

A Study of Family Carers of Older People with Intellectual Disability in Ireland and the Social Policy Context of their Caregiving

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Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university and it is entirely my own work.

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Maureen D'Eath

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Abstract

Background

Older people with intellectual disability and the family carers of older people with intellectual disability have been identified by the World Health Organization (2000) as two joint vulnerable groups as they deal with the effects of the ageing process while also fulfilling a mutual caregiving role. Little prior research has focussed family carers of older adults with intellectual disability and there is a dearth of longitudinal data.

Informal or family caregiving forms the bedrock of social care provision in many societies and family care takes place within the context of prevailing social policy. Social policy organises and ascribes value to such care and the supports made available to care; these reflect the implicit objectives of a State's care policies and have significant consequences to those providing care.

Aims

This study had three key aims;

1. to explore how 'care' has been conceptualised and theorised and to review the extant research about the impacts of caregiving on caregivers.
2. to examine social policy responses to care and to critically analyse Irish social policy as it is expounded in the Carer's Strategy (2012).
3. to answer the research question: what is the health and well-being status of the family caregivers of adults with an intellectual disability, how has it changed over time and what factors impact on the health and wellbeing of the caregiver?

Methods

The exploration of the conceptualisation and theorising of care was achieved through a narrative literature review. The critical analysis of Ireland's social policy response to care was conducted using Bacchi's "What's The Problem Represented To Be?" framework.

The study used data from Waves 1, 2 and 3 of the Intellectual Disability Supplement to The Longitudinal Study on Ageing, Carer's Study to identify the health and wellbeing status of the participating caregivers. A subset of carers had participated in both **Wave 1**

and **Wave 3** of the IDS-TILDA Carer's Study thereby providing longitudinal data which was subject to a separate and extra analysis.

The study utilised a mixed methods approach generating both quantitative and qualitative data. The study questionnaire is largely quantitative in design allowing for statistical analysis, however the strategic inclusion of text boxes allows carers to expand on their answers and provide contextual elaboration.

Results

As a group, the carers who participated in both **Wave 1** and **Wave 3** of the IDS-TILDA Carer's Study reported a good quality of life, good general health and most carers in both waves compared their own health favourably with the health of others of the same age although the degree of positivity decreased between the two waves. Many of the carers, at each point in time, were enjoying good health and a good quality of life. However, it is also evident that a small number of carers are living a difficult and increasingly difficult life and are severely burdened by their care responsibilities.

Findings indicate the imperative for future research focussing specifically on siblings of older adults with intellectual disability. Sibling carers are a specific and increasing category of carers and it is important to understand their experiences in order to support them with their care responsibilities enhancing both their lives and the lives of those for whom the care.

With the exception of young carers, the Irish Carer's Strategy (2012) does not differentiate between carers and thus is directed at a generic caregiver. Much of its focus is not inclusive of older carers of people with intellectual disability who experience a number of unique challenges including the longevity of the caregiving role and issues relating to mutual ageing (Ryan *et al.* 2014).

Conclusion

Caregivers deserve integrated, responsive, relevant supports to protect and enhance their capacity to care to the extent that they wish to care and for as long as they choose to continue to care. The socio-political context is the constant back-drop to the caregiving experience and currently, in Ireland, this context does not reflect the centrality of care to human life.

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Chapter 1. Introduction

1.1 Introduction to the study

The Carer’s Study of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) is a unique body of research documenting the lives of family carers of older adults with an intellectual disability in Ireland over time. This study utilises the data from **Waves 1, 2 and 3** of the IDS-TILDA Carer’s Study to answer the research question: what is the health and well-being status of the family caregivers in the IDS-TILDA study of adults with an intellectual disability, how has it changed over time and what factors impact on the health and wellbeing of the caregiver? The question will be addressed through the key objectives of:

1. Exploring how ‘care’ has been conceptualised and theorised and reviewing the extant research about the impacts of caregiving on caregivers.
2. Examining Ireland’s social policy response to informal care.
3. Identifying the health and wellbeing status of the caregivers in the IDS-TILDA study in **Waves 1, 2 and 3**.
4. Identifying intrapersonal changes in the health and wellbeing in the subset of caregivers who participated in both **Wave 1** and **Wave 3**.
5. Exploring whether the health and wellbeing status of siblings differ to those of parent caregivers and to consider whether these suggest a specific policy or service provider response is needed to support sibling caregivers of people with an intellectual disability.

This study will address an important lacuna in the research evidence about health and wellbeing of family members caring for older people with intellectual disability in Ireland and in the absence of prior longitudinal evidence. The research is particularly timely as informal care is increasingly an issue of concern in Ireland and across Europe.

The term “carer” is more consistently used in literature from the UK whereas “caregiver” is the most commonly used term in North America. The terms are also used in reference to formal, professional or paid service providers to people with care or support needs. The focus of this study is on informal, family care and within this study the terms “carer(s)” and “caregiver(s)” are used interchangeably.

1.2 Context for the study.

Informal or family caregiving forms the bedrock of social care provision in many societies. It takes place within political and cultural contexts and care of dependent people “is central to the boundaries drawn between state and family, as seen in the formal definitions of family obligations” (Leira & Saraceno 2002, p. 10). Across the European Union 80% of care is provided by families, neighbours and friends (Hoffmann & Rodrigues 2010). There is a continuing upward trend in most countries in the number of family carers; the increase in numbers providing informal care in the United Kingdom increased at a faster pace than did the population between the census of 2001 and 2011 (Vlachantoni *et al.* 2016). It is predicted that the demand for informal care for older people in England will increase by 40 – 60% by the year 2031 (Pickard *et al.* 2007). In Ireland, 4.1% of the total population identified as providers of unpaid assistance to others in the 2016 National Census representing an increase of 4.4% on the 2011 figure (Central Statistics Office 2017). Almost 50% of female carers reported spending between one and 14 hours per week giving care and 26% spent 43 hours or more per week, 52% of male carers reported spending between one and 14 hours per week giving care and 21% spent 43 hours or more per week. (Central Statistics Office 2017).

Rummery & Fine (2012, p. 321) muse that “For a seemingly innocuous and positive word, ‘care’ is a source of critical tension in current social theory, policy and practice”. The term ‘carer’ is so embedded in both social and policy discourse that it may be surprising both that its origin is recent and that there is no agreed definition of the concept. Rummery & Fine (2012) write that the historic use of the word carer was to describe a neurotic type of person, someone who worries constantly; likewise the Anglo Saxon derivation of the word ‘care’ implied burden, anxiety, concern or sorrow (Rummery & Fine 2012). Before the 1950s, the term carer does not feature in research or policy literature. ‘Carers’, as a social construction, is according to Bytheway & Johnson (1998, p. 241) “a category created through the interplay between individual experience and various interest groups – policy-makers, researchers and pressure groups”.

The economic value of caregiving is very significant estimated, for example, at \$470 billion in the USA in 2017 (Reinhard *et al.* 2019). Reporting on data from cross-sectional community surveys of individuals aged over 50 years in 20 countries (n= 13,892) Shahly *et al.* (2013, p. 870) concluded that “The magnitude of these estimates is staggering”. Hanly & Sheerin (2017) conservatively estimated the value of informal care in Ireland at €5.3 billion, equating to 3.8 per cent of Irish Gross National Product (GNP) in 2011. This, the authors point out, far exceeds the €1.34 billion spent by the State on home-based long-term care and the €2.69 billion spent on long-term residential facilities in

2013). However, the value of care does not feature in the financial accounts of states; the domain of informal care is the home rather than the marketplace (Davis & McMaster 2020). Informal care is essential, according to Parker & Clarke (2002), to meet the “unholy trio” of policy objectives of deinstitutionalisation, managing the costs of formal care and encouraging families to take responsibility for the provision of care. Over recent decades much care has shifted from the public domain to the private domain.

However, as the need for and provision of informal care increases, the pool of potential caregivers is decreasing as it is subject to pressures including the increased participation of women in the paid workforce, an increase in the age of retirement, shrinking family sizes, greater geographical distances between family members and an ageing population (Marking 2017, Broese van Groenou & De Boer 2016). Murphy & Turner (2017) suggest that a number of demographic factors render Ireland particularly challenged in the provision of sustainable long-term care including the rate of population ageing and a predominantly rural population.

A vast diversity of experiences are located under the umbrella term of ‘carer/caregiver’. The context of informal caregiving is wide-ranging and includes care provided to spouses, partners, parents, children with disabilities and adult children with disabilities, friends, siblings or other relatives; it is frequently an extension of a close and ongoing relationship (Fine & Glendinning 2005). Care recipients may be in need of care because of a life-long disability, a terminal illness, a severe mental illness, a chronic or debilitating condition or ageing (Fine & Glendinning 2005). The spectrum of caregiving experiences is extremely broad encompassing different caregiving contexts and a range of specific caregiving tasks. Caregivers may be the primary or supplemental caregiver to the care-recipient and may be co-resident or not. Caregivers take on the role at different stages in the contexts of their own lives and the lives of the people for whom they care. Caregiving can take place over a short but intense period of time, over a prolonged period and may be planned/anticipated or be the result of a sudden crisis (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences 2016). Caring, for parents of people with an intellectual disability, is often a life-long commitment. The range of tasks that may be undertaken by family caregivers is myriad. The domains of the caregiver role include self-care, household tasks, advocacy and care coordination, each of which involves multiple tasks and activities and all of which are cut across by the continual cognitive and interpersonal processes integral to the caregiver role (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences 2016).

To date much of the research literature on informal caregiving focuses on spousal carers or adult children caring for parent(s) who have become ill or infirm and, in recent years, particular attention has been paid to the care of people with dementia (Roth *et al.* 2015, Pinquart & Sörensen 2003b). The focus of literature relating to caregiving and disability has largely been on families with children with disability. There is a less research focusing on the specific context of caring for adult children with intellectual disability (Mahon *et al.* 2019, Cairns *et al.* 2014). Although research evidence on caregiving generally will have some applicability to caregivers of adults with intellectual disability, the context-specific evidence is limited (Cairns *et al.* 2014). The extant evidence will be explored in the literature review chapter.

People with intellectual disability are now living longer. Earlier generations of people with intellectual disability predeceased their parents, however, this is no longer necessarily the case and people with intellectual disability and their parent(s) may now be ageing concurrently in the family home (Baumbusch *et al.* 2017, Brennan *et al.* 2017). Parents of people with intellectual disability may be lifelong carers (Yannamani *et al.* 2009) and in the event of the death of one parent, the surviving parent will carry the full responsibility for caregiving (Ryan *et al.* 2014). As people with intellectual disability age, they are unlikely to have the support of a spouse or of their own children; their social networks and social activities will probably be limited and they are unlikely to be in employment (Taggart *et al.* 2012, McCarron *et al.* 2011, Watson & Nolan 2011). People with intellectual disability who also have challenging behaviour have a compounded risk of social exclusion (Bigby 2012). The social interactions of people with intellectual disability outside their family home are at increased risk as they age as many rely on their ageing carers to support them, accompany them and/or transport them to social activities (Ryan *et al.* 2014). Older people with intellectual disability may be less likely to be in receipt of day care services, respite, social and domiciliary support (Ryan *et al.* 2014, McCallion & Kolomer 2003). Social and health services are largely organised around client groups with little integration between them (Murphy *et al.* 2007) and without cooperation and coordination between intellectual disability services and services for older people, older people with intellectual disability and their parents may find it difficult to access appropriate support and services. Older people with intellectual disability and the family carers of older people with intellectual disability have been identified by the World Health Organization (2000) as two joint vulnerable groups as they deal with the effects of the ageing process while also fulfilling a mutual caregiving role. Ryan *et*

al. (2014) characterise being both old and intellectually disabled as a ‘double jeopardy’ and suggest that

the statutory services need to ensure that this growing older population with ID can continue to be cared for at home by ageing parent(s) within a proactive model rather than the crisis approach that exists today (p. 233).

1.3 Thesis Structure and Outline

This thesis is laid out in three sections:

- A. Introduction to, and context of, the study
 - Chapter 1: Introduction
 - Chapter 2: Literature Review
 - Chapter 3: Social Policy Review
 - Chapter 4: Methodology
- B. Findings
 - Chapter 5: Data
- C. Discussion and Conclusions
 - Chapter 6: Discussion, Conclusions and Recommendations

Chapter 2: Literature Review

2.1 Introduction

In the forty years since the term carer became common currency, a plethora of research has been conducted. Milne & Larkin (2014) argue that this can be considered as two distinct and separate bodies of carer-related research. The first explores the conceptual and experiential nature of care and aims to extend thinking and theory about caring and is referred to by the authors as *Conceptualising and Theorising* (Milne & Larkin 2014). The second body of work is nominated *Gathering and Evaluating*; Milne & Larkin suggest that this conceptually and theoretically narrow body of work dominates the public perception about caring. This body of work is concerned with “evidence of the extent of caregiving, who provides care to whom and with what impact; it also focuses on evaluating policy and service efficiency” (Milne & Larkin 2014, p. 4).

This division will provide a useful framework within which to overview the extant literature. Thus, this chapter will first present an overview of the ways in which ‘care’ and ‘caring’ have been conceptualised and theorised and the issues raised by each of these. Secondly, the chapter will critically review the research which focuses on the impacts of caregiving its with particular attention to literature pertaining to intellectual disability.

2.2 Theorising and Conceptualising

2.2.1 Definitions

The term ‘carer’ is now endorsed in legislation and policy, including the UK Carer’s Act 2014 and the Irish National Carer’s Strategy (2012), yet no agreed definition of the concept of ‘carer’ has developed. The search for a definition is complicated by the diversity of disciplines from which the research emanates including feminism, disability and social policy and further complicated by the use of the word in a professional context. Care is complex; Browne (2010) writes

Care is both theoretical and practical, descriptive, and normative, a scientific construct and ethical stance, a tool of classification and evaluation, a means of analysis and a weapon of critique. It is rooted both in academic disciplines and the manifold practices of health and social care. (p. 5777)

Some argue that such a definition is not possible

to search for a single “ideal” dichotomous definition of a “carer” is over-ambitious and probably futile, in view of the multi-faceted nature of caring. (Arber & Ginn 1990, p. 430)

O’ Connor (2007, p. 165) posits that

Conceptually, there is an assumed general understanding of a family caregiver that is translated into relatively generic definitions such asHowever, attempts to move beyond this common-sense, task-based understanding to something that is more observable and concrete begin to highlight the difficulty associated with pinning down what/who a caregiver actually is (p. 165)

Others have suggested that ‘care’ is a descriptive rather than a theoretical concept (Thomas 1993) or that the term ‘carer’ is a meaningless, bureaucratically generated notion transforming “what is a normal human experience into an unnecessarily complex phenomenon” (Molyneaux *et al.* 2011, p. 422). Carol Thomas (1993) argues that in order to have a concept of care – as distinct from the existing ‘pseudo concepts’ – it would be necessary to make

a case that ‘care’ constitutes a distinct form of social production by virtue of its social relations, whether capitalistic, patriarchal or in terms of some other social-scientific category. (p. 665)

She contests that it is not possible to make such a case.

However, without a comprehensive conceptualisation of care, it may only be possible to have a fragmented understanding of what care is and what it means (Thomas 1993). The carer’s movement, Lloyd (2006) argues, lacks the sound theoretical foundations which drove other movements such as the disability movement onto the political agenda and, without a generally accepted definition, the conceptualisation and measurement of the concept is difficult (Hermanns & Mastel-Smith 2012, José 2016). Despite the lack of a generally accepted definition, a plethora of definitions have been proposed. Caregiving is widely acknowledged to involve the provision of care that exceeds that which may be considered normal. Caregiving extends beyond the provision of assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) and can include emotional support and support to interact with healthcare systems. (Aggar 2016). Many definitions of caregiving are task-focussed and do not account for the affective dimension of caregiving or capture its dynamic nature. The Irish Carer’s Strategy

defines a carer as: “someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty” (Irish Carer’s Strategy 2012, p. 8).

2.2.2 Naming carers

Early conceptualisations of care emanated from feminism; however the focus differed across geographical regions. In Scandinavia, the focus was primarily on the conditions and value of women in the paid, formal care settings and the boundaries between paid and unpaid care provision. In the UK the feminist focus was on challenging the presumption of the natural order of women’s provision of unpaid caregiving in the home. Women, it was argued, were in a disadvantaged position caregiving because of the social construction of women as caregivers and therefore it was important to recognise care as an economic activity in its own right (Fine 2006).

Barnes (2012) places the naming of ‘carers’ as a distinct social group in the UK back to the establishment of The National Council for the Single Woman and her Dependents (NCSWD) in 1963. Originally established to represent unmarried women to whom the duty of caring for elderly relative ‘naturally’ fell, its remit soon expanded and Barnes (2012) states

(t)he identity of ‘carer’ emerged following the realisation that it was not only unmarried, but also married and divorced women who were unable to take up paid work because of caring responsibilities. (p. 8)

In 1981 The Association of Carers was launched to, inter alia, encourage carers to recognise that their needs were equally important as those of the person they care for. This campaign politicised the assumption that women care naturally and should “care rather than undertake paid employment” (Rogers & Barnes 2003, p. 17). Unmarried women carers were granted an Invalid Care Allowance in the United Kingdom 1976 and a successful appeal to the European Court of Justice extended eligibility for this allowance to married and divorced women ten years later. The NCSWD was renamed the National Council for Carers and their Elderly Dependents before joining with the Association of Carers and re-launching as the Carers National Association in 1986 marking an expansion of the identity of carers to include “all carers, regardless of sex, age, marital status or relationship to the person they cared for” (Barnes 2012, p. 8)

Fine (2006, p. 29) asserts that the

The recent (re)invention of the term ‘carer’ is a consequence of the need to name and make visible the hidden work of caring that occurred in the home. ‘Carer’ may therefore be considered a product of the cultural policies of the move of care from the private, domestic sphere, to the public realm. (p. 29)

The 1960s and 1970s in the UK were a time of diverse pressures on welfare provision including an ageing demographic, public funding contractions, left-wing criticism of institutional care provision and right-wing policies stressing self-help and family support (Allen 2000). The UK policy of ‘community care’ originally covered a range of provision including community hospitals, hostels, day hospitals, residential homes, day centres and domiciliary support (Parker 1990). However, by the 1980s community care had been re-defined as care by the community – family and neighbours with state support – rather than care provided by the state in the community (Allen 2000). Indeed, it is argued that community care is often a synonym for family care (Power 2010) and most European social care policies now assume that family care in the community is the best option (Milne & Larkin 2014). Yet this is occurring in the employment context where the previously taken-for-granted assumption of a pool of women available and women to provide this care is no longer valid.

