information you provided individually, because we will summarise all participants' information in any publications produced from this project. Nobody will know that you participated in this project.

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Your rights

You do not have to take part in this study. Participation in the study does not affect any services you may receive from statutory, private or organisations. If you participate and later change your mind, please contact us to let us know. You have the right to withdraw your information from this study at any time, should you decide that you no longer wish to be involved.

Risks in taking part

There is no anticipated risk in taking part in this research. However, if you have a query relating to your relative with learning disabilities, you can contact the Mencap Helpline on 0808 808 1111 for free support and advice.

At the end of the study

You will receive a summary of the study's findings. We will also publish our findings in places where you and other people can access them: e.g., newsletters, voluntary organisation websites and our Facebook page (www.facebook.com/BangorIDDD).

If you would like to take part either go to the web link to complete the on-line questionnaires (web-link) or complete and return the paper copies of the questionnaires.

Research Team

Jillian Grey (Doctoral Researcher)
Dr Vasiliki Totsika (Lecturer in Psychology)
Prof. Richard Hastings (Professor of Psychology)

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www.bangor.ac.uk www.bangor.ac.uk/psychology

Any concerns or queries?

For any questions about the research, please do not hesitate to contact Jillian Grey on telephone: 01248 388255 or email j.m.grey@bangor.ac.uk

Post: Jillian Grey
School of Psychology
Bangor University
Brigantia Building
Penrallt Road
Bangor, Gwynedd. LL58 2AS

If you have any concerns about your relative or need some support and advice call the Mencap Cymru helpline on tel: 0808 808 111 or visit www.mencap.org.uk/cymru.

Complaints

If you have any complaints about the way this research is being conducted you are welcome to address unresolved concerns to:

Mr Hefin Francis,
School Manager
School of Psychology,
Bangor University,
Brigantia Building,
Penrallt Road,
Bangor,Gwynedd.
LL58 2AS

Thank you for considering this project

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SCHOOL OF PSYCHOLOGY

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TAFLEN WYBODAETH I RAI SY'N CYMRYD RHAN

Iechyd Corfforol a Meddyliol Teuluoedd sy'n Cyd-fyw gyda Pherthynas sy'n Oedolyn ag Anabledd Dysgu.

Rydym ni'n grŵp o ymchwilwyr o'r Ysgol Seicoleg ym Mhrifysgol Bangor. Hoffem eich gwahodd i gymryd rhan mewn astudiaeth newydd sy'n cael ei chynnal ym Mhrifysgol Bangor, ar y cyd â Mencap Cymru a Cartrefi Cymru, rhai sy'n darparu cefnogaeth i bobl ag anableddau dysgu a'u teuluoedd.

Beth yw pwrpas yr astudiaeth?

Rydym yn gwybod nad yw gofalu am oedolyn ag anabledd dysgu am 24 awr y dydd yn dasg hawdd. Hoffem ddarganfod sut mae gofalwyr yn ymdopi, sut maent yn teimlo, a sut maent yn cynllunio ar gyfer y dyfodol.

Pam ydw i'n cael gwahoddiad i gymryd rhan?

Oherwydd eich bod chi'n byw gydag oedolyn sydd ag anabledd dysgu (18 oed neu hŷn) a chi yw'r prif ofalwr ar gyfer yr unigolyn yma.

Beth mae cymryd rhan yn ei olygu?

Gofynnir i chi lenwi ychydig o holiaduron. Bydd hyn yn cymryd tua 20 i 30 munud, a gellwch ddewis ei wneud ar-lein neu medrwn ni eu postio atoch. Bydd yr holiaduron yn gofyn i chi amdanoch eich hun a'ch amgylchiadau presennol, eich iechyd a'ch lles, sut cewch eich cefnogi yn eich swyddogaeth rhoi gofal, ac a ydych chi'n meddwl am lety arall ar gyfer eich mab neu ferch yn y dyfodol.

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www.bangor.ac.uk www.bangor.ac.uk/psychology

Os byddwch chi'n cytuno, hoffem gysylltu â chi hefyd tua 12 mis ar ôl i chi lenwi'r holiaduron am y tro cyntaf. Bryd hynny, yr unig beth y byddwn ni'n ei ofyn i chi yw a yw eich perthynas yn dal i fyw gyda chi. Gellwch ddewis ateb y cwestiwn hwn ar y ffôn neu drwy'r post. Bydd yn cymryd rhyw funud i ateb.

Pam ddylwn i gymryd rhan?

Drwy wneud yr astudiaeth hon, gobeithiwn wella dau brif beth:

(1) Faint yr ydym yn ei wybod am iechyd a lles gofalwyr sydd wedi bod yn gallu ers amser hir am eu perthynas yn eu cartref eu hunain.