The campaigns fought by the early Carers’ Associations in the UK sought to challenge the assumptions that women ‘naturally’ volunteered to provide care regardless of the impact or limitations on their lives and on their opportunities to engage in paid employment (Bytheway & Johnson 1998). Feminist scholars characterised community care policies as “regressive and patriarchal, effectively transferring responsibility from the state to the family and, within the family, to women” (Fine 2006, p. 603). The positioning of care work as the ‘natural’ work of women carried out in private, personal and domestic settings reinforced the invisibility of care work (O’Riordan *et al.* 2010). The feminist struggle was to liberate women from the gendered oppression of care and the predominance of women in the provision of care was a result of patriarchal power structures inherent in society. Early feminist theorists strove to re-conceptualise unpaid domestic work, including unpaid care, as both work and an activity of great value and significance to society (Leira & Saraceno 2002).

The early characterisation of a caregiver was a white middle-aged woman giving care to an elderly or infirm relative, most often a parent. The care given was conceived and quantified in terms of physical tasks supporting people to meet their basic physiological

requirements. The publication of the 1985 UK General Household Survey Data on Informal Care confounded the received knowledge about the demographics of carers by identifying a surprising number of male carers thereby challenging the assumptions about caring as a female issue. A growing sense of the inadequacy of the concept developed and an awareness of need to broaden the conceptualisation to include caregivers from different social classes and ethnicities, paid caregivers and male and non-kin caregivers (José 2016). Concepts of 'care' also came under increasing challenge, most particularly from the disability community who saw them as infantilising people with disability and positioning them as passive, powerless, dependant, burdensome and without agency (Kröger 2009). The caregiver/care recipient relationship was criticised as unidirectional, vesting power with the carer and assigning dependency to the care recipient. The polarisation of people into the cared for and the carer, it was argued, obscured the sharing relationship that characterised much care and pitched them on opposing sides (Molyneaux *et al.* 2011). Molyneaux *et al.* (2011, p. 433) suggested that

Despite achieving its original aim of increasing the recognition given to the care work of women (Montgomery 1999), the term defeats its purpose by pursuing this aim too narrowly. Indeed in some cases the needs of 'carers' are over-represented to the detriment of the person requiring care (Claderbank 2000). (p. 433)

2.2.3 Disability critique of the concept of care

Kelly (2014) identifies the three strands of the disability critique as: (1) the lack of acknowledgement of the potential for abuse and coercion within a care interaction Fine's - "dark side of care"; (2) by focussing on the caregiver, care research denies the agency of the care recipient and (3) 'care' is tainted by a legacy of institutionalisation. Care has traditionally been conceptualised from the perspective of the caregivers (Daly 2012). Disabled activist Tom Shakespeare asserts that the construction of the concept of the "carer" was founded on generalisations of the negative aspect of the caregiver/care recipient relationship placing heavy emphasis on the strain and burden of care and blaming the care recipient rather than the social structure for such strain (Shakespeare 2006).

Rejecting the notion of care, disability activists advocated a reframing in terms of support and support from personal assistants rather than from carers. Hughes *et al.* (2005) argue that the use of direct payments through which people with disability can purchase their own personal assistance reconstructs the relationships between the caregiver and the cared-for whereby the cared-for becomes the employer and the carer becomes the

employee. While acknowledging the significant emancipatory effect, Hughes *et al.* (2005, p. 263) suggest that the system of direct payments takes care “out of the household of feelings” positioning it “in the masculine, bourgeois domain” and “effectively, closes off the possibility of an ethic of care and responsibility in which many feminists place much hope”. This, they assert, reflects

a pragmatic and materialist interpretation of care that is commensurate with its masculinist ethic and idealizes masculinist notions of autonomy. (p. 263)

2.2.4 Care as a moral theory

In the USA Carol Gilligan and Nel Noddings framed their feminist discourse on care as a moral theory. They argued for an ethics of care that emphasises the importance of relationships and focuses in particular on the relationship between a caregiver and the person being cared for (Noddings 1984). Noddings and Gilligan claimed that historical and prevailing moral justice theories were biased towards a male perspective. Gilligan argued that men and women, largely, employ different moral perspectives: men tend to a justice, rule-based perspective whereas women tend to the care perspective. Women, then, are more likely to be driven by a moral imperative to enter into and maintain relationships (Collins 2015); although men may also be driven to care (Green 2012).

Ethics of care locates the concept of care within relationships and on the contextual experiences of those relationships. In contrast to other ethical theories, ethic of care values rather than rejects emotion; care ethics, as described by Held (2006, p. 10) is

The compelling moral salience of attending to and meeting the needs of particular others for whom we take responsibility.

Ethics of care asserted that everyone needs care at different stages of their lives and, therefore, persons are essentially “relational and interdependent rather than self-sufficient and independent” (Löhms 2015, p. 186). Gilligan (2003, p. 62) characterised caring as a relationship involving two parties – the ‘one-caring’ and the ‘cared-for’ – and identified this relationship as one of reciprocal dependency.

...The ideal of care is thus an activity of relationships, of seeing and responding to need, taking care of the world by sustaining the web of connection so that no one is left alone. (p. 62)

Although the reciprocal dimension of the relationship between a caregiver and a care recipient may not be apparent “it is almost always ... a relationship of interdependency, mutuality and trust”. (Lynch & Baker 2009, p. 224)

Educationalist, Nell Noddings (1984) applied ethics of care to the educational sphere exploring the relationship between the ‘one-caring’ and the ‘cared-for’ (Noddings 1984). Noddings (1984, p. 16) proposed that we act to care because “apprehending the other’s reality, feeling what he feels as nearly as possible, is the essential part of caring from the view of the one-caring”. Caring requires engrossment in the caring relationship and this is what distinguishes it from duty or obligation. Distinguishing between ‘caring-for’ – hands-on caring- and ‘caring about’ – caring ideas or intentions and with a focus on the emotional aspect of caring, Noddings’ perspective was essentially maternal and she advocated for a feminising of public life with a greater acknowledgement of the importance of caring and caring activities. Noddings’ ‘feminine’ rather than ‘feminist’ perspective, accepted that men may have tendencies to care but that women’s inherent biological characteristics of compassion and empathy predisposes them to caring nurturing.

2.2.4.1 Ethic of care

Both Gilligan and Noddings’ early conceptualisations of an ethic of care was subject to a number of challenges including its focus on the private rather than the public realm, that it was western-centric and that it reinforced rather than challenged gender norms about women as natural carers (Fitzgerald 2015, Lynch & Lyons 2009). Barnes *et al.* (2015) argue that

Policies that derive from an essentialised view of the superiority of family care and a concept of responsibility that locates this within private lives and not within collective responsibilities, including those of states to ensure well-being and justice, do not fulfil the requirements of what Tronto describes as a democratic and caring society ‘whose account of justice balances how the burdens and joys of caring are equalized so as to leave every citizen with as much freedom as possible’ (Tronto 2013, p. 46). (p. 36)

The early theories of an ethic of care was taken up by other feminists to elevate the value of care work as part of the recognition of women’s rights (Rummery & Fine 2012). Political scientists, including Joan Tronto, and Selma Sevenhuijsen broadened the concept of an ethic of care, politicising care with a focus on the marginalisation, invisibility and devaluation of care (Gray 2009). Selma Sevenhuijsen (1998) positions

care as an inherently democratic practice and applied an ethic of care to social policy. Moving the debate away from gender alone and onto the concept of citizenship aligned the concept with social rights placing, according to (Phillips 2007, p. 29), “the notion of care as a pervasive human condition with interdependent and lifecourse aspects”. Thus care is a requirement of all humans and caregiving is not a natural expression of women’s capabilities. Sevenhuijsen (1998) argues that

all people are vulnerable, dependent and finite, and that we all have to find ways of dealing with this in our daily existence and in the values which guide our individual and collective behaviour. (p. 28)

While acknowledging that care concerns interdependencies between people, the focus of the second wave of feminist care theorists turned from care as a private, interpersonal issue to a public welfare issue wherein “citizen-consumers have a democratic right to care and policy makers and care providers have a responsibility to listen to their concerns” (Gray 2009, p. 1803). Tronto locates ethic of care within a political context identifying the power structures within which women are situated and which serve to exclude them from public life (Fitzgerald 2015). The conceptual approach developed by Jean Tronto and Bernice Fisher envisaged care as both a practice and a disposition. Caring, Tronto (1993) wrote is

... a set of moral sensibilities, issues and practices that arise from taking seriously the fact that care is a central aspect of human existence ... a species activity that includes everything that we do to maintain, continue and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, ourselves and our environment, all of which we seek to interweave in a complex, life-sustaining web. (p. 103)

Tronto’s definition of care extended the notion of care beyond care for another person to include care, for example, for the environment and also implied that care results in some form of action (Phillips 2007). Tronto sought to resist the portrayal of caring as an emotional rather than a rational act and Fine (2006) argues that Tronto’s approach to care is intended to position care as a social value and a general ethic for our being in the world with care encompassing issues including the environment and global affairs.

Emphasising that interdependence rather than dependence that typifies the human existence Tronto & Fisher (1990) envisaged care as involving four linked but distinct phases which, in later work, Tronto (1993) coupled with the associated ethical elements of: attentiveness; responsibility; competence; responsiveness.

1. **Caring about:** This involves the recognition of a care need in another person or thing and aligns to attentiveness. Recognising a need for care but not assuming responsibility for it is a moral failing, according to Tronto and without attentiveness, it is not possible to address the needs.
2. **Taking care of:** This involves assuming some responsibility for the need and making a plan to respond to the need and aligns to the ethical element of responsibility. An individual acts morally if they fulfil the responsibility to act to the best of their ability at the time.
3. **Care-giving:** This aligns to competence and involves meeting the care needs or some of the care needs and requires direct contact with, what Tronto calls, “the objects of care” (Tronto 1993, p. 107). Tronto differentiates care-giving from ‘taking care of’ which might be accomplished by, for example, providing the finances for another to give the required care.
4. **Care-receiving:** In this fourth phase the care needs are met and involves the response of the care recipient to caring about, taking care of and caregiving. Care has then come full circle with responsiveness requiring more attentiveness.

Eva Feder Kittay is a philosopher and the mother of an adult with profound intellectual disability, a position which she states is intimately “connected to my theoretical preoccupations regarding equality” (Kittay 2002, p. 239). She argues that philosophy rarely engages with caregiving because by nature and training the tone of philosophy is “detached, abstract and impersonal” (Kittay 2002, p. 239) resulting in a whitewashing of disability. Whereas, she writes, the lives of dependants can actually direct us to the very point of philosophy which is the pursuit of wisdom; lives such as that of her daughter

help us in our quest to discern what the meaning of life is; what makes life worth living or what makes a life a good life; what makes relationships ethical; what personhood is; how to understand beauty, anomaly, function, capacity, joy; what justice and equality are. (Kittay 2002, p. 239)

Kittay introduced the concept of “nested dependencies” arguing that dependency is a fundamental condition of human life and dependency workers (paid or unpaid) require support. Kittay advocates an ethical framework and a moral obligation for society to

look after dependency workers in recognition of care an indispensable, central good; dependency workers can not function as free and equal citizens unless they too are cared for. She proposes a public ethic based on the obligation and responsibility of society as a whole to enable and support the dependency work that takes place in the private realm. Kittay (1999, 2015) argues for a right to supported caregiving via a right to doulia

Just as we have required care to survive and thrive so we need to provide conditions that allow others – including those who do the work of caring – to receive the care they need to survive and thrive” (1999, p. 68)

To survive and thrive Kittay argues, dependency workers need the same rights and benefits as other workers receive for their labour including social security rights, the right to leisure time away from their dependency work and the right to not to live in poverty as they themselves age. Dependency workers who work in the paid labour market should be able to purchase care at a reasonable cost and paid dependency workers should enjoy good pay, working conditions and employment benefits. As the state, service providers, employers and local communities all benefit from the efforts of the dependency workers they all have a role and a responsibility to ensure their wellbeing.

2.2.4.2 Love labour

Lynch *et al.* (2009) places interdependencies at the centre of her concept of love labour. Lynch identifies love labouring as a form of primary caring that is “morally and other-centred driven” (p. 10) with moral imperatives about what constitutes good and bad care. Lynch & Walsh (2009) distinguish love labour from other forms of care by the increased levels of attentiveness and responsiveness that it requires

One of the defining features of love labour that distinguishes it from secondary care labour more generally is that it is not only a set of tasks, but a series of perspectives and orientations integrated with tasks. It is a feeling and a way of regarding another while relating to them. While it involves respect for the other like all forms of care, it involves more demanding forms of attentiveness and responsiveness than would apply to other forms of care.

Love labour is embedded in a set of relationships and the desire to sustain these relationships, sustains care. Lynch, Baker & Lyons (2009, p. 11) argue that love labouring is central to the personal identities of primary caregivers and that it is love labouring which leaves such carers vulnerable to the lack of respect and material supports. In their consideration of love labour in family caring in Ireland, O’ Riordan *et al.* (2010) identified love labour in the accounts of their participating family carers in a number of ways. They note that carers spoke of their

caring primarily in relational terms and located it within close family relationships; carers emphasis was on achieving a good quality of life for the care recipient. Brennan *et al.* (2016) explored family strategies that sustained family care for older people with intellectual disability and described the love felt by family members for the care recipient as the “bedrock” which “bolstered” capacity to care (p. 49). Despite the bolstering family carers reported physical, emotional and psychological challenges to their resilience and identified that they needed support from the formal services. Lynch (2009) contends that although the personal commitments and feelings involved in love labouring cannot be substituted and therefore cannot be commodified, paid or formal care can be a necessary support for the primary caregiver(s).

2.3 Gathering and Evaluating

This section will review the literature that documents the impact of caring on the caregiver under Larkin & Milne’s (2014) phrase of ‘gathering and evaluating’ research (Larkin & Milne 2014). They identify that the key concerns of ‘gathering and evaluating’ research are to 1) enumerate carers, their activities and the effect of their activities and 2) assess the impact and effectiveness of policy and services. A scoping review of carer-related research and knowledge, published by the Social Care Institute for Excellence (SCIE) in 2017, reported that 39% of the literature included in the review were concerned with the impacts of caregiving (Henwood *et al.* 2017). This scoping review captured 3,434 references and these were coded into 62 themes; the report included a table showing the most and least frequently identified themes across the literature and this is reproduced below

Table 1: Most and least frequently identified themes in the literature (Henwood *et al.* 2017, p. 26)

Top 12 themes	Number	Bottom 12 themes	Number
Carers and health	1,926	Cash for care	33
Carer support	1,546	Expert Carers	33
Carers’ needs	851	Social work education and carers	32
Caring for older people	612	Dual and sandwich carers	27
Dementia care	599	AIDS/HIV and carers	25
Emotional and physical impact	456	Friends, neighbours & sibling carers	25
Mental health	438	Caring and the lifecycle	24
Burden of care	404	Projections and care demography	24
Relationships	332	LGBT & carers	18
Quality of Life	328	The Care Act and Carers	16
Measuring and evaluating	312	Caring at a distance	12
Psychological impacts	297	Post-caring	8

This section will first present some of the difficulties which have been identified with the wide body of caregiver research before considering the findings of positive or beneficial impacts of caregiving. The research on the psychological, physical, financial and social effects of caregiving will then be explored with a final focus on literature specific to caregivers to people with intellectual disability.

2.3.1 The difficulties of caregiver research

There is consistency across the relevant literature that it is of great importance to establish the impacts and effects of caregiving on the caregiver. Such understanding can guide resource allocation to ensure that the caregiver receives appropriate support to protect their wellbeing and also that of the care recipient. Caregivers are also an important economic resource and therefore it is in the interest of states to protect that valuable resource. Caregiver stress, depression and poor health are key reasons many caregivers of people with intellectual disability cease caring (Grey *et al.* 2020).

Caregiver stress and negative physical and psychosocial impacts may result in poor standards of care (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences 2016). However, caregiving is a multidimensional process and multiple factors contribute to the health and wellbeing status of caregivers including the characteristics of the caregiver, characteristics of the care recipient, the context within which care is given and received, socioeconomic status and the adequacy of formal support services (Roth *et al.* 2015).

Measuring the impacts of care on the caregiver is complex and findings are inconsistent across studies (Vlachantoni *et al.* 2016) and therefore it is difficult to draw conclusions. The experiences of caregivers are heterogeneous. Studies which include a diversity of care giving circumstances cannot address the particularities of the experiences whereas caregiver research that is disease-specific which makes it difficult to generalise beyond the results (Aggar 2016) and limits the applicability of the research (Totsika *et al.* 2017). A considerable amount of the caregiver literature is based on samples of dementia caregivers; such caregivers constitute a small proportion of all caregivers and may experience more difficulties than caregivers to other care recipients (Roth *et al.* 2015, Pinquart & Sörensen 2003b).

Caregiver research is complicated by the range of definitions used in studies and sampling techniques. Roth *et al.* (2015). Roth also argues that the non-caregiver controls in many studies are volunteers recruited from a range of sources and therefore the findings of poorer health among caregivers is equivalent to the finding of better health among

the socially active volunteers who derive health benefits from their active volunteering. (Roth *et al.* 2015). This argument is supported by evidence that fewer health differences are found in studies using population-based samples than those using convenience sampling (Pinquart & Sörensen 2003b).

It is also important to note that extant measures do not measure caregiving but rather the effects or impacts of caregiving (Hermanns & Mastel-Smith 2012). The variety of measures used in caregiver research renders it very difficult to compare across studies (Hill 2015). For example, Saban *et al.* (2010) reviewed 24 studies of caregivers of stroke survivors and reported little consistency between the studies in the variables measured and a wide array of instruments used to measure those variables. Under half the studies used a theoretical or conceptual framework to guide the choice of variables. Almost all the studies included a measure of caregiver stress or burden however, across the studies, eight different measures were used. Many studies are not underpinned by a theoretical framework; studies based on a common theoretical framework would allow for greater comparisons (Saban *et al.* 2010).

Chadwick *et al.* (2013, p. 129) characterises the lives of caregivers as “a series of ups and downs with the need for continual adaptations”. Certain points in the caregiving journey appear to leave the caregiver particularly vulnerable to negative outcomes notably in the first year after assuming the caregiver role and in the aftermath of the cessation of caregiving. Although a number of longitudinal studies exist, the preponderance of studies are cross-sectional and comprise non-population-based (Capistrant 2016). However, caregiving is an inherently dynamic process and the importance of understanding changes in the process of caregiving has been emphasised (Grant & Ramcharan 2001). Longitudinal studies particularly those examining with-in person and between person differences are uncommon (Liu *et al.* 2014).

Likewise, cross-sectional studies cannot take account of the health or socioeconomic status of the caregiver before they take on the caregiver role and differences found in cross-sectional studies may reflect differences which predated the assumption of the caregiving role (Schulz & Sherwood 2008). It has been proposed that individuals who take on the role of caregiver, or who continue in the role of caregiver, are healthier than those who do not do so (McCann *et al.* 2004). Conversely, there is also contrary evidence that the poorer ill health of caregivers may predate caregiving (Brown & Brown 2014). Individuals who take on the role of caregiving may be older and less likely to be employed and may have poorer mental health prior to becoming caregivers (Alpass *et al.* 2017, Brown & Brown 2014, Lee & Gramotnev 2007). Alpass *et al.* (2017), in a longitudinal comparison of carers and non-carers, concluded that although the health of caregivers

had poorer mental health than non-caregivers at baseline their rate of change in health status over time was no different from that of non-caregivers (Alpass *et al.* 2017).

Schultz (2006) suggest that biases may confound the results of even large, longitudinal studies. Thus, for example, people with a lower socioeconomic status may be more likely to become caregivers and people with lower socioeconomic status are at greater risk of poor health. Similarly, poor health among older, spousal caregivers may not be a consequence of their caregiving but because of assortative mating - choosing a spouse similar to yourself- or because of sharing the same lifestyles and health behaviours as well as the same access to health care. In their 2003 review of caregiver health Pinquart & Sörensen (2003b) point out that the health of older caregivers is more likely to be compromised than that of older non-caregivers as they have less psychological, physical and financial resources; less stress-buffering roles and activities than younger people and may be less likely to use formal support services (Pinquart & Sörensen 2003a).

It is also argued that much of the research on caregiving is methodologically flawed by conflation self-perceived health status with self-perceived impact (Brown & Brown 2014, Totsika *et al.* 2017). Thus, reported or objectively measured poor health indicators are not necessarily an impact of caregiving. The outcomes attributed to caregiving may, in fact, be the consequence of the illness or disability of the care recipient which may, in itself, cause stress or depression (Amirkhanyan & Wolf 2003). Caregivers do not experience impacts consistently and a number of factors have been implicated in influencing this including gender, care recipient health and disability, relationship between caregiver and care recipient and caregiver appraisal (Maguire *et al.* 2019, Vlachantoni *et al.* 2016, Savage & Bailey 2004).

Participant numbers in much of the caregiver research tend to be small, limiting the generalisability of the findings. Participants tend to be recruited through organisations/gatekeepers. Thus, the hidden carers, those who are not in touch with services or support groups are not represented or underrepresented. Carers from minority ethnic populations are less likely to receive support (Greenwood 2018, Milne & Chryssanthopoulou 2005). It may that caregivers that are known to services may be disproportionately stressed (O'Reilly *et al.* 2008) or otherwise not representative of caregivers. The issue of 'hidden' caregivers and caregiver identity will be considered in more detail below.

The experiences of sub-groups including males and non-Caucasians are also under-represented in research. Cultural differences exist in attitudes to both providing care, perceived stigma and coping strategies (Greenwood *et al.* 2015, Grady & Rosenbaum 2015). Ireland's transition to an ethnically diverse country is very recent and to date little attention has been paid to the intersection of ethnicity and informal care in Ireland. African-American

and Hispanic caregivers are reported to have higher values of familism and a stronger traditional ideology of caregiving. Families belonging to minority cultures may also experience language and communication barriers to accessing services to family members in need of services (Greenwood 2018, McCallion & Grant-Griffin 2000). In a review of 116 studies of ethnic differences in stressors, resources and psychological outcomes of family caregiving, Pinquart & Sörensen (2005) concluded that ethnic minority caregivers were younger, provided more care than White caregivers, had a lower socioeconomic status, were less likely to be a spouse, and more likely to receive informal support (Pinquart & Sörensen 2005). The term care does not directly translate into some other languages because no cultural notion of caregiving exists within some societies; rather caregiving is conceived as a natural extension of family life (Greenwood 2018, Aggar 2016). Likewise, in cultures where women are expected to be submissive, it may be unacceptable for them to admit to or vocalise caregiver burden (Bastawrous 2013). The country context may also influence the extent to which the health of caregivers is impacted by their caregiving role (Kaschowitz & Brandt 2017). For example, a study of the mental health of women caring for older parents in a number of European countries demonstrated a significant negative impact on the caregivers in the Southern Mediterranean countries where social services were most limited (Brenna & Di Novi 2016).

2.3.2 Gender and care

Gender is a fundamental consideration in any account of care (Browne 2010). Men do provide care; in the most recent Irish Census almost 40% of self-identified carers were male. However, most caregivers world-wide are women and evidence suggests that men care less and care differently. Lynch, Lyon & Cantillon (2009) characterises men's role in informal caregiving as care commanders whereas women hold the rank of foot-soldiers. Care commanders are positioned to more easily accommodate paid employment alongside their caring role whereas the daily care regime for the foot soldiers may be more relentless and less flexible. Economic and political focus has been on the public sphere, traditionally a male sphere, with hegemonic masculinities representing the male as provider and protector. Providing and protecting may align with two of Tronto's four phases of caring – those of caring about and taking care of – but they lack the physical, emotional and cognitive aspects that are at the centre of the work of caregiving (Hanlon 2009). The male breadwinner/female homemaker model which peaked in Western Europe in the 1950s (Trappe 2015) had been enshrined in the Irish Constitution in 1937. Men are left “care free” while care takes place in the private feminised world of the family,

dependency and relationships (Jordan 2020, Hanlon 2009, Gilligan 2003). Women's inequality in the social, financial and political spheres are all impacted by their unequal care responsibilities (Hanlon 2009).

Elliott (2016) highlights Kittay's problematising of the early feminist assumption that gender equality would be achieved by women becoming more like men and by demanding that which men had. Kittay (1998) argued that men had become

The reference class for what is understood as human, and for what benefits and burdens are to be shared. In this way, the presumption of humanity as male – and of a certain class and complexion – underlies much of what is striven for in the name of equality. (p. 9)

Traditional constructions of masculinity are still dominant and caregiving is still associated with femininity; Lynch & Baker (2009, p. 220) suggests: "caregiving is culturally encoded as feminine and as such it is an identity that most men actively avoid". Gerstel & Gallagher (2001) found that the care men gave is socially patterned and contingent on women. Men with wives did more caregiving than men without wives. Men with sisters did less, whereas having brothers had no effect on extent of caring; where a woman was available, the woman did the caring. Similarly findings were reported by Hequembourg & Brallier (2005) who reported that men undertake the caregiving role in the absence of someone else to do so and by Lynch & Lyons (2009) in the Irish context.

Critical studies on men and masculinities have increasingly focussed on caring masculinities and have moved beyond its early concentration on paternal engagement in child-rearing. Shifting away from hegemonic masculinities, the key features of caring masculinities are, according to Elliott (2016, p. 241) the "rejection of domination and their integration of values of care, such as positive emotion, interdependence, and relationality, into masculine identities". However, Jordan (2020) argues that Elliott's vision of positive forms of caring masculinities is beset with difficulties including that caring masculinity is frequently expressed in ways that incorporate rather than reject domination.

2.3.3 Hidden caregivers and caregiver identity

Research mainly involves those who are known to services in some way; therefore the needs of those not involved in the services are not known and not addressed. Cavaye (2006) writes that

The terms 'hidden' or 'invisible' carers began to emerge in the literature soon after the results of the first authoritative national survey of the population to address the issue of carers was published. The results of this survey revealed that the numbers of people caring for another person were greater than previous estimates. (p. 15)

Self-identification as a caregiver is the gateway to support services. Yet studies consistently document that family members may not self-identify as carers even when they are fulfilling many of the tasks which would objectively qualify them as such (Andréasson., Andreasson & Hanson 2018, Eifert *et al.* 2015, O'Connor 2007, Ribeiro *et al.* 2007). The promotion of greater self-identification is one the aims of Family Carers Ireland's current strategic plan (O' Sullivan 2017). Hidden carers are, by definition, not included in statistics about caregiving and do not access support. Caregivers may prefer to identify themselves according to their relationship with the care recipient. Caregivers may not recognise that they are fulfilling the role of a caregiver either because they considered the duties that they performed to be intrinsic to their relationship with, for example, their spouse or child or because the transition into caring was a gradual one (Carduff *et al.* 2014). Others may reject the term as it may open them up to professional intrusion into the existing caring situation or because they do not feel that they need help from outside sources; caregivers may resist a label which they fear will lead to a 'bureaucratisation' of their personal relationships (Hughes *et al.* 2013). Accepting the term carer may also represent an acknowledgement of the health status or dependency of the care recipient and the caregiver may wish to preserve the self-identity of the care-recipient (Knowles *et al.* 2016). Henderson & Forbat (2002) suggest that there is a tension between the meanings of the words care, carer and care recipient as used in policy and the meaning of care constructed by people in their own lives: "The terms suggest "otherness" which places meaning outside of the interpersonal arena" (p. 683). Caregivers too may associate the term carer with paid caregiving and disassociate the affection, love and emotional labour with being a carer. This type of care is not commodifiable and is more than the instrumental value of the activity (Held 2002). Baumbusch *et al.* (2017) suggests that the

term caregiver does not reflect the lived reality of people with intellectual disabilities and their families and argues that

it is by focusing on the multiple and complex ways in which family members from different generations rely and intersect with one another in mutual interdependence that we can come to understand how dynamic family relations are embedded within the broader contexts of policy and service provision. (p. 346)

A telephone survey conducted in 2001 by the American Association for Retired Person (AARP) with 4,037 adults asked respondents whether they had been a caregiver over the past year and also asked about caregiving activities they may have performed. Fifteen percent of respondents who indicated that they had performed caregiving activities did not identify as a caregiver (Kutner 2001). O'Connor (2007) suggests that the identity of 'carer' is very rarely "sought, embraced or consciously taken on" (p. 170) and disputes the assumption that caregiving is a role characterised by defined tasks and suggests that, rather, it is a 'position' and as such "provides on with a set of rights and duties that supply meanings to one's acts and reveal the nature of one's identity" (O'Connor 2007, p. 166). The concept of a position, the authors argue, is more consistent with the fluid, dynamic and negotiable nature of the relationship. Molyneaux *et al.* (2011) argue for the abandonment of the term carer and suggest that "descriptions of the caring relationship that focus on the relationship from which it arose would be both more acceptable and useful to those it concerns" (Molyneaux *et al.* 2011, p. 422).

Following a review of literature Eifert *et al.* (2015) proposed a theoretical framework to explain the key, relevant factors to the development of family caregiver identity under the themes of:

- **Role engulfment and losing self:** When the role of caregiver and responsibilities of caring begin to consume a person, leaving little time for other activities and behaviours that may have defined the person previously
- **Loss of shared identity:** Changes to a person's dyadic identity because the dyad is diminishing or lost.
- **Family obligation and gender norming:** A system of assumptions, beliefs, and values created by a society that frame how a family should respond to a caregiving situation and who is expected to be the caregiver, especially females.
- **Extension of former role:** Caregiving is seen as a normal and natural part of being a spouse/partner or child.

- **Master identity:** When the caregiver role becomes the dominant identity, replacing or overtaking any other important identity, partly influenced by other people (Eifert *et al.* 2015).

Eifert *et al.* (2015) proposed that through a greater understanding, by policy makers and service providers, of the process through which caregivers come to assume the identity of caregiver, they may more successfully involve caregivers in interventions designed to support them (Eifert *et al.* 2015).

Todd & Shearn (1996) in their research with parents of adults with intellectual disability distinguished between ‘captive’ and ‘captivated’ parents. Captivated parents are committed to their enduring caring role on which they base their self-identity and do not attach a significant value on maintaining a substantial ‘self’ outside the family. Captive parents had envisaged an alternate lifestyle to the ones they were living and keenly felt the loss of opportunity and freedom that was a consequence of their enduring role.

For these parents, there was a feeling that they were losing aspirations to a life beyond parenting which they valued. Over time they had realised that a normal life, a symbol of some value to them, was increasingly beyond their scope. (Todd & Shearn 1996, p. 393)

Walden, Pistrang & Joyce (2000) included the open-ended question: *How different do you think that your life would be if (name) was not living at home* in their study of 62 parents of adults with intellectual disability (Walden *et al.* 2000). Using Todd & Shearn’s (1996) concept the authors coded the responses into one of three categories: captive, captured and unsure and concluded that 29% of the sample were “captive” while 61% were “captivated”. Captive parents had significantly higher levels of stress and anxiety, were significantly less satisfied with the level of informal support which they received and their adult children were more likely to have challenging behaviour. Captivated parents felt a greater sense of mastery and competence in managing their environment and their external world.

Todd & Shearn (1996) argued that when services failed to acknowledge the ‘person’ that is distinct from the ‘parent’ of an individual with intellectual disability, they therefore failed to support their need for meaningful personal and social engagements reinforcing the sense of “capture”. Parents spoke of living their lives under the tyranny of the clock and timeslots allocated by systems. Services were not seen to legitimate any desire that parents may have for greater participation in a life beyond parenting and the organisation of support structures, where available, did not facilitate and often frustrated parents’ following through on their own interests.

2.3.4 Impacts of Caregiving

2.3.4.1 benefits/positive impacts of caring

The preponderance of caregiver research has focussed on the negative impacts of caregiving and it has been argued that this may serve to skew perceptions of the caregiver experience (Kramer 1997). Hill (2015) proposes that “Perhaps the emphasis in research on the negative aspects of caregiving has obscured the benefits” (p. 10). Indeed, Brown & Brown (2014) excoriate much of the extant caregiver literature for, what they perceive to be, “a widespread and skewed assessment of the impact of informal caregiving” (p. 93).

The orientation of attention towards the positive was driven by caregivers who, in qualitative studies, repeatedly spontaneously identified benefits accruing from their caring role (Kramer 1997, Vlachantoni *et al.* 2016) and a more nuanced understanding of the complexities of the caregiving experience is emerging. Caregiving “involves cognitive, emotional, and motivational components emerging from complex life experiences” (Reizer & Hetsroni 2015, p. 257) and is a multidimensional experience. Positive and negative impacts of caregiving are not mutually exclusive (Toljamo *et al.* 2012, López *et al.* 2005) and caregivers may derive benefits from their role even when highly distressed (Beach *et al.* 2000). Positive and negative impacts of caregiving can co-exist (Yannamani *et al.* 2009) and Broese van Groenou *et al.* (2013) state that

...positive and negative evaluations of caregiving seem to reflect separate dimensions of caregiving that have different predictors and differing outcomes (p. 301)

The positive aspects of caregiving may serve as a buffer against negative impacts of caregiving and lead to a reduction in stress and burden, greater subjective health and better emotional outcomes (Hilgeman *et al.* 2007, Cohen *et al.* 2002).

The caregiving experience is heterogeneous and multi-dimensional and increasing recognition is being given to the benefits which may accrue to caregivers. Caregivers may enjoy, and even rely on, the companionship and support that they receive from the care recipient. Studies have reported that parents find satisfaction in caregiving (Rowbotham *et al.* 2011, Grant 2007, Grant & Ramcharan 2001) despite also experiencing stress and this supports them to continue to care. Satisfaction has been demonstrated to mediate depression, stress and anxiety (Pryce *et al.* 2015, Yoong & Koritsas 2012, Dillenburger & McKerr 2011, Hill & Rose 2009). Personal satisfaction has also been associated with positive impact on quality of life. An Australian qualitative study with twelve parents explored the impact of caring for an adult with intellectual disability on their quality of

life and reported that whereas caring had negative impacts, it was also associated with personal satisfaction and enabled a positive appraisal of their lives (Yoong & Koritsas 2012). When asked to rate their quality of life, most parents (43 of 45) of children and adults with intellectual disability in Ireland rated their quality of life between ‘good’ and ‘excellent’ (Caples & Sweeney 2011). Likewise, 69% of Canadians in a study by Minnes *et al.* (2007) reported that they were delighted, pleased or mostly satisfied by their quality of life (Minnes *et al.* 2007).

Whereas reported positive impacts of caregiving are often conceived as a meaning-focused coping strategy, (McConnell *et al.* 2015, Folkman 2008), it is also suggested that the reports emanate from a more fundamental phenomena. Scorgie & Sobsey (2000) argued that parental response to having a child with a disability went beyond developing strategies to cope with the experience and that, in fact, most parents reported positive changes in their lives that were characterised as ‘transformations’. Such transformations were identified in the three major areas of (a) personal growth, (b) improved relations with others, and (c) changes in philosophical or spiritual values (Scorgie & Sobsey 2000).

It is argued that the dominant focus on the negative outcomes of caregiving has impeded the advancement of an understanding of caregiver coping (De Oliveira & Hlebec 2016, Folkman & Moskowitz 2000). Through an understanding of the factors which underpin positive gain from caregiving, it may be possible to more effectively support caregivers in their role. Caregiver benefits have been defined and measured in numerous ways including self-esteem, caregiver satisfaction, personal growth, uplifts, competence of mastery, personal growth, finding or making meaning through caregiving and closer relationships (Schulz & Eden 2016, Hunt 2003). Analyses of the Third European Quality of Life Survey (De Oliveira & Hlebec 2016) demonstrated that most informal caregivers (n=4,941) have a high level of satisfaction with life – average of 7 on a scale of 1 to 10). The most important predictors of satisfaction with life were being able to make ends meet financially, better perceived health and living with a partner. Other predictors included participation in physical exercise, ease of access to formal long-term care services in the previous twelve months, being employed; having larger informal social support networks and being able to take care of their own health. Pryce *et al.* (2015) identified that notwithstanding high levels of depression, anxiety and stress, family caregivers of people with intellectual disability also derive great satisfaction from their caring role; this finding is consistent with those of previous studies (Dillenberg & McKerr 2009, Perkins & Haley 2013, Yoong & Koritsas 2012, Rowbotham *et al.* 2013). Rowbotham *et al.* (2011), in a study of parents of adults with intellectual disability, suggests that role

satisfaction accumulates over time and protects against the potentially damaging effects of other role demands.