(2) Sut mae teuluoedd yn meddwl am lety arall, ac yn cynllunio hynny. Bydd y wybodaeth a roddwch yn ein helpu i ddeall sut mae gofalwyr fel chi angen cael eich cefnogi, a sut mae ar wasanaethau angen cynllunio ar gyfer llety y tu allan i'r cartref.

Cyfrinachedd

Bydd yr holl wybodaeth a gesglir ar gyfer y project hwn yn cael ei thrin yn unol â Deddf Gwarchod Data 1998. Yr unig bobl a fydd â mynediad at wybodaeth o'r hyn y gellir eich adnabod yw'r tîm ymchwil yn Ysgol Seicoleg Prifysgol Bangor (gwelwch isod). Ni fydd unrhyw wybodaeth sy'n datgelu pwy ydych chi na'ch teulu yn cael ei throsglwyddo i drydydd parti y tu allan i'r tîm ymchwil heb eich caniatâd ymlaen llaw.

Bydd gwybodaeth a gesglir gan deuluoedd yn cael ei gwneud yn ddienw gan ddefnyddio system godio. Bydd yr holl ddata a gesglir yn cael eu cadw mewn drôr dan glo, neu'n ddienw mewn cronfeydd data diogel. Pan fydd yr astudiaeth yn dod i ben, bydd yr holl wybodaeth o'r hyn y gellir adnabod rhywun yn cael ei dinistrio'n ddiogel.

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Ni fyddwn yn dweud pa unigolyn sydd wedi rhoi'r wybodaeth, oherwydd byddwn yn crynhoi gwybodaeth pawb sy'n cymryd rhan mewn unrhyw gyhoeddiadau a gynhyrchir o'r project hwn. Ni fydd neb yn gwybod i chi gymryd rhan yn y project hwn.

Eich hawliau

Nid oes raid i chi gymryd rhan yn yr astudiaeth hon. Nid yw cymryd rhan yn yr astudiaeth yn effeithio ar unrhyw wasanaethau yr ydych yn eu derbyn o bosibl gan sefydliadau statudol, preifat neu wirfoddol. Os byddwch yn cymryd rhan, ac wedyn yn newid eich meddwl, cysylltwch â ni i roi gwybod. Mae gennych hawl i dynnu'ch gwybodaeth o'r astudiaeth hon yn ôl unrhyw bryd, os penderfynwch nad ydych yn dymuno cymryd rhan mwyach.

Risgiau mewn cymryd rhan

Ni ddisgwylir bod unrhyw risg drwy gymryd rhan yn yr ymchwil hon. Fodd bynnag, os oes gennych chi ymholiad yn ymwneud â'ch perthynas ag anableddau dysgu, gellwch gysylltu â llinell gymorth Mencap ar 0808 808 1111 am gefnogaeth a chyngor am ddim.

Ar ddiwedd yr astudiaeth

Byddwch yn derbyn crynodeb o ganfyddiadau'r astudiaeth. Mi fyddwn ni hefyd yn cyhoeddi ein canfyddiadau mewn llefydd lle gellwch chi a phobl eraill gael mynediad atynt: e.e. newyddlenni, gwefannau sefydliadau gwirfoddol a'n tudalen Facebook (www.facebook.com/BangorIDDD).

Os hoffech gymryd rhan, naill ai ewch i'r cyswllt gwe i lenwi'r holiaduron ar-lein (cyswllt gwe) neu llenwch y copïau papur o'r holiaduron a'u hanfon yn ôl.

Y Tîm Ymchwil

Jillian Grey (Ymchwilydd Doethurol)
Dr Vasiliki Totsika (Darlithydd mewn Seicoleg)
Yr Athro Richard Hastings (Athro Seicoleg)

Unrhyw bryderon neu ymholiadau?

Os oes gennych unrhyw gwestiynau am yr ymchwil, mae pob croeso i chi gysylltu â Jillian Grey drwy ffonio: 01248 388255 neu e-bostio j.m.grey@bangor.ac.uk

Postio at: Jilllian Grey
Yr Ysgol Seicoleg
Prifysgol Bangor
Adeilad Brigantia
Ffordd Penrallt
Bangor, Gwynedd. LL58 2AS

Os oes gennych unrhyw bryderon am eich perthynas, neu os oes arnoch angen cefnogaeth a chyngor, ffoniwch llinell gymorth Mencap Cymru ar: 0808 808 111 neu ewch i www.mencap.org.uk/cymru.