Other literature identifies a number of factors that are associated with positive aspects of caregiving experience including socio-demographic factors, the relationship between the caregiver and care recipient and contextual, interpersonal and personal resources (Yumi *et al.* 2009). Broese van Groenou *et al.* (2013) compared the positive evaluations from spousal, adult children and other informal care givers and identified high levels of positive evaluation from spousal caregivers despite high caregiver burden (Broese van Groenou *et al.* 2013).

Lloyd *et al.* (2016) argue that the positivist perspective of the quantitative methods which dominate caregiver research is inadequate to develop an understanding of the predictors of positive caregiving experiences. They critically evaluated 14 qualitative studies that explored positive aspects of caregiving in dementia to explore how a) it has been conceptualised in the qualitative literature, b) how caregivers perceive the process of positive caregiving and c) the qualitative differences between different care-giver groups such as spouses vs children or husbands vs wives. The conceptualisations of the positive aspects were identified as: role satisfaction, emotional rewards, personal growth, competency and mastery, faith and spiritual growth, relationship gains, a sense of duty, and reciprocity. Role satisfaction was most frequently reported and included satisfaction associated with doing a good job, with keeping the care recipient safe or making them comfortable. The quality of the prior relationship between the caregiver and the care recipient reflected the level of satisfaction which caregivers derived from their role, with less satisfaction and pride expressed by those who characterised the previous relationship less positively. The emotional rewards identified in the studies often related to feeling appreciated or successful; and personal growth included increased patience, a sense of peace, self-awareness and self-respect. Personal growth was a gain that was more frequently identified by male caregivers and adult children caregivers than by females and male caregivers were most likely to describe personal growth in terms of humbleness. Lloyd *et al.* (2006) reported that caregivers in US studies emphasised spiritual growth to an extent not found in studies from other countries; other caregivers identified experiencing new meaning to their lives and a shift in their philosophical perspective. Relationship gains were consistently reported in the studies included in the review. The care requirements necessitated by the dementia was described as increasing and strengthening relationships even when the care recipient was no longer able to reciprocate; adult children identified it as an opportunity to reinforce bonds which may have weakened. Spouses, particularly those whose previous relationship had been positive, found rewards in

fulfilling their marital vows. Fewer adult children identified fulfilling a sense of duty as a positive outcome of caregiving except American Indian caregivers who expressed pride in upholding the values of their culture to care for their elderly. The opportunity to reciprocate love and care was welcomed by caregivers – particularly husbands – and, once again, this was most commonly identified where the previous relationship was most positive (Lloyd *et al.* 2016).

Six studies included in Lloyd *et al.*'s review (2016) explored the caregivers' perceptions of positive aspects of caregiving. Acceptance of the situation, including letting go of previous plans and accepting the new limitations of the care-recipient, was identified as key. Likewise, caregivers identified that they made active choices to focus on positive thoughts and avoid negative ones and, in doing so, appeared to empower themselves for their role. Caregivers also identified counting blessings, cherishing what remained and using humour to frame the situation positively; these techniques were more frequently used by spousal caregivers than adult children caregivers. Spousal caregivers identified that their commitment to their relationship with the care recipient and the love they felt towards them enabled them to maintain a positive attitude towards caregiving. Caregivers in most of the studies included in this part of Lloyd *et al.*'s (2016) review, reported that they gained from ensuring that the care recipient was happy, well-cared for and engaged in meaningful activities. Caregivers drew strength from various sources including faith, past challenges and supportive friends, family or services; caregivers who were caring in isolation found it difficult to report gains in their caregiving experience. The authors of the review highlighted a number of factors that appear to contribute to the process of positive caring. Key among these was that the positive aspects were achieved through strategies and choices engaged in by the caregiver, particularly in their acceptance of the situation. Lloyd *et al.* (2016) suggested that this

enabled carers to make a choice to view the situation with a positive attitude and be compassionate and empathic towards their loved one. Furthermore, choosing to commit to the relationship whilst drawing upon sources of strength and creating meaningful opportunities for the PwD to be happy and comfortable appeared to empower carers to continue in their caregiving role. Using such adaptive strategies enabled carers to go beyond just coping with the situation, to growing and taking something positive from it. (p. 1554)

Carbonneau *et al.* (2010) developed a conceptual framework of positive aspects of caregiving based on an integrative literature review; developed with a particular focus on caregivers of people with dementia the framework may have a broader applicabil-

ity. Carbonneau *et al.* (2010) distinguish their model from stress process models which identify positive aspects of caregiving as moderating factors but do not illuminate how the positive aspects arise in the daily caregiving experience. Carbonneau *et al.*'s (2010) framework identifies three central domains of positive aspects of caregiving: the quality of caregiver/care receiver daily relationship; the caregiver's feeling of accomplishment and meaning of the caregiver's roles in daily life.

The model suggests that positive aspects emerged through the occurrence of enrichment events in the caregiver's daily life. The occurrence of enrichment events is greatly conditioned by the caregiver's sense of self-efficacy. Thus, the caregiver's sense of self-efficacy in generating such enrichment events influences the enhancement of the positive aspects of caregiving. Self-efficacy also plays a role for the quality of caregiver and care-receiver daily relationship as well as the caregiver's feeling of accomplishment. The model also illustrates the influence of the quality of the caregiver/care-receiver's daily relationship and for the caregiver's feeling of accomplishment on the evolution of meaning of the caregiver's role in daily life. According to this viewpoint, the quality of the daily relationship and the caregiver's feeling of accomplishment work together to lead to the construction of meaning in everyday experience. Finally, it postulates that the various components of the conceptual framework are interdependent and all work together to reinforce the caregiver's well-being and doing so support their involvement. Thus, caregivers' well-being and involvement continuity correspond to positive outcomes related to occurrence of positive aspects in caregiving experience. (Carbonneau *et al.* 2010, p. 330 - 331).

2.3.4.2 Psychological impacts of caring

Much of the early literature on caregiving emanated from psychology (Capistrant 2016) and there is a large body of extant literature which has explored the psychological well-being of caregivers. Although some studies have concluded that most caregivers enjoy good mental health (Ranak *et al.* 2013) many record negative psychological outcomes for caregivers (Kaschowitz & Brandt 2017, Hiel *et al.* 2015, Simon *et al.* 2009, Savage & Bailey 2004, Pinquart & Sörensen 2003a). Such negative effects, according to Schulz and Eden (2016)

span a continuum ranging from the perception that caregiving is stressful or burdensome, to symptoms of depression and/or anxiety, to clinical depression diagnosed by a health professional, to impaired quality of life (p. 92).

Using data from the Survey of Health, Ageing and Retirement (SHARE, waves 1, 2, 3, and 5) and from the English Longitudinal Study of Ageing (ELSA, waves 2–5) (n= 82,524), Kaschowitz & Brandt (2017) explored the connection between informal caregiving and self-perceived general health as well as mental health in a country comparative perspective (Kaschowitz & Brandt 2017). The results indicated differences in self-perceived health and mental health between caregivers who provided care within the household and those who provided it outside the household with worse outcomes for the former leading the authors to conclude that

This strongly suggests that caregiving inside the household affects mental health negatively in almost all countries and across different welfare state types. (Kaschowitz & Brandt 2017, p. 76).

Colombo *et al.* (2011) reporting on data from OECD countries reported that the prevalence of mental health problems was 20% higher among caregivers than non-caregivers.

Depression is the most commonly reported negative outcome of caregiving (Aggar 2016). Vitaliano and colleagues' meta-analysis of twenty-three studies found an 11% prevalence rate for major and minor depression among non-caregivers compared with a 22% rate among caregivers. (Vitaliano *et al.* 2003). Likewise, Grossman & Webb's 2016 review of ninety-seven US studies of older caregivers reported higher levels of depression among caregivers than non-caregivers across all disability and relationship types (Grossman & Webb 2016). An earlier meta-analysis of 84 studies reported that caregivers experienced more depression, more stress and less general subjective well-being than non-caregivers (Pinquart & Sörensen 2003b). Cuijpers (2005) review of 10 studies focussing on caregivers of people who had a stroke, identified a prevalence rate of 22.3% for depressive disorders. Similarly, Cuijpers' (2005) systematic review of six studies of dementia caregivers found that the relative risk for clinical depression ranged from 2.80 to 38.68 as compared to non-caregivers (Cuijpers 2005). Caregivers of people with dementia are consistently reported to have worse mental health outcomes than non-caregivers and also than caregivers to other groups of care recipients (Lee *et al.* 2019, Covinsky *et al.* 2003). Depression among caregivers of older persons with dementia have been reported to be as high as between 40% and 50% (Bass *et al.* 2012, Schulz & Sherwood 2008).

Caregivers may be more vulnerable to negative psychological impacts at certain points during the caregiving trajectory including at the start of caregiving and when caregiving ends (Dunkle *et al.* 2014, Hirst 2005). Using data from the British Household Panel 1991-2000, Hirst (2005) explored the distress levels of caregivers as they entered and left caregiving. They reported that intensity of caregiving was associated with higher

levels of distress and that those providing more than 20 hours of care per week were at twice the risk of distress than non-caregivers and the effect on women was greater than that on men (Hirst 2005). The correlation between poor mental health and the intensity of caregiving is reported in a number of studies (Parmar 2020). Lyons, Cauley & Fredman (2015) reported that the intensity of caregiving, as measured by number of ADLs and IADLs, predicted caregiving stress in older women. Likewise, in a longitudinal study of a nationally representative sample of older adults, spousal caregivers providing more than fourteen hours of care per week had more depressive symptoms than non-caregivers (Taylor *et al.* 2008). Other studies have also linked poorer mental health to greater hours of caregiving (Parmar 2020, Colombo *et al.* 2011, Tsai & Jirovec 2005); to co-residency (Parmar 2020, Covinsky *et al.* 2001), and to poor family dynamics (Siminoff *et al.* 2010). Negative impacts may be experienced by family members of adults with intellectual disability living in residential settings due to concerns about level and quality of the care given to their family member and high levels of staff turnover (Cuskelly 2006, Llewellyn *et al.* 2010).

Piquart & Sørensen (2003a) review of 228 studies explored the association between caregiver burden, depression and the level of impairment of the care recipient (level of physical impairment; level of cognitive impairment and presence of behaviour problems) and the level of caregiver involvement (amount of care given and the duration of caregiving). They also investigated whether the size of the caregiving effects was influenced by whether the caregivers were the spouse or the adult children of the care recipient. The results demonstrated medium association of care-recipient behaviour problems with greater care-giver burden and depression and small, significant, positive correlations of burden and depression with physical and cognitive impairment of the care-recipient, hours of care provided per week, number of caregiving tasks, and negative correlations with perceived uplifts. Only very small correlations were found between caregiving burden and depression and the duration of caregiving. A stronger association between burden and depression was found among caregivers of people with dementia than among other caregiver groups of mixed groups. Depression was found to be more closely related to the time spent giving care among the caregivers of older people with physical impairments and caregiver burden was more closely related to the time spent caring by caregivers of older adults with dementia than among other caregiver groups. Care recipients' physical impairment and behavioural problems were more strongly associated with burden among spouses than among adult children; the same association was not found for depression (Piquart & Sørensen 2003a). Spousal caregivers have been found to experience fewer negative impacts than other caregivers and it is suggested that

caring for a spouse may be perceived as part of the marriage contract and therefore more normative than other forms of caregiving (Grossman & Webb 2016, Chappell *et al.* 2014). However, studies have also concluded that caring for primary kin, including one's spouse, was associated with greater stress than caring for other family members or individuals outside of family (Penning & Wu 2015, Pinqart & Sörensen 2011).

An Irish study examined the extent of caregiver burden experienced by older carers of adults with an intellectual disability and the effect of socio-demographic factors on the caregiver burden experience (Egan & Dalton 2019). The sample of thirty participants were mainly female (77%) and mainly over 70 years of age. The analysis found that most were experiencing caregiver burden however, the older caregivers – those in the 65-74 year age group experience statistically significantly higher levels of caregiver burden than did those in the older age group of 75 years and older.

The quality of the relationship between the caregiver and the care recipient may be associated with the mental health outcomes for the caregiver (McPherson *et al.* 2011, Savage & Bailey 2004). The type and closeness of the relationships may impact on caregiver depression and caregivers who care for a confidante may experience fewer depressive symptoms (Litwin *et al.* 2014, Fauth *et al.* 2012). A systematic review of fifteen studies of the quality of the relationship between the caregivers of people with dementia and the care recipient found that both the pre-caring and current relationships impacted on the wellbeing of the caregiver (Quinn *et al.* 2009)

Doebler *et al.* (2017) linked the data from the Northern Ireland Census 2011, the Northern Ireland Enhanced Prescribing Database and the Proximity to Service Index from the Northern Ireland Statistics and Research Agency to investigate the relationship between informal caregiving and mental ill-health. In doing so, the authors sought to overcome methodological weaknesses such as small samples sizes and the use of subjective measures of mental ill-health which, they argue, are inherent in much of the extant literature on the subject. They reported that although caring per se was not related to mental-ill health, as evidenced by prescription rates for antidepressants, certain sub-groups were at a statistically higher rate of such ill-health. These sub-groups included women aged less than 50 years who were either unemployed or in part-time employment and caregivers living in remote areas with limited access to shops and services (Doebler *et al.* 2017).

Despite Doebler *et al.*'s (2017) criticism of the use of subjective measures other researchers argue that self-reported health has been found to be a robust predictor of disease, morbidity, mortality and health care utilisation and a reliable predictor of future health (Berglund *et al.* 2015).

A number of studies have considered the association between age and caregiver stress or mental health outcomes and results are inconsistent. Some studies have reported poorer mental health outcomes among older caregivers compared to non-caregivers (Yamaki *et al.* 2009, Caldwell 2008). Other studies have found opposing evidence. Anderson *et al.* (2013) reported that caregivers aged 65 years or older had significantly lower rates of mental distress than caregivers who were of working age although they also reported more fair or poor health and physical distress (Anderson *et al.* 2013). Capistrant (2016) points out that older age is, in itself, associated with an increased risk of depression. A narrative review and synthesis of peer reviewed studies of the impacts of caregiving on caregivers aged over 75 years included 18 studies. The results from the studies were inconsistent however, interestingly, the authors found that quantitative studies generally reported negative findings whereas qualitative studies more often reported positive outcomes emphasising the rewards of caregiving (Greenwood & Smith 2016)

The extent to which caregivers' poorer mental health predates their caregiving role has been considered. Kaschowitz & Brandt (2017) concluded from their analysis of longitudinal and multi-national data that caregiving is a selective process and that individuals with poorer health were the ones who took up the caregiving role. Similarly, a longitudinal study of New Zealand caregivers and non-caregivers over a 10-year period found that the mental health of both groups remained stable over time with no differences in the trajectories between the two groups. However, the caregivers had worse mental health at baseline leading the authors to suggest that this may indicate a health selection bias into caregiving (Alpass *et al.* 2017)

2.3.4.3 Physical impacts of caring

The physical health impacts of caregiving have received less theoretical and empirical research attention than the psychological ones (Saban *et al.* 2010, O'Reilly *et al.* 2008, Pinguart & Sørensen 2007). As with the research on mental health, the results of the extant research is mixed with some reporting poorer health among caregivers as compared to non-caregivers (Hiel *et al.* 2015, O'Reilly *et al.* 2008, Young *et al.* 2005, O'Connell *et al.* 2003, Pinguart & Sørensen 2003b) and other studies reporting no significant physical health impacts from caregiving (Jenkins *et al.* 2009, Salter *et al.* 2010, Alpass *et al.* 2017, Vlachantoni *et al.* 2016). These differences in findings may be attributable to varying samples, outcome measures and method (Roth *et al.* 2015). Independent risk factors for physical ill health among caregivers include older age, lower income, lower educational attainment and co-residency (Grady & Rosenbaum 2015). Poorer caregiver physical

health has been associated with greater caregiver burden and depressive symptoms and is associated to a lesser degree with hours of care provided, the number of caregiving tasks, months in the caregiver role, as well as the physical, cognitive, and behavioural impairments and problems of the care recipient (Pinquart & Sörensen 2007).

The pathways through which physical health can be impacted include 1) the effect of physical exertion, 2) changes in health-related activities 3) the physical effects of psychological distress and 4) changes in sympathetic arousal and cardiovascular responses (Pinquart & Sörensen 2007).

The physical exertions required by some caregiving tasks, particularly those involving lifting and manual handling can result in negative consequences and caregivers have been identified as suffering from high levels of physical strain and musculoskeletal problems (Darragh *et al.* 2013). A high incidence rate of self-reported accidents has been found in caregiver groups (Hartke *et al.* 2006). Caregivers may find it difficult to engage in positive health behaviours as opportunities to exercise and eat well may be limited by caring responsibilities. Lynch, Lyons & Cantillon (2009, p. 154) reported that a number of caregivers in their Irish study “were clearly endangering their own health due to the undue responsibilities they had for caring”. The role of leisure activities as a moderator of the negative impacts of caregiving was investigated in a study which concluded that greater use of leisure facilities buffered the association between more hours of care and lower mental and physical wellbeing for informal caregivers (Schryer *et al.* 2016). A German study of 1,380 informal caregivers reported that the amount of time spent caregiving and performing nursing care services were associated with higher BMI and fewer sporting activities (Hajek & Konig 2016). However, Fredman *et al.* (2006) advise that although elderly caregivers may engage in less leisure time activity, this should not be conflated with overall physical activity as caregivers who climbed stairs at least fifteen minutes per day during caregiving tasks reported more overall physical activity than non-caregivers (Fredman *et al.* 2006). Risky health behaviours such as lack of exercise, poor nutrition, reliance on alcohol or drugs and lack of exercise may be provoked by psychological distress and which may, in turn, result in health problems (Alpass *et al.* 2017, Grossman & Webb 2016, Vitaliano *et al.* 2003). Hoffman *et al.* (2012) reported that caregivers were more likely to engage in negative health behaviours than non-caregivers including an increased likelihood to smoke and consume fast food on a regular basis (Hoffman *et al.* 2012). Equally caregivers have been found to be restricted in their ability to access self-care and health services for themselves (Schultz 2016, Grossman & Webb 2016, O’Connell *et al.* 2003). Lack of sleep also takes a toll on the physical health of caregivers and sleep deprivation is highly correlated with negative effects of caregiving (Spillman *et al.* 2015).

Stress can result in negative physical impacts through a process described by Elmore (2014)

Stress is a state of intensive mind–body activity that occurs in the context of stressful life events. The individual seeks physiological stability in the face of stress induced change. This process is called allostasis. This balance, however, comes at the cost of metabolic wear and tear, referred to as allostatic loading. When allostatic loading is persistent or excessive, vulnerability to disease increases. (p. 16)

Caregiver stress has been implicated in hypertension and a heightened risk of cardiovascular disease (Torimoto-Sasai *et al.* 2015, Lee *et al.* 2003). Caregiver stress can reduce the ability of the immune system to function optimally, making the caregiver more susceptible to infections and illness (Damjanovic *et al.* 2007, Kiecolt-Glaser *et al.* 1991) and more specifically, increase the healing time for standardized wounds (Kiecolt-Glaser *et al.* 1995). Increased insulin levels among caregivers has also been reported (Langa *et al.* 2001, Vitaliano *et al.* 1996). Caregivers' physical health has been measured through objective measures such as antibodies, stress hormones and medication use (Vitaliano *et al.* 2003). However, Roth *et al.* (2015) cautions that many of the studies investigating biomarkers of poor health relate to samples of dementia caregivers and most rely on clinical or convenience samples with distinctly different recruitment methods for the caregivers and non-caregivers (Roth *et al.* 2015). The authors also notes that of the 42 papers included in Lovell & Wetherell's (2011) review on caregiving and biomarkers, only five had samples of over 100 caregivers.

A number of meta-analyses have explored the association between caregiving and physical health. Vitaliano *et al.* (2003) combined the results of 28 studies to compare 1,594 caregivers of persons with dementia with 1,478 demographically similar non-caregivers (Vitaliano *et al.* 2003). The authors concluded that caregivers had a slightly elevated risk for health problems although, this risk was moderated by gender and the health category assessed (Vitaliano *et al.* 2003). Pinguart & Sörensen's (2003b) meta-analysis of 84 studies of caregivers providing care to frail older adults found small but statistically significant differences in physical health in favour of non-caregivers (Pinguart & Sörensen 2003b). In a later meta-analysis by the same authors which integrated the findings from 176 studies identified the correlates between worse physical caregiver health as: negative care recipient behaviour and cognitive impairments, duration of caregiving role, co-residence, not being a spousal caregiver, higher caregiver burden and depression, higher age, lower socio-economic status and lower levels of informal support (Pinguart & Sörensen 2007).

Results from the longitudinal cohort (2004/2005–2010/2011) of the Survey of Health, Ageing and Retirement in Europe (SHARE) (n = 7858) reported that a significant association between the provision of personal care with poorer mental and physical health over an eight year period even when the participants health status at previous waves was accounted for and adjustments were made to account for socio-demographic variables (Hiel *et al.* 2015). However, other longitudinal studies have, largely, reported no negative physical impacts associated with caregiving; Alpass *et al.* (2017) found no differences in physical decline over a 10-year period between caregivers and non-caregivers. A study which used data from the Caregiving in the U.S. 2015 study, (Danilovich *et al.* 2017) explored self-reported changes to the health of 1,087 caregivers of recipients 50 years or older. The average age of the caregivers was 50 years and 76% of the caregivers had been caring for 4 years or less. Just over 73% of the participants reported no change in their health due to caregiving, 5.4% reported that it had improved their health and 21.3% reported worsened health. An interesting finding from this research was that worsened self-reported health was significantly associated not only with duration of caring but also with lack of choice about taking on the role as caregiver. In fact, having chosen to take on the caring role was associated with an over fourfold increase in the odds ratio (OR) of better health in response to caregiving (OR = 4.21; confidence interval [CI] = [1.95, 9.08]; $p < .001$). Worsened self-reported health was associated with being in the 50-64 year old age range, being a member of a racial or ethnic minority, the presence of cognitive caregiving limited availability of accessible and affordable care services. Caregiving burden was not found to be associated with either positive or negative change in overall health although the authors advise that this finding may be a consequence of the limited scale options used in the data collection.

2.3.2.4 Gender differences in impact

Despite an increase in the proportion of men providing informal care, throughout the world, such care is predominantly provided by women (Sharma *et al.* 2016, Davys *et al.* 2017). The prevalence of male caregivers increases with older age as men become caregivers to (typically) their spouses (Dahlberg *et al.* 2007, Colombo *et al.* 2011). Research also suggests that the differences exist in the type of care most frequently given by men and that given by women. Thus, men are more involved in the instrumental tasks of care whereas women provide instrumental and emotional support (Bastawrous 2013, Stein 2009). Emotional support may take a greater toll on psychological wellbeing than instrumental support therefore women may be more vulnerable to negative impacts

(Bastawrous 2013). However, the evidence on the differential impacts of caregiving on men and women is mixed and inconsistent with some studies reporting worse outcomes for males (Ranak *et al.* 2013) and others reporting the converse (Cuijpers 2005, Covinsky *et al.* 2003). Oshio (2015), using six waves of panel data obtained from a nationwide population-based survey in Japan, identified that women caregivers experienced an increased level of psychological stress whereas male caregivers did not (Oshio 2015). Likewise, Revenson *et al.* (2016) found that women reported more depressive symptoms, more stress and more burden than men but suggests that the illness context may impact on the gender effects (Revenson *et al.* 2016). However, other research has found that gender has no moderating influence on the impact of caregiving (Alpass *et al.* 2017; Pinquart & Sörensen 2006). In the context of mental illnesses (Sharma *et al.* 2016) concluded that the evidence about the size and magnitude of the gender differences between male and female caregivers is uncertain and that the explanations about greater stress and burden among female caregivers is not supported. They also note the methodological variations between studies which, they argue, may obscure the actual nature and extent of gender differences. The authors suggest that further, robust research is needed to focus the development of gender-specific caregiver interventions.

In the context of intellectual disability, two recent reviews of the literature have focussed specifically on fathers. Davys *et al.* (2017) included twenty-seven studies of father of children and young people up to the age of twenty-two years of age in their review and, of these, two found greater paternal stress and dissatisfaction among fathers of children with intellectual disability, three reported no such differences and one found higher levels of psychological well-being among the fathers of children with intellectual disability compared to fathers of children without intellectual disability. A UK national survey of fathers of children with learning disabilities identified reported that the majority of fathers experienced stress with 41% experiencing stress most of the time and half the fathers felt that their physical health had been affected by being a parent of a child with learning disability (Towers 2009). Most fathers did not feel emotionally or practically supported by their extended families and almost 40% did not have a good friend that they could talk to and the report suggested that services have a role to play in developing opportunities for fathers meet other fathers and families.

Marsh, Brown & McCann included 14 studies in their 2020 review of the evidence on fathers of children – aged under 18 years of age – with intellectual disability. Their thematic analysis of the identified the four key themes of: emotional consequences, mental health and coping, systems of support, hopes and fears for the future. The authors reported that several studies found poor levels of mental health among the fathers. Risk

factors for poor mental health included the attitudes of healthcare professionals, family members and the public in general towards the role of fathers of children with intellectual disabilities, the intensity of care required by the child and concerns about the future. Education about the risk factors and interventions to promote positive mental health were recommended as proactive supports for father. Positive gains were also noted in some of the studies included in the review often associated with acceptance and positive coping strategies.

2.3.2.5 Mortality

In a seminal exploration study of the mortality rate of caregivers Schultz & Beach (1999) concluded that caregivers who experience mental or emotional strain are more likely to die than non-caregiver controls and that such strain is an independent risk factor for mortality (Schulz & Beach 1999). The study used data from the Caregiver Health Effects Study but is somewhat limited by the sample which included spousal caregivers only and was predominantly Caucasian. Roth *et al.* (2015) identified that an unreported finding from the study showed that when the mortality data from caregivers who reported strain were combined and compared with the spouses of non-disabled partners, the overall caregiving mortality effect was not statistically significant (RR = 1.37, 95% CI = 0.90–2.07)

However, subsequent studies also reported higher mortality rates among caregivers (Perkins *et al.* 2013, Ganguli *et al.* 2002, Fried *et al.* 1998,). Perkins *et al.* (2013) using data from a national, population-based prospective study of men and women over 45 years of age, reported that caregivers with high caregiver strain had significantly higher adjusted mortality rates than those who had no strain (hazard ratio [HR] = 1.55, $p = .02$) or some strain (HR = 1.83, $p = .001$). These results were found to be consistent across race, gender and caregiver type. The mortality risk from caregiver strain was found to be equivalent to that of cardiac disease. The authors conclude that the association between perceived mental or emotional strain is a more important association with mortality than that of the relationship between the caregiver and care recipient or the time spent caring. Further, demographic variables, self-rated health, history of cardiac disease, and diabetes were also found to be associated with all-cause mortality of the caregivers, findings consistent with other studies (Perkins *et al.* 2013).

Conversely, other studies have reported that caregivers, in fact have a lower mortality rate than non-caregivers (Mikkola 2020, Ramsay *et al.* 2013, Fredman *et al.* 2010, O'Reilly *et al.* 2008, Brown *et al.* 2003) including caregivers with higher levels of caregiver burden. Following an analysis of Office for National Statistics-Longitudinal Study of England

and Wales, Ramsey *et al.* (2013) reported that caregivers had a lower mortality rate than non-caregivers despite reporting poorer health at baseline (Ramsay *et al.* 2013). Brown *et al.* (2009) posited that previous studies of the link between caregiving and caregiver morbidity and mortality failed to disentangle the effects of the provision of care from the effects of continuous exposure to a loved one with serious health problems (Brown *et al.* 2009). Brown *et al.*'s (2009) findings from a national, longitudinal survey of elderly married individuals (n = 3,376), found decreased caregiver mortality among caregivers providing at least 14 hours of care to a spouse independent of behavioural and cognitive limitations of the care recipient and of other demographic and health variables. The authors conclude that under some circumstances, caregivers may benefit from caregiving.

Roth *et al.*'s (2013) study of 3,503 caregivers examined differences in all-cause mortality between caregivers and a propensity-matched sample of non-caregivers between 2003 and 2012. The study found that caregivers had an 18% reduced rate of death compared to non-caregivers and that no subgroups (race, age, gender, caregiving relationship and caregiving strain) had an increased rate of mortality. The authors concluded that caregiving may be associated with modest survival benefits (Roth *et al.* 2013)

Fredman *et al.* (2010) in a prospective cohort study, examined the separate and combined effects of caregiver status and high stress on mortality risk over 8 years in a sample of 375 caregivers and 694 non caregivers. Caregivers in their study were more stressed than non-caregivers but had a lower mortality rate than non-caregivers [adjusted hazard ratio, (AHR)=0.74, 95% confidence interval (CI)=0.56–0.89]. The highly stressed caregivers had a higher mortality risk over the first 3 years of follow-up but not in subsequent years. Caregivers experiencing low stress had a lower mortality risk than both highly-stressed caregivers and non-caregivers and a significantly lower mortality than did non-caregivers, whether perceived stress or caregiving-related stress was measured [AHR=0.67 and 0.57]. Similar results were observed in analyses comparing spouse caregivers with married non-caregivers. The authors conclude that older caregivers may be at risk of health decline as a result of the short-term effects of stress but not caregiving per se (Fredman *et al.* 2010).

2.3.2.6 Financial impact of caring

Caregiving can have negative financial implications for caregivers and their family (Gardiner *et al.* 2020, Lai 2012, Nepal *et al.* 2007, Langa *et al.* 2001). A systematic scoping review of the economic costs incurred by family caregivers of adults with long-term health issues or disabilities included one hundred and twenty-six articles and formed the basis of the development, by the authors of a taxonomy (Keating *et al.* 2014) which is reproduced below:

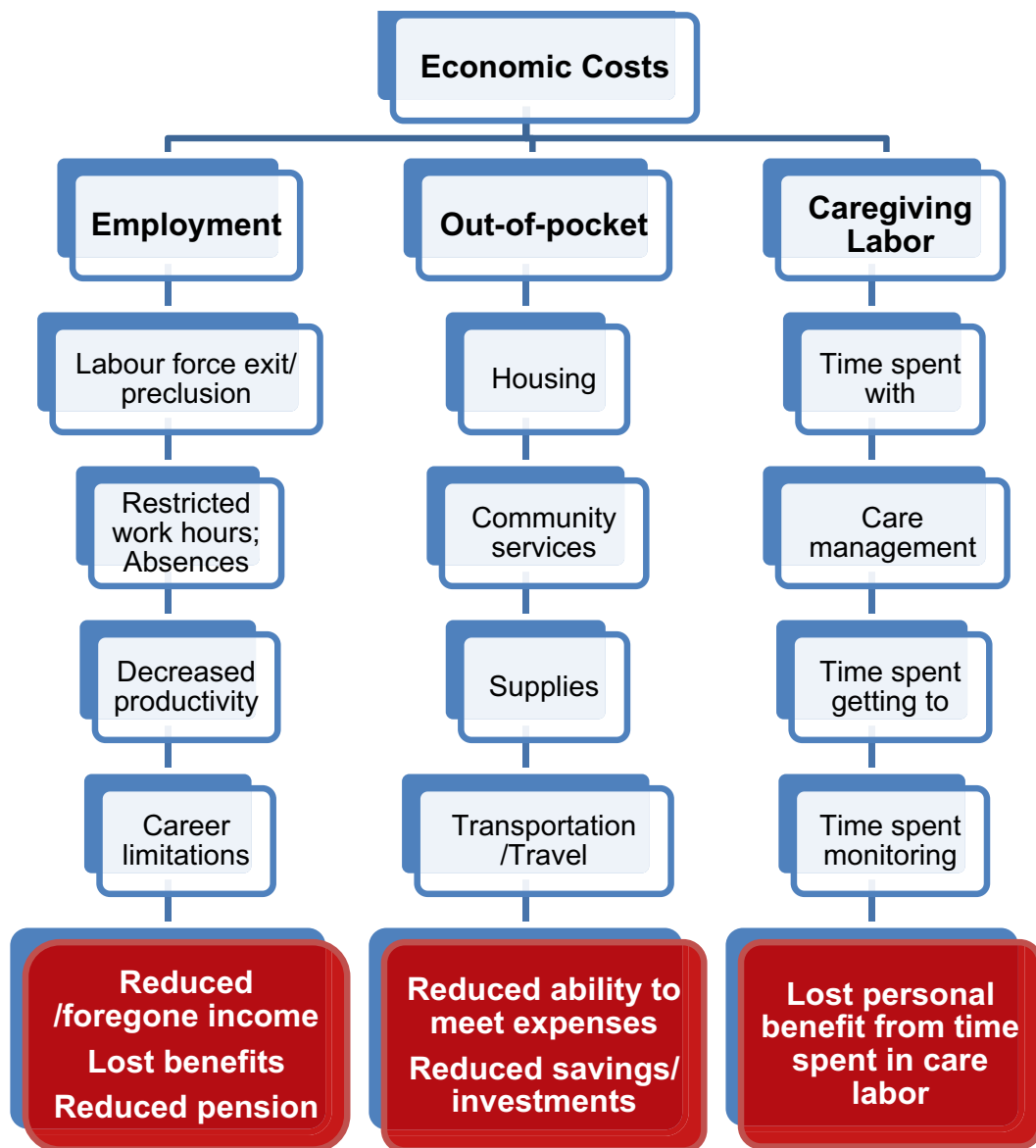


Figure 1: A taxonomy of the economic costs of family care to adults
Keating N., Fast J., Lero D., Lucas S. & Eales J. (2014) A taxonomy of the economic costs of family care to adults. *The Journal of the Economics of Ageing*, **3**, 11–20

Financial instability is associated with increased negative psychological outcomes for caregivers whereas financial security can act as a buffer to stressors associated with the role (Savage & Bailey 2004). Caregiver depression and distress have been shown to be associated with a caregiver’s level of income adequacy (Covinsky *et al.* 2003).

2.3.2.7 Employment and caregiving

Working age carers are at a higher risk of poverty than non-caregivers (Colombo *et al.* 2011). The European Foundation for the Improvement of Living and Working Conditions (2017) reported that, across Europe in 2016, 45% of informal caregivers who were not in the labour market were in the lowest income quartile compared to 25% of non-carers. The report also noted that 54% of caregivers who were not in the labour market were finding it difficult to make ends meet compared to 38% of non-caregivers. Family caregivers miss more days at work, work fewer hours and take more unpaid time off work than non-caregivers (Lai 2012). Caregivers may have to reduce working hours or withdraw completely from paid employment (Larkin & Milne 2014, Colombo *et al.* 2011) which may have lifelong impacts on income, pension entitlements and vulnerability to poverty (Orloff 2009). The intensity of care provided has been demonstrated to impact on employment; the OECD reported in 2011 that an increase of 1% in hours spent caring results in carers being more likely to stop working by 10% (Colombo *et al.* 2011). In a survey of 270 carers of people with dementia in Ireland, Trepel (2011) identified that 63% of the sample were below retirement age and half these caregivers had left employment to provide care. Of those in fulltime employment, 61% had reduced their working hours and 71% of the caregivers in part-time employment had reduced their working hours to less than 20 hours per week (Trépel 2011).

The extent of financial burden experienced by some caregivers was demonstrated in the results of cross-sectional community surveys carried out in 19 countries (n=43,732) which reported that:

Concerning financial burden, the 3.6% of people in low/lower-middle income countries who report financial burden associated with caregiving for ill relatives devote up to 44% of median household income to these activities, as do 32% of those in upper-middle income countries (among those 4.1% reporting this burden). (Viana *et al.* 2013, p. 123).