Cwynion

Os oes gennych unrhyw gŵynion ynglŷn â'r ffordd y mae'r ymchwil hon yn cael ei chynnal, mae croeso i chi fynd ag unrhyw bryderon heb eu datrys at:

Mr Hefin Francis,
Rheolwr yr Ysgol
Yr Ysgol Seicoleg,
Prifysgol Bangor,
Adeilad Brigantia,
Ffordd Penrallt
Bangor, Gwynedd, LL58 2AS

Diolch am ystyried y project hwn

Lle bo'n bosibl, rydym wedi defnyddio'r iaith Gymraeg ar gyfer gwybodaeth a holiaduron. Yn anffodus, nid yw hyn yn bosibl ar gyfer yr holl holiaduron, nad ydynt wedi cael eu profi yn y Gymraeg ar gyfer eu dibynadwyedd.

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FOR OFFICE USE ONLY:

Participant No. ☐

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Consent form

Study Title: Physical and Mental Health of Families Co-residing with an Adult Relative with a Learning Disability.

Please take your time to read this consent form. Sign one copy and return to Jillian Grey at Bangor University and keep one copy for your records.

Today's date ☐ (DD-MM-YY)

	Please initial boxes below:
I confirm that I have read and understood the study information and have had the opportunity to ask questions.	☐
I understand that participation in the study is voluntary and that I am free to end my involvement at any time, or request that my data be removed from the study, without giving a reason.	☐
I agree to participate in the above study	☐

Name: ……...

Address:…….……..

I would be happy for the research team to contact me in 12 months' time to ask whether my adult relative is still living at home Yes ☐ No ☐

a. If yes, would you prefer to be contact by Post? ☐ Telephone? ☐

b. Please provide your telephone number with area code: ……

Signature……

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AT DDEFNYDD Y SWYDDFA YN UNIG:

Rhif y sawl sy'n cymryd rhan:

PRIFYSGOL BANGOR UNIVERSITY

Ffurflen Gydsynio

Teitl yr Astudiaeth: Iechyd Corfforol a Meddyliol Teuluoedd sy'n Cyd-fyw gyda Pherthynas sy'n Oedolyn ag Anabledd Dysgu.

Cymerwch eich amser i ddarllen y ffurflen gydsynio yma. Llofnodwch un copi a'i dychwelyd at Jillian Grey ym Mhrifysgol Bangor a chadwch un copi ar gyfer eich cofnodion.

	Llofnodwch y bocsys isod:
Rwy'n cadarnhau fy mod wedi darllen a deall y daflen wybodaeth ar gyfer yr astudiaeth ac wedi cael cyfle i ofyn cwestiynau.	
Rwy'n cytuno i gymryd rhan yn yr astudiaeth uchod.	

Enw: ……..... Dyddiad: ……....

Cyfeiriad:.....

Llofnod …...……..

Os ydych chi'n hapus i ni gysylltu â chi ymhen 12 mis i ofyn a yw eich perthynas yn dal i fyw gyda chi, a fyddech cystal â llofnodi isod:

Llofnod……

Byddai'n well gen i petaech yn cysylltu â mi drwy'r (*ticiwch un o'r bocsys isod)*

Post

Ffonio Nodwch rif ffôn .....

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Demographic Questionnaire

The following questions ask for background information about you, your family and adult relative with a learning disability. Please tick the appropriate boxes or write in the spaces provided.

What is your gender? Male ☐ Female ☐

Your date of birth _____/_____/_____(DD-MM-YY)

What is your relationship with your adult relative with learning disabilities (e.g. mother, father, step mother/father, sister, brother)?_____

What is your current marital status?

Married and living with spouse/civil partner…….. ☐

Living with partner …… ☐

Divorced/Separated/Single/Widowed/Not currently living with a partner…… ☐

Prefer not to answer …… ☐

In total how many people currently live in your home? _____

a. Aged under 14_____ b. .Age 14+ _____

Please tick the highest level of your educational qualifications:

No formal qualifications..... ☐

O Levels/GCSEs/CSEs or equivalent……..……. ☐

Vocational Qualifications/FE (Apprenticeship, NVQs, RSAs) or equivalent ..…… ☐

'A' Levels /BETECH or equivalent……..…… ☐

Professional Qualifications (Engineering, Accountancy) or equivalent…….. ☐

Higher Education (BA, BSc) or equivalent ……. ☐

Masters/Doctoral Degree or equivalent …….…….. ☐

Prefer not to answer ……. ☐

. **Do you currently have a paid job outside the home?**

Yes ☐ No ☐ Prefer not to answer ☐

*If yes, is your job/occupation full or part-time***?** Full-time ☐ Part-time ☐

Date of birth of your relative with learning disabilities___/___/____(DD-MM-YY)

Gender of your relative with learning disabilities Male ☐ Female ☐

Can your relative with learning disabilities speak or sign using more than 30 words or signs in their vocabulary?

Yes ☐ No ☐ Prefer not to answer ☐

Does your relative with learning disabilities have sensory impairments which impacts on his/her quality of life:.

Yes ☐ No ☐ Prefer not to answer ☐

If yes, what is the impairment?

Visual impairment? Yes ☐

Hearing impariment? Yes ☐

Do you need to assist your adult relative with learning disabilities with eating?

Yes ☐ No ☐ Prefer not to answer ☐

Is your relative continent during the day?

Yes ☐ No ☐ Prefer not to answer ☐

Is your relative continent during the night?

Yes ☐ No ☐ Prefer not to answer ☐

Does your relative currently have epileptic seizures?

Yes ☐ No ☐ Prefer not to answer ☐

Does your relative with learning disabilities attend any of the following:

Yes ☐ No ☐ Prefer not to answer ☐

If yes, please select all that apply.

☐ Paid work

☐ Workshop

☐ Voluntary work

☐ Day Centre

☐ Respite care

Number of hours attends activities in total per week ☐

Data from research with families with a family member with a disability has shown that a family's financial resources are important in understanding family member's views and experiences. With this in mind, we would be grateful if you could answer the additional question below. We are not interested in exactly what your family income is, but we would like to be able to look at whether people with different levels of financial resources have different experiences.

What is your total weekly household income (after any deductions e.g. income tax), including income from paid work, pension, Social Services Benefits (e.g. Job Seekers Allowance, DLA, Carers' Allowance, Attendance Allowance, Tax Credits, Housing Benefits, Pension Credits) etc? Please tick one box only:

£200 or less…… ☐

Between £201 and £300…… ☐

Between £301 and £400…… ☐

Between £401 and £500…… ☐

Between £501 and £600…… ☐

Between £601 and £700…… ☐

Between £701 and £800…… ☐

Between £801 and £900…… ☐

Over £1,000…… ☐

Prefer not to answer ☐

Please provide your postcode (full or partial e.g. ‘CF15’ or CF15 2DA’)

This information will only be used to to find out more about the area you live (e.g. classification of area - urban or rural, economic status etc).

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AT DDEFNYDD Y SWYDDFA YN UNIG:
Rhif y sawl sy'n cymryd rhan: ☐

Holiadur Demograffig
Iechyd Corfforol a Meddyliol Teuluoedd sy'n
Cyd-fyw gydag Oedolyn ag Anabledd Dysgu

Mae'r cwestiynau canlynol yn gofyn am wybodaeth gefndir amdanoch, eich teulu a'ch perthynas sy'n oedolyn ag anabledd dysgu. Ticiwch y bocsys priodol neu ysgrifennwch yn y lle a roddir.

1. **Dyddiad heddiw: _____**

2. **Beth yw eich gender?** Gwrywaidd ☐ Benywaidd ☐

3. **Eich dyddiad geni _____/_____/_____**

4. **Beth yw eich perthynas gyda'r oedolyn ag anableddau dysgu** (e.e. mam, tad, llysfam/llystad, chwaer, brawd)? _____

5. **Beth yw eich statws priodasol presennol?**

   Yn briod ac yn byw gyda phriod /partner sifil ..... ☐

   Yn byw gyda phartner ..... ☐

   Wedi cael ysgariad/ wedi gwahanu/ yn sengl/ gweddw /ddim yn byw gyda phartner ar hyn o bryd ☐

6. **Faint o bobl i gyd sy'n byw yn eich cartref ar hyn o bryd?**

   ____ 14 oed a hŷn Dan 14 oed____

7. **Ticiwch lefel uchaf eich cymwysterau addysgol**:

   Dim cymhwyster ffurfiol ..... ☐
   Lefel O /TGAU/CSE neu gyfatebol ..... ☐
   Cymwysterau Galwedigaethol/FE (Prentisiaeth, NVQ, RSA) neu gyfatebol ..... ☐
   Lefel A /BETECH neu gyfatebol ..... ☐
   Cymwysterau Proffesiynol (Peirianneg, Cyfrifeg) neu gyfatebol ..... ☐
   Addysg Uwch (BA / BSc) neu gyfatebol ..... ☐
   Gradd Meistr/Doethur neu gyfatebol ..... ☐

Oes gennych chi swydd gyflogedig y tu allan i'r cartref ar hyn o bryd? Oes ☐ Nac oes ☐

Os oes gennych, a yw eich swydd/galwedigaeth yn un llawn-amser neu ran-amser?

Llawn-amser ☐ Rhan-amser ☐

8. **Dyddiad geni'ch perthynas gydag anableddau dysgu _____/_____/_____**

9. **Gender eich perthynas gydag anableddau dysgu** Gwrywaidd ☐ Benywaidd ☐

10. **A ydi'ch perthynas ag anableddau dysgu yn gallu siarad neu arwyddo gan ddefnyddio mwy na 30 o eiriau/arwyddion yn eu geirfa?**

Ydi ☐ Nac ydi ☐

11. **A oes gan eich perthynas ag anableddau dysgu nam ar y synhwyrau sy'n effeithio ar ansawdd ei fywyd / ei bywyd?** Oes ☐ Nac oes ☐

Os oes, beth yw'r nam?