2.3.2.8 Social support and social activity

Although separate concepts, social support and social activity are often linked and each may impact on the mental and physical wellbeing of individuals. Some studies have found no correlation between social support and carer burden and no evidence that social support improves adjustment to stressful caregiving (Smerglia *et al.* 2007) however, other studies have concluded that social support may be an important moderator of the impact of caregiving (Maguire, Hanly & Maguire 2019, Perkins & LaMartin 2012,

Llewellyn *et al.* 2010, Walden *et al.* 2000). Social support has been described by Oshio (2015, p. 2) as “the perception and/or actuality that one is cared for and has assistance from other people” whereas social participation is described as “participation in activities involving interpersonal interactions with others in their neighbourhood, community, or other domains of society”. An Irish study reported that one quarter of the sample of carers of people with an intellectual disability had low levels of social connectedness and that this was particularly prevalent among compound caregivers (Lafferty *et al.* 2016).

Social support can be instrumental or emotional and it may be informal – from friends, family, church or community – or formal – from voluntary or statutory services (Savage & Bailey 2004). Social support may reduce stress, support effective coping, reduce caregiver burden (Rodakowski *et al.* 2012) and promote positive health behaviours (Chappell & Funk 2011, Pinquart & Sörensen 2006) and, conversely, lack of social support may result in feelings of loneliness, helplessness and social isolation (Kiral *et al.* 2017). A meta-analysis of fifty-six studies exploring social support and subjective burden in caregivers of adults and older adults concluded that perceived social support has a greater effect size on subjective burden than that of received social support and that the relationship between received social support and subjective burden was clinically irrelevant. However, perceived social support may be a good predictor of subjective burden (del-Pino-Casado *et al.* 2018).

Likewise, the size of a caregiver’s social network may not, of itself, impact positively on caregiver burden (Chang *et al.* 2001) whereas the quality and relevance of the network may predict caregiver burden (Scharlach *et al.* 2006, Chiou *et al.* 2009). A study of caregivers of people ageing with a spinal cord injury, negative social interactions strongly predicted caregiver burden (Rodakowski *et al.* 2012).

Tolkacheva *et al.* (2010) suggest that, in the context of adult children caring for parents, the caregiver is usually embedded in an informal care-giving network which may comprise siblings, a spouse, friends, relatives and neighbours. Following their study of 602 adult child caregivers to a parent, they found that

... an adult child experiences lower levels of care-giver burden when he or she can count on a larger care-giving network, shares tasks with others for a longer period, and shares more types of tasks with others. At the same time, the findings also suggest that the informal care-giving network can increase care-giver burden if there are disagreements among the network members. (Tolkacheva *et al.* 2010, p. 46)

Social involvement and engagement in social and leisure activities can reduce caregiver stress and burden and buffer the negative impacts of caregiving (Schulz *et al.* 2015). Lafferty *et al.* (2016) reported that one in four caregivers in their Irish survey reported low levels of social connectedness. However, the nature of the role may make it difficult to participate in social and health types of activities. Caregivers may find it difficult to maintain social relationships and caregiving demands often restrict access to social support and results in a reduction of social support over time (Perkins 2009). Indeed, the more demanding the caregiving duties are, the less social support may be accessible to the caregiver (Perkins *et al.* 2009). In a review of ninety-seven articles Grossman and Webb (2016) identified that across multiple types of caregiving, caregivers spent less time on social activities and reported higher levels of social isolation than non-caregivers (Grossman & Webb 2016). A scoping review of the social consequences of family care of adults identified that carers' social relationships are changed in relation to care receivers, to other family members and to broader social networks" (Keating & Eales 2017, p. 166). A nine-wave longitudinal, population-based study from Japan (n= 24,193; aged between 50 and 59 years at baseline) concluded that participation in social activities substantially mitigated the negative impact of caregiving on the mental health of the caregivers. This mitigating effect was more important for men than for women and largely off-set the negative effects of caregiving (Oshio & Kan 2016).

Parents of children with intellectual disability report significantly lower rates of social participation than parents without children with intellectual disability (Seltzer *et al.* 2011). Cramm & Nieboer (2011) in a study of parents of children with intellectual disability found an indirect relation of restricted caregiver social activities with parental stress. Little research attention has considered the social activities of carers of adults with intellectual disability.

2.3.2.9 Caregiver interventions

Interventions developed to support caregivers included mentoring, meditation-based interventions and educational, psychosocial, psychoeducational and skills training interventions which may be community-based or illness-specific individualised interventions (Thomas *et al.* 2017, Bastawrous 2013). However, caregivers who most need support have been found to be those least able to access it (Thomas *et al.* 2017).

A scoping review of services provided to family caregivers of adults with an intellectual disability, found that the most commonly used services were respite and daytime activities, financial support services and information provision services (Lunsky *et al.*

2014). Respite is recognised as a key component of family-centred services, however the findings of a study of fifty Irish caregivers of people with intellectual disability reflected other studies in identifying ambivalence towards respite care for reasons including caregivers reluctance to relinquish care and feelings of guilt about doing so (Mannan *et al.* 2011). Caregivers also expressed concerns about the quality of care which the person with intellectual disability would receive in the respite setting. Merriman & Canavan (2007), in identifying what is best practice in relation to respite care, set out a number of key principles which are listed below:

1. That respite services be person-centred and family-centred;
2. That respite services be provided on a rights basis;
3. That respite be defined as a support service and regarded among a system of support services;
4. That there be a single point of access to respite care services in a given administrative area;
5. That respite services be designed in consultation with families in acknowledgement of their expertise in providing care;
6. That respite be designed to facilitate the service user in building relationships in their community;
7. That respite services be age-appropriate and develop as the service user develops;
8. That respite care services have clear goals and that systematic and regular review ensure achievement of those goals. (Merriman & Canavan 2007, p. vii – viii)

Other interventions to support caregiving include general education; support groups, behaviour therapy; and counselling (Bastawrous 2013). A plethora of caregiver interventions have been documented in the literature with inconsistent results. An updated meta-review of evidence on supports for carers published in 2017 included sixty-one systematic reviews (Thomas *et al.* 2017). Of these 27 were rated as being of high quality, 25 were rated medium quality and the remaining nine were deemed to be low quality reviews. Most (n=14) of the high quality reviews focussed on caregivers of people with dementia with the remaining high quality reviews focussing on caregivers of people with stroke (n=4), caregivers of people with mental health problems (n=2) and those caring for people at the end of their lives (n=3). No review focussed on caregivers of people with intellectual disability. Montgomery & Kosloski (2009) note that most interventions failed to address the diversity of the caregiving experience and its inherent dynamism. The general conclusion of the review was that there is no ‘one-size-fits-all’ intervention to support carers although potential exists for effective support in specific groups of carers.

2.3.2.10 Irish studies of caregiver health and wellbeing

A limited amount of research has focussed on the health and wellbeing of Irish caregivers. Although McGee *et al.* (2008) reported that the older adults in the study who provided informal care had lower levels of depression than those who did not provide care most Irish studies have reported that caregivers experience poorer health than non-caregivers (McGee *et al.* 2008).

A study by O' Brien (2009) for The College of Psychiatry of Ireland in collaboration with the Carer's Association randomly sampled 10,000 carers on the database of the Carers Association. The self-complete questionnaires were returned by 1990 carers, a response rate of 20%. Caregivers were predominantly female (82%) and married or living with a partner (76%) and over one half were aged between 45 and 64 years of age. The majority of carers (57%) had been caring for more than 6 years; 80% spent more than 35 hours per week caring and 71% spent more than 50 hours per week caring. Most respondents (71.3%) described their health as "very good" or "quite good" and 28.6% described their health as "not very good" or "not good at all". However, 63.4% reported that they felt mentally or emotionally drained by their caring responsibilities and 56.5% felt physically drained. Carers experienced sleep deprivation (55.3%), frustration (54.7%), stress/nervousness/panic attacks (42.7%), anger (35.6%), and fear (29.1%) (O' Brien 2009).

A number of Irish studies on caregiver wellbeing have used samples of Carer's Allowance recipients which while resulting in a large sample size, this method of recruitment excludes the majority of caregivers in Ireland who are not in receipt of this State support. O' Sullivan (2008) recruited 2,834 recipients of Carer's Allowances to complete a self-administered questionnaire. The sample was representative of Carer Allowance recipients with regard to marital status, age, gender and county of residence and were mainly aged between 35 to 64 years of age. More than one half were caring for someone aged 60 years or older; nearly one half of the care recipients had a physical disability, one in six had an intellectual disability and one in nine care recipients had both. Caregivers were statistically less likely to report very good or excellent health than the general population. The majority (70.1%) were either satisfied or very satisfied with their health although nearly one-third felt that their health had suffered as a consequence of their caring responsibilities. Negative health impacts were correlated with stress, lack of sleep or tiredness, emotional strain and isolation. Negative health impacts were also significantly associated with leisure – negative health impacts were 7.8 times more likely to be reported where leisure was limited a great deal than where it was not affected at all. Restricted leisure time was likewise associated with lower quality of life. The most com-

monly cited coping strategies were talking to friends, watching TV, faith-based activities and exercise (O' Sullivan 2008).

Lafferty *et al.* (2016a) sought to determine the prevalence of potentially abusive behaviours towards older people by family caregivers. The postal cross-sectional survey was returned by 2,311 carers of older people (aged over 65 years) in receipt of Carer's Allowance, a response rate of 58%. Respondents were mainly female (71%), married or in a civil partnership (62.5%), caring for a parent (51.5%) or spouse (31.1%) and had been caring for an average of 6.8 years. More than one half of the respondents had no formal education or some primary or secondary education and 88.4% were not employed or engaged in study. Over one-third of the respondents reported engaging in potentially harmful behaviour towards the older person for whom they provide care in the 3 months previous to completion of the survey. One third of these reported that they engaged in potentially harmful psychological behaviours and 8% reported engaging in potentially harmful psychological behaviours. Lafferty *et al.* suggest that the results indicate the need for greater support or training for caregivers (Lafferty *et al.* 2016b).

Although Ireland is increasingly becoming an ethnically diverse country, little research, to date, has included a focus on the experiences and needs of caregivers with different cultural backgrounds (Carer Alliance 2018).

2.3.2.11 Intellectual disability specific research

Much of the early literature on caregiving and disability focussed on the impacts of parenting children with disabilities (Hill & Rose 2009). Parents of children with disability have been reported to have poorer physical and psychological health and higher levels of stress (Smith & Grzywacz 2014, Miodrag & Hodapp 2010, Singer 2006). Parental stress has been identified as a strong predictor of their psychological wellbeing and is highly correlated with the decision to place children out of home (Cramm & Nieboer 2011). Seltzer *et al.* (2011) reported that although parents of children with intellectual disabilities have been shown to have worse psychosocial functioning than the general population, overall they are resilient and cope effectively with their responsibilities (Seltzer *et al.* 2011). Green (2007) argued that the positive benefits which mothers derive from caring for a child with disability is largely unacknowledged in the research literature. She further argues that the burden of care experienced by mothers is not a consequence of subjective burden (ie emotional distress) but is as a result of socio-cultural constraints (objective burden: ie impact of the child's disability on the mother's financial, work, family, social and recreational activities) (Green 2007).

Although the experiences of families caring for older people with intellectual disabilities will mirror the experiences of carers in other contexts, a number of features also distinguishes these carers including the longevity of the caring relationship (Mahon 2019, Taggart *et al.* 2012), the impact of ageing on both the caregiver and the care recipient and concerns about the future of the care recipient when the caregiver dies or is no longer in a position to continue caring. An early theoretical approach to stress and caregiving was the ‘wear and tear’ approach which posited that caregiving over an extended time period led to negative health outcomes through a process of erosion. Parents of adults with intellectual disability would therefore be at heightened risk of negative outcomes due to the length of their exposure to chronic stressors (Ha *et al.* 2008). In contrast, adaptive theories of family stress, including McCubbin & Patterson’s (1983) Double ABCX model, posit that caregivers develop strategies overtime which work with available resources to act as potential buffers to negative outcomes (Grey *et al.* 2018). Older parent-carers, suggests Llewellyn *et al.* (2010, p. 1177) “may enjoy better health-for-age because they have enhanced self-confidence, a sense of control and a well-honed repertoire of coping strategies” (p. 1177). Variables which have been reported to impact on the health and wellbeing of caregivers include the characteristics of the care-recipient particularly the presence of maladaptive or challenging behaviour (Lafferty *et al.* 2016b, Minnes *et al.* 2007), the severity of the intellectual disability (Robinson *et al.* 2015), co-morbidity such as epilepsy (Thompson *et al.* 2014), low social connectedness (Lafferty *et al.* 2016b), co-residency (Namkung *et al.* 2018, Seltzer *et al.* 2011), and coping strategies. Studies into the health and wellbeing of parents of adults with intellectual disability have reported a diversity of findings, however as Grant & Ramcharan (2001) noted the lives of families of people with intellectual disability are not readily compartmentalised nor should they be.

Lafferty *et al.* (2016b) reported on a study of family carers of people with an intellectual disability in receipt of a Carer’s Allowance. The study included a postal questionnaire which was sent to six hundred carers, two hundred and forty-seven of whom returned the questionnaire. The care recipients of the participating caregivers were aged between 16 and 86 years, with an average age of 19 years. Two thirds of the caregivers described their general health as good, very good or excellent; one third described their health as poor or fair. Just over 40% of the caregivers scored over the threshold for psychological distress and one quarter reported low social connectedness. Most caregivers were found to be relatively resilient however low levels of resilience was found to be associated with a number of factors including co-residency with the care recipient, challenging behaviour on the part of the care recipient, compound caring, high levels of psychological distress,

poor/fair self-reported general health, low levels of social connectedness and low levels of formal and informal support.

Two recent UK studies considered the health of caregivers of adults with intellectual disability. Totsika *et al.* (2017) identified two hundred and sixty carers of people with intellectual disability within the 2,199 carers in the English Survey of Carers in Households 2009/10 and analysed this data both to describe the health, quality of life and impact of caring of informal caregivers of people with an intellectual disability. They also compared these findings to both the whole sample and to similar sized groups of caregivers of people with dementia and mental illness. Although caregivers of people with an intellectual disability did not have a poorer quality of life than other caregivers, they had an 82% higher risk of reporting poor health status. However, these carers did not report that their poor health was a consequence of caregiving. The authors suggest that this supports the hypothesis that health differences found among caregivers may predate their caregiving. Compared to the complete sample of caregivers, caregivers of people with intellectual disability had a 27% higher risk of report a negative impact on their personal life eg on their spare time, hobbies and relationships with other people. Although this increased risk was evident in the comparison with the larger sample it was largely equivalent to the risk associated with caregiving to people with dementia and mental illness. This, the authors suggest, may be a consequence of common characteristics of the care-recipients such as challenging behaviour. Caregivers of people with intellectual disability were found to have been caring for a longer period of time, to provide more intensive care and to spend more hours per week caring than carers in other carer groups (Totsika *et al.* 2017).

Grey *et al.* (2018) compared the physical and psychological health of one hundred and ten caregivers of adults with an intellectual disability to population norms. Caregivers perceived their general health worse than the population norms across the domains of mobility, self-care, ability to carry out usual daily activities, pain/discomfort and anxiety/depression. They reported levels of distress above the clinical cut-off point indicative of risk of serious mental illness at a significantly higher than that of US norms (in the absence of UK population data). Caregivers who used active coping strategies reported less psychological distress whereas caregiver age and socioeconomic position were significantly negatively associated with psychological distress. The older age of the caregiver and their satisfaction with available support were associated with lower levels of caregiver burden; and satisfaction with available support and also associated with perceived positive gain from caregiving. The use of active coping strategies was associated with lower levels of caregiver burden, perceived positive gain from caregiving and reduced

family stress. The authors state that this study was the first to explore differences in the self-reported health status of UK caregivers co-residing with an adult with intellectual disability with the health status of the general population. However, it also suffers the limitations of much caregiver research with a cross-sectional design and recruitment through voluntary and statutory organisation (Grey *et al.* 2018).

In 2001 Seltzer *et al.* reported analyses from the Wisconsin Longitudinal study which found that parent caregivers in midlife were largely comparable to other parents in terms of their health and psychological wellbeing although parents of adult children who co—resided with them were more likely to be overweight and experience cardiovascular problems (Seltzer *et al.* 2001). However, and importantly, 12 years later when an enlarged sample from the same dataset was analysed the outcomes for the parents caregivers who were now in their early old age showed greater divergence from those of their counterparts who did not have adult children with disabilities. Seltzer *et al.* (2001) reported that:

by the early years of old age, there was evidence of more pervasive health impacts, indicated by continued likelihood of being overweight, poorer self-rated health (among mothers whose adult child lived away from home, relative to fathers), more musculoskeletal conditions, and more impaired daily functioning and poorer HRQoL. (p. 497)

Seltzer *et al.* (2011) suggest that the significant elevations in depressive symptoms among the older parents of co-residing adult children may signify that this is the time in their lives when

parents grapple with the need to plan for their adult child's long-term future, beyond the time when they can be the primary caregivers or overseers of their son or daughter's services and care, and as they struggle with their own functional limitations, they become vulnerable to feelings of depression that were not problematic in midlife. (p. 495)

Indeed, future planning has been frequently identified as a particular stressor of caregivers to adults with intellectual disability, an issue which has taken on a heightened focus in recent decades due to the increasing longevity of people with intellectual disability (Dillenberg & McKerr 2009). The issue of future planning is considered later in this review.

Studies have identified increased rates of depression among parents of adult children with intellectual disability (Piazza *et al.* 2014, Caldwell 2008) and increased levels of stress (Dillenberg & McKerr 2010). Taggart *et al.* (2012) reported that 31% of the

caregivers in their UK study were suffering from depression and caregivers identified that their depression was a direct consequence of the demands of caregiving (Taggart *et al.* 2012). An Australian study of sixty-four older parent caregivers found significantly poorer mental health (compared to population norms) in the 55- 64 age group but not in the parent caregivers aged over 64; the authors conjecture that this difference is a result of an increased acceptance of their situation by the older parents (Llewellyn *et al.* 2010). Yamaki *et al.* (2009) found that older caregivers (aged at least 60 years) had poorer perceived psychological wellbeing (Yamaki *et al.* 2009). However, other studies have reported that age has no relationship with depression among female caregivers of adults with intellectual disability (Caldwell 2008).