Nam ar y golwg? Oes ☐

Nam ar y clyw? Oes ☐

12. **A oes arnoch angen cynorthwyo'ch perthynas ag anableddau dysgu wrth fwyta?**

Oes ☐ Nac oes ☐

14. A yw eich perthynas yn gallu dal dŵr yn ystod y dydd? Ydi ☐ Nac ydi ☐

A yw eich perthynas yn gallu dal dŵr yn ystod y nos? Ydi ☐ Nac ydi ☐

15. A yw eich perthynas yn cael ffitiau epileptig ar hyn o bryd? Ydi ☐ Nac ydi ☐

16. A yw eich perthynas gydag anableddau dysgu yn mynd i unrhyw un o'r canlynol:

Os ydyw, ticiwch y bocs(ys) perthnasol a nodwch nifer yr oriau maent yn mynd iddynt yr wythnos.

Gwaith â thâl ☐ Nifer yr oriau'r wythnos _____

Gweithdy ☐ Nifer yr oriau'r wythnos _____

Gwaith gwirfoddol ☐ Nifer yr oriau'r wythnos _____

Canolfan Ddydd ☐ Nifer yr oriau'r wythnos _____

Gofal seibiant ☐ Nifer yr oriau'r wythnos _____

15. *Mae data o ymchwil gyda theuluoedd gydag aelod o'r teulu ag anabledd, wedi dangos bod adnoddau ariannol teulu yn bwysig wrth ddeall safbwyntiau a phrofiadau aelod o deulu. Gan gofio hyn, byddem yn ddiolchgar pe gallech ateb y cwestiwn ychwanegol isod. Nid oes gennym ddiddordeb mewn gwybod beth yn union yw incwm eich teulu, ond hoffem allu edrych a yw pobl gyda gwahanol lefelau o adnoddau ariannol yn cael profiadau gwahanol.*

Beth yw cyfanswm incwm wythnosol eich cartref (ar ôl tynnu pethau fel treth incwm), yn cynnwys incwm o waith â thâl, pensiwn, Budd-daliadau Gwasanaethau Cymdeithasol (e.e. Lwfans Ceisio Gwaith, DLA, Lwfans Gofalwyr, Lwfans Gweini, Credydau Treth, Budd-daliadau Tai, Credydau Pensiwn) etc?

Ticiwch un bocs yn unig:

£200 neu lai……..…… ☐…

Rhwng £201 a £300…… ☐..

Rhwng £301 a £400……...…… ☐...

Rhwng £401 a £500…… ☐....

Rhwng £501 a £600…….…… ☐...

Rhwng £601 a £700…….. ☐....

Rhwng £701 ac £800…… ☐.....

Rhwng £801 a £900…….. ☐

Dros £1,000…….…… ☐..

A fyddech cystal â rhoi'ch cod post llawn:

Defnyddir y wybodaeth hon i ddarganfod mwy am yr ardal yr ydych yn byw ynddi yn unig (e.e. Dosbarthiad yr ardal – trefol neu wledig, statws economaidd etc).

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Family Resource Scale

This questionnaire is designed to find out if there are enough resources for you and your family (time, money, energy and so on). For each item, please tick the response that best describes how well the need is met on a month to month basis.

	0 Does not apply	1 Not at all	2 Seldom adequate	3 Some-times adequate	4 Usually adequate	5 Always adequate	6 Prefer not to answer
1. Food for 2 meals a day .							
2. House or flat							
3. Money to buy necessities.							
4.. Clothes for your family							
5. Heat for your house or flat.							
6. Money to pay monthly bills**.**							
7. Good job for yourself or spouse/partner.							
8. Money to buy supplies for your relative.							
9. Reliable transport (own car or provided by others).							
10. Time to get enough sleep/rest.							
11. Furniture for your home.							
12. Time to be by yourself.							
13. Time for family to be together.							
14. Time be with your child(ren) or other relatives.							
15. Time to be with your spouse/partner or close friend.							

Family Resources (Contd.)

16. Telephone or access to a phone.							
17. Day care/day sitting for your relative with a learning disability							
18. Money to buy special equipment/supplies for your relative.							
19. Dental care for your family .							
20. Someone to talk to.							
21. Time to socialise							
22. Time to keep fit/exercise.							
23. Money to buy things for yourself.							
24. Money for family entertainment							
25. Money to save.							
26. Time and money for travel/take a holiday.							

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EQ-5D-3L

By placing a tick in one box in each group below, please indicate which statements best describe **your own** health state today.

Mobility

I have no problems in walking about ❑
I have some problems in walking about ❑
I am confined to bed ❑
I would prefer not to answer ❑

Self-Care

I have no problems with self-care ❑
I have some problems washing or dressing myself ❑
I am unable to wash or dress myself ❑
I would prefer not to answer ❑

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities ❑
I have some problems with performing my usual activities ❑
I am unable to perform my usual activities ❑
I would prefer not to answer ❑

Pain/Discomfort

I have no pain or discomfort ❑
I have moderate pain or discomfort ❑
I have extreme pain or discomfort ❑
I would prefer not to answer ❑

Anxiety/Depression

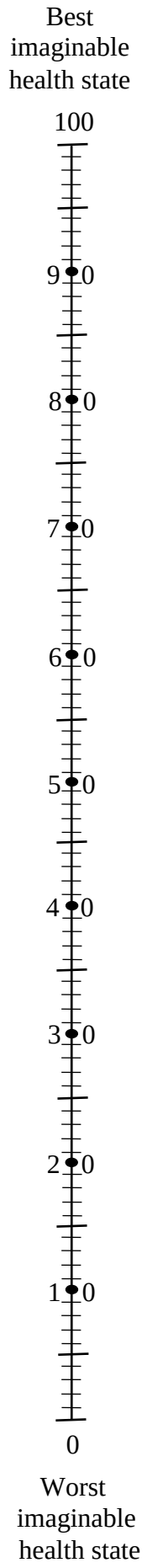
I am not anxious or depressed ❑
I am moderately anxious or depressed ❑
I am extremely anxious or depressed ❑
I would prefer not to answer ❑

EQ-VAS

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today



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EQ-5D-3L

Drwy osod tic mewn un blwch ym mhob grŵp isod, dangoswch, os gwelwch yn dda, pa osodiadau sy'n disgrifio cyflwr eich iechyd chi heddiw orau.

Symudedd

Dydw i ddim yn cael anhawster wrth gerdded o gwmpas ❑
Rydw i'n cael rhywfaint o anhawster wrth gerdded o gwmpas ❑
Rydw i'n gaeth i'r gwely ❑
Byddai'n well gennyf beidio ag ateb ❑

Hunan-Ofal

Dydw i ddim yn cael anhawster gofalu amdanaf fy hun ❑
Rydw i'n cael rhywfaint o anhawster ymolchi neu wisgo amdanaf ❑
Dydw i ddim yn gallu ymolchi na gwisgo amdanaf ❑
Byddai'n well gennyf beidio ag ateb ❑

Gweithgareddau Arferol (*e.e. gwaith, astudio, gwaith tŷ, gweithgareddau teuluol neu hamdden)*

Dydw i ddim yn cael anhawster gwneud fy ngweithgareddau arferol ❑
Rydw i'n cael rhywfaint o anhawster gwneud fy ngweithgareddau arferol ❑
Dydw i ddim yn gallu gwneud fy ngweithgareddau arferol ❑
Byddai'n well gennyf beidio ag ateb ❑

Poen/Anghysur

Does gen i ddim poen nac anghysur ❑
Mae gen i boen neu anghysur cymedrol ❑
Mae gen i boen neu anghysur ofnadwy ❑
Byddai'n well gennyf beidio ag ateb ❑

Pryder/Iselder

Dydw i ddim yn teimlo'n bryderus nac yn isel ❑
Rydw i'n teimlo'n weddol bryderus neu isel ❑
Rydw i'n teimlo'n ofnadwy o bryderus neu isel ❑
Byddai'n well gennyf beidio ag ateb ❑

Y cyflwr iechyd gorau y gellwch ei ddychmygu

Er mwyn helpu pobl i ddweud pa mor dda neu ddrwg yw cyflwr iechyd, rydym wedi tynnu llun graddfa (eitha tebyg i thermomedr). Ar hon mae'r cyflwr gorau y gellwch ei ddychmygu wedi ei nodi fel 100 a'r cyflwr gwaethaf y gellwch ei ddychmygu wedi ei nodi fel 0.

Hoffem i chi ddangos ar y raddfa hon pa mor dda neu ddrwg ydy'ch iechyd chi eich hun heddiw, yn eich barn chi.

Os gwelwch yn dda, gwnewch hyn drwy dynnu llinell o'r blwch isod at ba bwynt bynnag ar y raddfa sy'n dangos pa mor dda neu ddrwg ydy cyflwr eich iechyd chi heddiw.

Cyflwr eich iechyd chi eich hun heddiw

Y cyflwr iechyd gwaethaf y gellwch ei ddychmygu

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Questionnaire on Resources and Stress Short Form
Parents and Family Problem Scale (QRS-F)

The following statements deal with your feelings about caring for your relative who has a learning disability. Please give your honest feelings and opinions. If it is difficult to decide 'true' or 'false', (please circle) answer in terms of what you or your family feel or do most of the time.