It is suggested that older parents cope better because they have adjusted to their role and benefit from the experiences which they have had over their caring career (Iacono *et al.* 2016) or, alternatively that the mental health of caregivers may fluctuate according to key periods in their own lifecourse (Caldwell 2008). Likewise, Ha *et al.* (2008) identified that the wellbeing of older parents of disabled children diverged less from the comparison group than did the younger group which, they argue, supports their hypothesis that the impact of parenting a disabled child attenuates in old age. They also concluded that the age of the parents at the time at which their child was diagnosed with a disability and the duration of the disability were important predictors of parental wellbeing (Ha *et al.* 2008). Minnes & Woodford's (2005) mixed methods study with eighty older parents of adults with intellectual disability noted no difference in perceptions and stress between older and younger parents and concluded that

it appears that all parents of adults with DD shared many common concerns regardless of age. This finding suggests that many issues noted as stressful for parents are chronic stressors that need to be reassessed and managed at intervals. (p. 58)

Parental coping strategies have been found to mediate the impact of caregiving. A religious or spiritual belief has been shown to provide a coping mechanism for caregivers reducing caregiver burden and depression (Choi & Kim 2008). Using data from the 4th Wave of the Wisconsin Longitudinal Study (2002-2006), Piazza *et al.* (2014) used Pearlin's stress process model to examine the effectiveness of different coping strategies on caregiver burden (Piazza *et al.* 2014). Eighty-six parents (mean age 65) of adults with developmental disabilities including 60 whose adult children were co-resident comprised the sample. Accommodative coping strategies were found to buffer the impact of stress whereas disengagement and distraction strategies exacerbated the effects of burden on

depression. Parents whose children reside with them and who used disengagement and distraction strategies were more vulnerable to caregiver burden whereas those who used engagement strategies were resilient (Piazza *et al.* 2014). Likewise, Hill and Rose (2009) reported that mothers with a higher internal locus of control and greater levels of social support reported lower levels of parental stress and that parental cognitions were associated with parenting stress (Hill & Rose 2009).

The link between maladaptive behaviour and caregiver depression and stress is frequently reported (Minnes *et al.* 2007). Aggressive behaviour by care recipients with intellectual disability may be particularly stressful for caregivers (Unwin & Deb 2011) and greater caregiver burden has been identified in mothers whose adult children exhibit violent or challenging behaviour (Unwin & Deb 2011, Miltiades & Pruchno 2001). In a qualitative study by Dillenburg & McKerr caregivers reported behaviour problems to be one of the greatest challenges that they faced (Dillenberg & McKerr 2010). Minnes and Woodford (2007) found that caregivers stress was significantly correlated with maladaptive behaviour and that such behaviour was also associated with amplified difficulty in future planning because it was less likely that another family member would take over the role of caregiver (Minnes *et al.* 2007). In contrast, Hill and Rose (2009) reported that maladaptive behaviour on the part of the care recipient was not associated with parental stress (Hill & Rose 2009).

The existence of mental health problems in the adult with intellectual disability may also impact on the wellbeing of the mother of the care recipients. Esbensen *et al.* (2006) explored the relationship between the depressive symptoms of adults with Down's Syndrome and mild to moderate intellectual disability and found significant correlations between these and maternal depressive symptoms. The depressive symptoms of the adult child were also found to be predictive of maternal depressive symptoms and caregiving burden three years later albeit only accounting for 3% to 4% of the variance in predicting later maternal well-being (Esbensen *et al.* 2006). A high level of psychiatric comorbidity is found among people with intellectual disability compared to the general population (Bratek *et al.* 2017). Buckles *et al.* (2013), in a review of 16 articles published between 2003 and 2009, found reported prevalence rates for co-occurring psychiatric symptoms or disorders ranging between 13.9% and 75.2%; the authors attributed the variation in prevalence rates to the differences in the diagnostic criteria utilized and the specific samples examined. Higher prevalence rates have been found in samples of adults living in residential rather than community settings (Dawson *et al.* 2016). An Australian study cross-linked the Western Australian population-based psychiatric and intellectual disability registers (total n=245,749; intellectual disability sample n=11,576) and reported that

31.7% of people with intellectual disability also had a psychiatric disorder (Morgan *et al.* 2008). Schizophrenia was the most common psychiatric comorbidity with a prevalence rate at least three times greater than population lifetime estimates; conversely the prevalence of bipolar depression was within the population estimates and unipolar depression was well below general population estimates. Families of people with a dual diagnosis of intellectual disability and mental illness, and the individuals themselves, experience misunderstanding and stigma (Nicholas *et al.* 2017). Dawson *et al.* (2016) compared the psychological health of caregivers of adults with a dual diagnosis of intellectual disability and comorbid psychopathology (n= 18) with caregivers of adults with intellectual disability alone (n=57). The caregivers of adults with a dual diagnosis of intellectual disability and a psychiatric condition had higher levels of both stress and psychological distress and were significantly more likely to fall within the clinical range of distress. The psychopathology of the care recipient was reported to predict approximately 28% of the variance in carer stress and psychological distress. Autism was the only measure of psychopathology which was found to significantly predict both stress and psychological distress (Dawson *et al.* 2016). An Irish study identified that caregivers of individuals who had both intellectual disability and a psychiatric disorder had significantly higher levels of psychological distress and stress than carers of individuals with intellectual disability alone (Dawson *et al.* 2016).

Parents of adults with intellectual disability may provide considerable care and support even when their adult child no longer lives in the family home including supporting social ties, shopping, managing finances and advocacy (Walker & Hutchinson 2018). However, co-residency has been found to be a risk factor for negative caregiving impacts. Studies have found that co-residency is associated with greater caregiver burden (Miltiades & Pruchno 2001) and that caregivers were less likely to visit with family and less likely to have a confidante (Seltzer *et al.* 2011). These parents were also more likely to have experienced divorce, widowhood and had higher rates of depressive symptoms (Seltzer *et al.* 2011). However, it is also the case the relationship between older caregivers and their son or daughter with intellectual disability can be one of mutual support and dependency as they age concurrently. The social participation of the person with intellectual disability impacts on the well-being of caregivers. Attending some form of daytime occupation for an adult with intellectual disability reduces the risk of social isolation for both the person with ID and also for their family members (Jecker-Parvex & Breitenbach 2012). Mutual dependency can be a feature of the parent – child relationship even when the child has a severe level of intellectual disability (Dillenberg & McKerr 2010). Parents may come to rely on their adult child for both daily tasks and emotional support (Bowey & McGlaughlin 2005, Grant *et al.*

2007) and Care Alliance Ireland (2015, p. 5) asserts that “It is inaccurate to continue with the belief that people with intellectual disabilities are exclusively consumers of care rather than providers of care”. Twenty-two percent of caregivers in Perkins & Hayley’s (2013) study perceived that they received more tangible support than they gave to their adult son or daughter with intellectual disability. The adult with intellectual disability may be an ageing parents’ main source of companionship and only source of personal and social support (Rimmerman and Muraver 2001). Relationships are dynamic and complex and Dillenberg and McKerr (2009) describe the relationships between caregivers, care recipients and their families as “an interwoven network of behavioural repertoires that [are] constantly adapted to circumstances” (Dillenberg & McKerr 2009, p. 161). Williams & Robinson (2001) called for services to acknowledge these mutually supportive roles and consider the needs of the caregiver and the service users in tandem as the existing relationship may pose a significant barrier to future planning. The dominant discourse that people with intellectual disability are the ‘cared-for’ results in mutually caring older families being unsupported by either intellectual disability services or generic carer support services (Care Alliance Ireland 2015, Foundation for People with Learning Disabilities 2010). Llewellyn *et al.* (2010) argue that the continued need of services to identify and label members of family systems

flies in the face of the family reality where their lives and that of their adult son or daughter with a disability are inextricably linked after a lifetime together (p. 1185)

Care Alliance Ireland identified, in a discussion paper in 2015, that the information provided by carer support services usually do not meet the accessibility requirements for people with intellectual disability and the increasing use of web-based supports may exclude caregivers with literacy problems (Care Alliance Ireland 2015).

Overall, much less research has looked at the health and wellbeing of fathers of adults with an intellectual disability; in 2011 Rowbotham *et al.* reported a study of 12 middle aged Anglo-Australian mother and father couples with an adult child with intellectual disability. The findings showed that the range of tasks carried out by the mothers and the fathers was similar although the mothers undertook more daily caregiving tasks than the fathers. Mothers reported more caregiving difficulties and more caregiving satisfaction than the fathers reported; however

an extremely high proportion of both mothers and fathers were in the clinical range for social dysfunction, anxiety/insomnia, and somatic complaints, although levels of depression were relatively low. (Rowbotham *et al.* 2011, p. 223).

The recruitment process for the study may warrant the findings to be treated somewhat cautiously. Twelve of fifty-two organisations providing services to caregivers of adults with an intellectual disability who were asked to forward recruitment letters to parents, agreed to do so and forty-five parents volunteered to participate; the fifteen families who took part were those where both parents agreed to participate. The authors acknowledge that it is not possible to know how many parents received an invitation to participate. The fifteen participating couples were self-selecting and known to formal services and therefore may not be typical of the wider population of caregivers of adults with an intellectual disability.

2.3.2.12 Compound caring/multiple roles

Given the longevity of the caregiving relationship between parents and children with intellectual disability, it is unsurprising that many such parents become compound carers. Grossman & Webb (2016) distinguish compound caring from ‘sandwich generation’ caring thus

Unlike the notion of the sandwich generation (i.e., parents taking care of their children and aging parents until the children leave the family home), compound caregiving recognizes the unique situation of undertaking new, long-term care responsibilities in addition to and simultaneous with existing, lifelong caregiving relationships. (p. 362)

An Irish study included interviews with fourteen compound caregivers aged between 38 years and 65 years who had been compound caring for an average of 5.1 years. The caregivers were found to approach their responsibilities in different ways with some caregivers ‘compartmentalising’ care requirements in order to meet the differing needs of each care recipient and some caregivers were characterised as having integrated their role into their lives and their identities (Lafferty *et al.* 2016b).

In a US study of 91 older caregivers of people with intellectual disability, 66% were either a current or previous compound caregiver (Perkins & Haley 2010). Contrary to the authors’ hypothesis, their findings indicated that compound caregivers physical or mental health, their levels of depression and their life satisfaction were on a par with those of non-compound caregivers. The authors suggest that such caregivers have become ‘experts’ and their experiences gained over many years have equipped them with the requisite knowledge, skills and empathy. However, Perkins (2009) reported that compound caregivers were more likely to desire a residential placement for their care recipient than

were non-compound caregivers (Perkins 2009). Perkins further suggest that a threshold of care hours exists beyond which additional hours does not result in greater caregiver distress; supporting this proposition with a study by Roth *et al.* (2009), of over 5,000 caregivers, which reported that extra hours of caregiving over 20 hours per week were not associated with reduced caregiver quality of life or increased caregiver depression.

A number of studies have explored the impact of multiple roles on the wellbeing of mothers of individuals with intellectual disability. Mothers of children with intellectual disability have less job stability and lower income than other mothers (Eisenhower & Blacher 2006) but the research suggests that their wellbeing is enhanced rather than diminished through occupying multiple roles (Eberl *et al.* 2017, Rowbotham *et al.* 2011). However, Eisenhower & Blacher (2006) argued that most relevant research did not control for socioeconomic status variable and therefore, did not consider whether the benefits identified were associated with the increase in socioeconomic resources deriving from employment (Eisenhower & Blacher 2006). Multiple roles include not just employment but also those of parent, marriage and social contacts. There is evidence that a multiplicity of roles can result in lower levels of depression (Hansen & Slagsvold 2015) leading to a hypothesis of the benefit of role accumulation. Eisenhower & Blacher's study (2006) reported results in line with previous research identifying that mothers who were married and/or employed had markedly better health than those who were unemployed and unmarried. However, they suggested that impacts resulted from role shortage rather than role enhancement ie that mothers who were at greater risk of poorer wellbeing were those who had a shortage of roles (Eisenhower & Blacher 2006). Eisenhower & Blacher, (2006) also reported that maternal education and family income mediated the impact of role occupancy on the wellbeing of the mothers with the benefits of these factors overshadowing any other benefits of role occupancy (Eisenhower & Blacher 2006). The all-encompassing nature of caring for a son or daughter with intellectual disability emerged as a theme in an Irish participatory study. Family caregivers described loneliness and isolation and the impact of losing a valued social role when it became impossible to continue to balance the responsibilities of caregiving with work outside the home (Chadwick *et al.* 2013).

2.3.2.13 Future planning

Concerns about the future for an adult child with intellectual disabilities is often cited as a cause of stress for parents. Much of the relevant research indicates that caregivers rarely engage in future planning (Brennan *et al.* 2018, Innes *et al.* 2012, Dillenberg & McKerr 2009) and their expectations about care for their adult child when they are no longer able to provide this, is often aspirational. Many parents may have only reached the stage of ‘planning to plan’ (Walker & Hutchinson 2018) however Leane (2020) identifies that future planning may be a gradual and iterative process evolving tentatively through connections between families and services. Older parents have a lifetime’s knowledge of what meets their adult child’s needs, maintain their dignity and protects their happiness; Grant (2007) characterised this as “invisible care” and parents may find it difficult to believe that anybody else can provide this care. Parents have expressed reluctance to engage in future planning for reasons that include lack of confidence in services (Bowey & McGlaughlin 2005, Bibby 2013); and a fear that their son or daughter will end up in an inappropriate care setting (Marsack-Topolewski & Graves 2020). Such lack of confidence in services is reported to be a consequence of prior negative interactions with service providers (Innes *et al.* 2012) and a poor relationship with professionals was identified as a key barrier to future planning in a review by Bibby *et al.* (2013). In their studies of Irish caregivers, Lynch and Lyons (2009a, p. 67) reported that institutional care was identified as “care of last resort” and they noted that Ireland’s history of institutional care is not a positive one. Relinquishing care may also mean, for some caregivers, relinquishing a role which had defined them for many decades and which provides them with an identity and a purpose in their lives (Bibby 2013). After decades of caregiving and as they themselves age, parents may be experiencing social isolation with few existing social supports that can be drawn upon when contemplating future care (Marsack-Topolewski & Graves 2020). However, an absence of future planning can result in rushed and inappropriate resettling of a person with intellectual disability when the primary caregivers dies or becomes unable to continue caring (Baumbusch *et al.* 2017); potentially creating Brennan *et al.*’s “inadvertent” primary caregivers (Brennan *et al.* 2018). Pryce *et al.* (2015) suggests that lack of future planning was a position of passive acceptance for most parents rather than a matter of active choice; and this was a consequence of the feelings of hopelessness they experienced when they considered what the services had to offer their children (Pryce *et al.* 2015). A study by Taggart *et al.* (2012) reported that the least preferred future care option identified by older caregivers for their adult child were general nursing homes or other none-specialist residential homes. The preferred options were that the adult child would be supported by family or paid carers to remain in their family home or

that they would live with a sibling. (Taggart *et al.* 2012). However, parents may also be reluctant to pass the challenges associated with care onto other family members even when a sibling of the individual with disability has expressed a willingness to provide future care (Marsack-Topolewski & Graves 2020, Leane 2020, Brennan 2018).

Walker and Hutchinson's (2017) systematic review included fourteen qualitative studies of future planning among older parents of adult children with intellectual disability. Although many of the studies reported that parents were not engaging in future planning, the authors concluded that, in fact, many parents are making plans or have preferences about the future care of their adult child with intellectual disability. They further report a lack of engagement by service providers to initiate or facilitate future planning leaving parents without formal support with this sensitive issue. The review also identified that parents experienced a number of emotional barriers to future planning including the mutual dependency of the parent and the adult child, anxiety, denial and avoidance. Walker & Hutchinson (2017) reported that few families involve the person with intellectual disability in discussions about future planning and many do not involve siblings even when the parent hopes that they may take over future care.

Davys *et al.* (2016) interviewed fifteen adult siblings of people with disability and reported that around half the families had engaged in future planning. However, a recent Irish study (Leane 2020, p. 4) involving twenty-five siblings of people with intellectual disability reported that only four had had "open and engaged discussions with their parents about future plans for their brother or sister". Some siblings described tension and distress created by parent's – usually a mother's – reluctance or refusal to discuss future care planning. Noting that future planning is often an incremental and iterative process for families, Leane (2020) emphasised the importance of professionals and services paying attention to how future care plans emerge.

Other studies have indicated that despite not having formal or definitive plans in place, many parents are not oblivious to the fact that their caregiving may cease or change. A qualitative study explored the experiences of eight aging families of community-dwelling adults with intellectual disability in Canada. Baumbauch *et al.* (2017) found parents were very aware that their caring role would change or cease and were working to strengthen links between their adult child and formal and informal sources of care. At the same time they were (Baumbauch *et al.* 2017)

continuing to shift their care activities from providing physical support to focusing on socio-emotional support and transferring their intimate biographical knowledge of their relative with ID to others who could provide care in the future. (p. 6)

A review by Lunsky *et al.* (2014) of 87 studies identified a consistent absence of proactive permanency planning on the part of caregivers for reasons that include lack of available information and anxiety about the availability of acceptable and appropriate options. Caregivers of individuals with less significant levels of intellectual disability have been found to be more likely to engage in future planning, possibly because there are more perceived options available. The authors of the review conclude although the ongoing involvement of family members should be encouraged, the availability of family members as long-term carers should not be taken for granted.

Garnham *et al.* (2019) argue that the “problem” of post-parental care planning should be viewed as part of the broader context of family care for people with intellectual disability. The focus of their paper was rural Australia, however their argument may also be more widely applicable. They identify that social policy normalises life-long family care and supports caregivers in order to sustain caregiving for as long as possible and this, coupled with the inadequacy of formal services, “ensures self-sufficiency emerges as the only reasonable life strategy” (p. 838). Choosing not to care or to relinquish care becomes non-normative and is not supported by the prevailing systems and may be characterised as transgressive until the caregiver experiences a mental or physical crisis and is forced to abandon care in a crisis situation. Lack of ongoing support services, inadequate support services and a limited supply of quality community residential provision ensures that the disability sector functions in a context of crisis which neither funds nor supports families to confidently plan for a timely transition from family-based care.

However, a number of studies have indicated that families will positively engage with future planning when it is provided carefully and sensitively (Deville *et al.* 2019, Ryan *et al.* 2014). McCausland *et al.* (2019) demonstrated that engagement in a future planning process can significantly enhance future planning however, the families must be emotionally, situationally and/or circumstantially ready to engage and that this “‘readiness’ of families to engage in future planning may be a critical factor in their agreeing to initiate planning” (McCausland *et al.* 2019, p. 426).