Caring for _____ puts a strain on me	TRUE	FALSE	PREFER NOT TO ANSWER
Other member of the family have to do without things because of _____	TRUE	FALSE	PREFER NOT TO ANSWER
Our family's social life has suffered because of caregiving responsibilities and financial stress	TRUE	FALSE	PREFER NOT TO ANSWER
I can go to visit friends whenever I want	TRUE	FALSE	PREFER NOT TO ANSWER
There are many places where we can enjoy ourselves as a family when _____ comes along.	TRUE	FALSE	PREFER NOT TO ANSWER
Members of our family get to do the same kind of things other families do.	TRUE	FALSE	PREFER NOT TO ANSWER
The constant demands for care for _____ limit growth and development of someone else in our family.	TRUE	FALSE	PREFER NOT TO ANSWER

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Family Support Scale

Below is a list of people and groups that are often helpful to members of a family caring for someone with a learning disability.

Please choose **one** of the numbers (0-5) to indicate how helpful these sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, tick the 'not available (0)' response.

	0 Not Available	**1 Not at All Helpful**	**2 Some-times Helpful**	**3 Generally Helpful**	**4 Very Helpful**	**5 Extremely Helpful**	**6 Prefer not to answer**
Your Parents							
Your spouse/partner's parents							
Your relatives/kin (other than parents e.g. sisters/ brothers, aunts/uncles etc.)							
Your spouse/partner's relatives/kin.							
Spouse/partner							
Your friends							
Your spouse/partner's friends.							
Your relative with a learning disability.							
Your own child/children (without a learning disability)							
Neighbours							
Other parents							
Colleagues/co-workers							
Parents' groups							
Social groups/clubs							
Church members/ Minister/Rabbi/Imam							
Your family or relative's doctor							
Day Centre							
Professional helpers (social workers, therapists)							
Professional agencies (e.g. health, social services, mental health)							
Voluntary services (e.g. Mencap, Mind, Cartrefi, Scope etc.)							

F-COPES

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Please read the list of 'Response Choices' and tick the response which best describes what you and your family do when there is a problem. .

When we face problems or difficulties in our family we respond by:

	1 Strongly disagree	**2 Moderately disagree**	**3 Neither agree nor disagree**	**4 Moderately agree**	**5 Strongly agree**	**6 Prefer not to answer**
Sharing our difficulties with relatives						
Seeking encouragement and support from friends						
Knowing we have the power to solve major problems.						
Seeking information and advice from persons in other families who have faced the same or similar						
Seeking advice from relatives (grandparents etc.)						
Seeking assistance from community agencies and programmes designed to help families in our situation						
Knowing that we have the strength within our own family to solve our problems.						
Receiving gifts and favours from neighbours(e.g. food, taking in mail etc.)						
Seeking information and advice from family doctor						
Asking neighbours for favours and assistance						
Facing the problem 'head-on' and trying to get a solution right away						
Watching television						
Showing that we are strong						
Attending religious services (e.g. going to church, mosque, temple).						
Accepting stressful events as a fact of life.						

F-COPES (contd.)

	1 Strongly disagree	2 Moderately disagree	3 Neither agree nor disagree	4 Moderately agree	5 Strongly agree	6 Prefer not to answer
Sharing concerns with close friends.						
Knowing luck plays a big part in how well we are able to solve our problems.						
Exercising with friends to stay fit and reduce tension.						
Accepting that difficulties occur unexpectedly.						
Doing things with relatives (e.g. get togethers, dinners etc).						
Seeking professional counselling and help for family difficulties.						
Believing we can handle our own problems.						
Participating in activities through church/temple/ mosque etc.						
Defining the family problem in a more positive way so we do not become too discouraged.						
Asking relatives how they feel about problems we face.						
Feeling that no matter what we do to prepare, we will have difficulties in handling problems.						
Seeking advice from a religious leader.						
Believing if we wait long enough, the problem will go away.						
Sharing problems with neighbours.						
Having faith in God, Allah etc.						

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Kessler 6

Please read the statements below and tick the response which best describes how you have been feeling during the past 4 weeks and how often you have felt like this.

During the past 4 weeks how much of the time did you feel….

	1 All of the time	2 Most of the time	3 Some of the time	4 A little of the time	5 None of the time	6 Prefer not to answer
. …so sad nothing could cheer you up?						
…nervous?						
….restless or fidgety?						
…hopeless?						
…that everything was an effort?						
…worthless?						

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Zarit Burden Index

The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement indicate how often you feel that way: 'never', 'rarely', 'sometimes', 'quite frequently', or 'nearly always'. There are no right or wrong answer.

	0 Never	**1 Rarely**	**2 Some-times**	**3 Quite Frequently**	**4 Nearly Always**	**5 Prefer not to answer**
Do you feel that because of the time you spend with your relative, you don't have enough time for yourself?						
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?						
Do you feel angry when you are around your relative?						
Do you feel that your relative currently affects your relationship with other family members?						
Do you feel strained when you are around your relative?						
Do you feel that your health has suffered because of your involvement with your relative?						
Do you feel that you don't have as much privacy as you would like because of your relative?						
Do you feel that your social life has suffered because you are caring for your relative?						
Do you feel uncertain about what to do about your relative?						
Do you feel that you should be doing more for your relative?						
Do you feel that you could do a better job in caring for your relative?						

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Positive Gains Scale

The following questionnaire will ask you about your own and your family's experiences of having a relative with a learning disability. Please respond to all questions by placing a circle around the number that best describes how you feel. Thank you.

Having a son/daughter with a learning disability has ……..

	1 Strongly Agree	2 Agree	3 Not Sure	4 Disagree	5 Strongly Disagree	6 Prefer not to answer
Helped me grow as a person.						
Helped me to learn new things/skills.						
Helped to put life into perspective.						
Has brought my family become closer to one another.						
Has made my family become more tolerant and accepting.						
Made me more determined to face up to challenges.						
Enabled a greater understanding of other people.						

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Physical and mental health of families living with an adult relative with a learning disability

THANK YOU FOR COMPLETING THIS SURVEY

We would like to thank you for taking part in this survey. We know your time is very valuable and we very much appreciate you taking the time to share your views with us.

If you are happy for us to contact you in 12 months' time to follow up the accommodation questionnaire, we will be in touch around this time next year.

The research will be written up at the end of 2014/15 and we will ensure you receive a summary of findings.

mencap cymru
Llais anabledd dysgu
The voice of learning disability

cartrefi cymru
Cefnogi Pobl a Chymunedau
Supporting People and Communities

kess
Ysgoloriaethau Sgiliau Economi Gwybodaeth
Knowledge Economy Skills Scholarships

ESF
Llywodraeth Cymru
Welsh Government
Ewrop & Chymru: Buddsoddi yn eich dyfodol
Cronfa Gymdeithasol Ewrop
Europe & Wales: Investing in your future
European Social Fund

Health and well-being of family carers (study 3)

Bivariate associations between predictor and outcome variables

Potential predictors	Psychological Distress (K6)	Burden (ZBI)	Family Stress (QRS-F)	Gains (PGS)	General Health (EQ-VAS)	Health summary (EQ-5D Index)
Carer's gender[2]	.115	.001	-.060	-.073	-.142	-.019
Carer's age[1]	**-.435**	**-.333**	**-.259**	.160	.145	-.088
Marital status[2]	.014	.194	.138	.072	**.295**	.073
Relative's age[1]	**-.246**	**-.267**	**-.293**	.123	.091	-.141
Relative's gender[2]	.032	.054	.141	-.041	-.042	-.048
Relative's support needs[1]	.110	.171	**.323**	.037	.083	-.142
Socio-Economic Position[1]	**-.262**	-.011	-.093	.057	**.276**	.018
Satisfaction with Support (FSS)[1]	**-.226**	**-.355**	**-.322**	**-.390**	**.202**	.151
Active coping (F-Copes)[1]	**-.235**	**-.308**	**-.361**	**-.223**	.084	.058

[1] rs, [2] r_{pb}

Proxy EQ-5D-3L

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By placing a tick in one box in each group below, please indicate which statements **<u>your relative</u> with learning disabilities** would choose to describe **his/her** health today.

Mobility

No problems in walking about ❑
Some problems in walking about ❑
Confined to bed ❑
I would prefer not to answer ❑

Self-Care

No problems with self-care ❑
Some problems washing or dressing himself/herself ❑
Unable to wash or dress himself/herself ❑
I would prefer not to answer ❑

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

No problems with performing his/her usual activities ❑
Some problems with performing his/her usual activities ❑
Unable to perform his/her usual activities ❑
I would prefer not to answer ❑

Pain/Discomfort

No pain or discomfort ❑
Moderate pain or discomfort ❑
Extreme pain or discomfort ❑
I would prefer not to answer ❑

Anxiety/Depression

Not anxious or depressed ❑
Moderately anxious or depressed ❑
Extremely anxious or depressed ❑
I would prefer not to answer ❑

Proxy EQ-VAS

36. To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad **<u>your relative with learning disabilities</u>** would say his/her health is today. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad you think **<u>your relative</u>** would say his/her health state is today.

Your relative with learning disabilities health state today