2.3.2.14 Siblings

Sibling relationships have a number of unique characteristics, not least that it is usually the longest lasting relationship that an individual will experience (Cicirelli 1995). Research considering the impact of having a sibling with intellectual disability have produced mixed results (Davys *et al.* 2011). Using multiple relationship measures including contact, warmth, conflict, rivalry and expressed emotion, Doody *et al.* (2010) explored the relationship of one hundred and twenty-three siblings who did not have a brother or sister with a disability and sixty-three siblings of an adult with and intellectual disability and the variables associated with the relationship dimensions (Doody *et al.* 2010). Their results identified few differences in adult sibling relationships between the two groups and those that did exist were mainly related to intellectual disability specific characteristics. Thus, no differences were found in the dimensions of conflict, rivalry and critical expressed emotion. However, there was less phone contact between siblings where one had an intellectual disability and less reported warmth particularly when the sibling had a severe or profound level of intellectual disability. The participants in this study were self-selecting and had responded to advertisements and the authors acknowledge that they are unlikely to be representative of siblings. A number of studies have explored the characteristics of positive and less positive sibling relationships where one has an intellectual disability and the characteristics of those siblings most likely to take on caregiving roles. Sisters have been reported to spend more time with their sibling with an intellectual disability than brothers (Hodapp *et al.* 2010, Orsmond & Seltzer 2000). Some studies have reported that the feelings of sisters towards their sibling with intellectual disability is not associated by their gender whereas brothers reported fewer positive feelings, more negative feelings and more worry about the future of a sister with intellectual disability compared to a brother with intellectual disability in a study (Taylor & Shivers 2011, Orsmond & Seltzer 2000); other studies have not found such differences by gender (Wilson *et al.* 1989). The type of intellectual disability may be associated with relationships between siblings. Siblings of adults with Down's Syndrome were noted to have higher levels of positive affect in their relationship, more optimism about their future and were less likely to report that their relationship with their parents had been affected than were siblings of adults with Autistic Spectrum Disorder (Orsmond & Seltzer 2007).

Compared with research exploring the childhood experiences of, and impacts on, siblings of children with intellectual disability, less attention has been paid to adult sibling relationships. This, it is suggested, represents a lacuna in knowledge in the context of siblings assuming care responsibilities for adults with intellectual disability in the

future (Doody *et al.* 2010, Orsmond & Seltzer 2007). The low levels of future planning by parents of adult children with intellectual disability (Dillenberg & McKerr 2009, Bowey & McGlaughlin 2005) means that the transition of care can often happen abruptly and at a time of crisis (Sonik *et al.* 2016) and siblings, commonly, are not involved in future planning (Heller & Arnold 2010). Brennan *et al.* (2016) reported siblings being unaware that they had been nominated as the guardian of their sibling until the death of the parent caregiver precipitating significant upheaval in their own lives. Burke *et al.* (2016) identified that the reality of caregiving differed from the anticipations that siblings had of caregiving. The limited extant research literature, emanating primarily from the US identifies that siblings need relevant information and support from formal services including for future planning and system navigation (Holl & Morano 2014, Arnold, Heller, & Kramer 2012; Heller & Kremer 2009). In a qualitative study of US sibling caregivers, the participants also identified a need for peer support from other sibling caregivers including as part of online communities (Arnold & Heller 2018). Otherwise, there is a paucity of research into the expectations and needs of adult siblings of people with intellectual disability (Burke *et al.* 2016, Hodapp & Urbano 2007, McCallion & Kolomer 2003) or the potential mediators of burden or stress which they may experience (Iacona *et al.* 2016). Namkung *et al.* (2017) suggest that it is important to understand the experiences and impacts of sibling caregiving as siblings are likely to play a greater role in family caregiving in the future due to population trend. Yet to date, they point out, siblings have been treated in most caregiver research studies as ‘other’ caregivers rather than a distinct caregiver group. Thus there is limited awareness of the unique challenges which may be experienced by sibling caregivers and few specific information or support services available to them. Namkung *et al.* (2017) theorise that sibling caregivers may be vulnerable to distress for a number of reasons including that the physical, emotional and financial consequences of taking on additional responsibilities at a time of life when they may have considerable work and family commitments; that providing care to a sibling is non-normative and therefore more stressful and also that service providers may not involve or provide information to a sibling caregiver to the extent that they would involve a parent caregiver.

Saxena (2015) applied Greenberg *et al.*'s (1999) Push-Pull model to explore the motivations and barriers to sibling caregiving as identified in three hundred and three research studies and position papers and reported the results under the four headings of: personal characteristics; personal relationships between siblings with and without disability; family related factors and community resources and support. Saxena (2015) identified that the personal characteristics which may push siblings into the caring role

were being female, and/or being an older sibling and/or being a lone sibling. Saxena (2015) suggested that further research was required to confirm the association, magnitude and/or direction of factors including the age of the sibling, residency, employment status, perceived social support, appraisal of caregiving and perception of caregiving burden. The type of disability was described as a factor which could either push a sibling towards caregiving or pull a sibling away; whereas a close relationship between the siblings was identified as a push factor. A number of family related variables were identified which, the author stated, required further research to ascertain association, magnitude and/or direction. Among these variables were family, race and ethnic values relating to caregiving, family expectations and circumstances, spousal support, children and socioeconomic and financial status. Similarly, the author recommended that further research was required to establish the extent to which community resources served as push or pull factors. Such community resources included availability of community resources and the extent to which siblings were included in family and social policies and subsidies.

Sonik *et al.* (2016) compared the social characteristics and material hardship levels of sibling caregivers of people with intellectual and developmental disabilities and adults in the general working age population (Sonik *et al.* 2016). The caregiving siblings were more likely to be women (67% vs 50%), less well educated and more likely to be Black (25% vs 12%). Male and females were both less likely to have ever been married (58% vs 80%) with this trend being more pronounced for males (44% versus 81%). The study found that levels of extreme material hardships were no greater among the caregivers than among the general population although a 'pervasive' level of moderate material hardship was identified. The siblings were also found to be less likely to report excellent, very good or good health compared to the general population (83% vs 89%), however, this difference was not statistically significant. The data used in the study was from the nationally representative Survey of Income and Program Participation which is a strength of the study. However, with a sibling sample size of 78 the stability, reliability and generalisability of the results are very limited (Sonik *et al.* 2016).

A study using data from the Midlife in the United States (MIDUS) study, a longitudinal study of health and ageing, (cohorts from MIDUS 11 and the Midus Refresher) compared outcome measures of non-caregivers (n=4,944) with those of 61 sibling caregivers, 99 spousal caregivers, 105 parent caregivers, and 366 adult child caregivers (Namkung *et al.* 2017). For the purpose of the analysis Namkung *et al.* (2017) classified brothers, sisters, brothers-in-law and sisters-in-law as sibling caregivers. These sibling caregivers were significantly more likely to be caring for a person with a developmental disability or a mental illness than were spousal or adult child caregivers and were less

likely to co-reside with the care recipient than were spousal caregivers. All the caregivers in the sample reported worse physical and psychological well-being than non-caregivers with greater impact evident among White (rather than minority group) caregivers. The sibling caregivers in their sample were found to

- be less likely to be married (47.5%) than non-caregivers (66.5%) and adult child caregivers (62.8%).
- be less likely to be employed than adult child caregivers or non-caregivers although no differences in levels of education were found between the four caregiver groups and the comparison group
- provide fewer hours of care per week than the other caregiver groups and less likely than spousal or adult child caregivers to assist with bathing, dressing, eating; getting around; managing money, making phone calls, or taking medications.
- experience more depression than non-caregivers but less than spousal and parent caregivers (Namkung *et al.* 2017).

White sibling caregivers reported significantly lower levels of life satisfaction than both White non-caregivers and minority group sibling caregivers. Whereas there was no such difference between minority group sibling caregivers and non-caregivers.

A 2018 systematic review of sibling caregivers included twenty-nine studies involving 2,388 adult siblings of people with intellectual (59.3%) or developmental disability (40.7%) (Lee *et al.* 2018). Among the key issues discussed by the authors was the extent to which research about sibling caregiving was limited by an absence of an agreed operational definition of the construct of sibling caregiving. The importance of more research on the benefits which siblings derive from caregiving was noted with the potential for designing effective support interventions based on that evidence. The authors noted that although there was a level of consistency in the included studies about some characteristics of sibling caregivers including the quality of the sibling relationship, the extent of contact between siblings and proximity between the siblings, there were mixed findings about other characteristics including sibling order, family size and the health of the parents of the siblings. They also suggested that future research should distinguish between future and current sibling caregivers as the proportion of siblings reported to be anticipating future caregiving at a point when it was not required was significantly greater than the proportion of siblings who actually live with the person with intellectual or developmental disability.

In 2019 Chung *et al.* reported that the extant literature on correlations between sibling caregiving and the characteristics of the person with the disability is limited and

mixed and that the extent to which siblings are involved in the care of their adult siblings with intellectual disability range from no caregiving involvement to the provision of full-time care (Chung *et al.* 2019). Their quantitative survey of 141 adult sibling of older people with intellectual disability in the US (Chung *et al.* 2019) identified that care-recipients with the lowest level of functional ability were most likely to have siblings providing caregiving, advocacy and future planning indicating a positive correlation between the extent of the disability and caregiving. Consistent with findings relating to parent caregivers, the results indicated a strong relationship between both maladaptive behaviour and internalising behaviours and caregiver burden suggesting a need for specific support to caregivers of individuals with these behaviours.

2.4 Conclusion

Care is a concept without an accepted definition and family caregiving is a phenomenon that is both common and idiosyncratic to individual circumstances. Therefore, it is unsurprising that efforts to measure or quantify the impacts of caregiving has produced diverse and often contradictory results. Family members caring for older adults with intellectual disability are a particular cohort of family caregivers whose circumstances have received relatively little attention. These caregivers have a number of unique concerns including the issue of future planning that may make their lives particularly stressful; however, many also benefit from the company of their adult son or daughter and may rely on them for personal and household tasks. The economic value of the work of caregivers to the economy is very significant, however the extent to which this contribution is recognised or supported varies according to the prevailing social policy. The following chapter will examine social policy responses to the issues of care and caregiving.

Chapter 3: Social Policy. The problem of carers in Irish Social Policy

3.1 Introduction

This chapter will explore the social policy context in which families in Ireland provide care to older adults with intellectual disability. Whereas the previous chapter identified the ways in which “care” and “caring” have been conceptualised and theorised and provided an overview of the research on the impacts of caregiving, this chapter will examine how Ireland addresses factors which support and challenge those who provide family care to older adults with intellectual disability. Public policies embody a society’s vision of care and care presents unique issues for public policy (Daly 2002). Bryant & Garnham (2016, p. 2) characterise care as “An unassuming feature of everyday life, [which] often only become visible at a point when it can no longer be taken for granted”. Social policy organises and ascribes value to care and the supports made available to care; these reflect the implicit objectives of a State’s care policies and have significant consequences to those providing care (Razavi 2007).

This chapter will start with an overview of typography of welfare systems and a review of social policy responses to informal care which will serve to position Irish social policy in an international context. The following section will examine Irish disability policy. An overview of The National Carers’ Strategy will be presented as this “sets out the Government’s vision in relation to carers” (p. 6); however, the lives of carers are shaped by policies located in a myriad of other government sectors including health, social welfare, employment and disability and these will also be considered.

The chapter will conclude with a critical analysis utilising Bacchi’s (2009; 2016) “What’s the Problem Represented To Be” (WPR) framework, an interpretative and Foucault-influenced post-structural analytical approach.

3.2 Welfare regimes

Public policy responses differ across countries. In his seminal works on welfare regimes Esping-Anderson proposed that societal welfare results from the sum-total of the interaction between three partners that make up a welfare regime: labour markets, the family and the welfare state (Esping-Andersen 1990, Esping-Andersen 1999). Coining the terms *familialistic* and *de-familialisation*, Esping-Anderson defined the first as a state that “assigns a maximum of welfare obligations to the household” whereas *de-familialisation* policies are those that “lessen individuals’ reliance on the family; that maximise individuals’ command of economic resources independently of familial or conjugal reciprocities” (Esping-Anderson 1999, p. 45). Esping-Anderson (1999) identified three welfare regimes: liberal, conservative and social-democrat and the principles underpinning the typology were *decommodification*: the extent to which welfare is dependent on the market; *social stratification*: the state’s role in maintaining or breaking down social stratification; and the *public private mix* (Bambra 2007). Within this typology Anglo-Saxon countries are largely market-based, the Southern European and Japanese regimes are highly *familialistic* and Nordic countries are highly *de-familialistic* with much of the welfare is delivered by the state.

Leitner (2013) suggests four ideal types of *familialistic* and *de-familialisation* policies:

- *explicit familialism*: in which the caring function of the family is explicitly enforced through provision of supports for caring and the absence of alternative market or public provision.
- *optional familialism*: wherein families have the right to care but are not obliged to care; families are supported to care but also have the option to be relieved or partly relieved from the responsibility
- *implicit familialism*: wherein there are no *de-familialisation* policies and neither are families supported to care; therefore families will be the primary caregivers by default.
- *de-familialisation*: wherein the state or market provide care and families do not have a right to care. This serves to exclude families from the provision of care.

Social-democrat regimes are characterised by universal social programmes based on citizenship and serve to minimise dependence on the market and collectivises familial responsibilities. The Latin welfare regime is the most *familialistic* regime, with few redistributive social policies and with family support dependent of the primary breadwinner (Saint-Arnaud & Bernard 2003). Liberal welfare regimes have minimal, residual social welfare expenditure and rely on the market economy and private provision; the ideo-

logical underpinning of such regimes is that of freedom. Conservative welfare regimes offer certain benefits arising from social insurance which is usually employment based. Individuals excluded from the labour force are ineligible for the benefits and such regimes thereby reinforce the male breadwinner model. Ireland is classified, according to the Epping-Anderson typology as ‘low liberal’ (Ferragina & Seeleib-Kaiser 2011) with a strong secondary Christian-democratic classification (Murphy & Dukelow 2017). Liberal welfare regimes have minimal, residual social welfare expenditure and rely on the market economy and private provision. Ireland’s familialistic regime locates primary family welfare obligations to the family and the primary objective of most initiatives to support carers is to prolong care in the informal setting and postpone or prevent the need for care in more expensive residential settings (Pertl *et al.* 2019, National Carer’s Strategy 2012). However, it is also argued that Ireland defies classification and is, in fact, a hybrid as a consequence of factors including:

the incongruous mix of historical influences on its welfare state; the colonial imposition of social security prior to industrialisation; the absence of comprehensive, status maintenance social insurance in a wholly Catholic population; the dominance of populist politics and the absence of definitively Left and Right parties; the cultural fusion of Catholicism and British liberalism (O’Connell and Rottman 1992; Carey 2008). (McCashin 2012, p. 549).

Ireland’s social welfare system consists, mainly, of three types of income support: contributory or social insurance-based payments, means-tested social assistance payments and universal child benefit payments (Cousins 2019). Ireland’s early social welfare provision of old age pensions and national insurance date back to colonial times and although it has subsequently expanded, evolved and diverged from the UK social welfare system, the UK and Irish systems means-test benefits to a greater extent than most EU and OECD countries (Cousins 2019).

Saraceno (2016) proposed three types of familiarisation: familiarisation by default, prescribed familiarisation and supported familiarisation. Familiarisation by default occurs in countries wherein no services or allowances are available to replace or support family care. In 2019, Le Bihan *et al.* took up the proposals of both Leitner (2013) and Saraceno (2016) to distinguish between supported and unsupported familiarism in the context of weak service policies. They explain

In both cases, families are considered responsible for care and expected to provide it. Under unsupported familiarism, policies do not recognise families’ need for support. Under supported

familiarism, families are helped in taking up care. The fact that these support measures also represent an enforcement of familiarism is due to lack of services and not necessarily to the existence of explicit informal care supporting schemes (p. 581). Thus, policies may be familialisitic or de-familialistic. De-familialisation policies relieve families of care through the public provision of services or through state subsidy of private provision of services. Familialisation policies which aim to support families to care include work leave entitlements; cash benefits and tax incentives; and social security schemes (Leitner 2013).

3.3 Policy provisions to support care

There is no widely agreed definition of a carer policy or the components that should make up such a policy (Triantafillou *et al.* 2010). Building on a review of informal care in the long-term care system in Europe Triantafillou *et al.* (2010) proposed that a policy targeted at carers should

- ensure that carers have a decent quality of life through comprehensive services which address issues including work and care, work and family and free time for leisure and hobbies
- be neutral about the choice between providing care, providing a level of care and not providing care.
- Provide informal carers with income, social protection and practical supports sufficient to support them to provide care at a level and for a length of their choosing.

Despite the fact that effective support for family care has benefits to the caregiver, the care recipient and public finances a report by the OECD in 2011 identified that, across the OECD countries, support for family carers is often tokenistic (Colombo *et al.* 2011). The following section will provide an overview of the three key types of policy provision: financial and social security benefits, employment related provisions and formal services each of which may have a familialisation or de-familialisation impact.

3.3.1 Financial benefits

Cash transfers are a common European response to care need as a supplementary or alternative response to the provision of expensive residential services. Cousins *et al.* (2016) identified three main types of payments to support caring:

- income support payments to carers similar to the Irish carer's payments (mainly Anglophone countries)
- payments to care recipient which include costs of informal care (continental Europe)
- payments to carer as part of a care agreement (Nordic countries)

Earlier, Ungerson (2002) proposed a typography identifying five types of payment which, cross-nationally, may be made to caregivers or care-recipients to support care.

1. *Carer allowances*: paid through social security and tax systems. These, Ungerson (2002) described as 'fascinating' because it was paid without evidence of any 'caring'; rather they are paid on the basis of a relationship between the caregiver and care recipient and on medical need. She argued that these payments "are essentially citizenship-based rights to income for carers; they are funded on the basis that the risks of becoming a carer should be pooled, and that there is a collective responsibility to alleviate at least some of the income needs of carers". (Ungerson 2002, p. 353).
2. *'Proper' wages*: paid by the state or state agencies. 'Proper' wages are paid to carers in some Scandinavian countries at a rate equivalent to the wages the carer could earn outside the home. Carers are effectively employed by the State and accrue the benefits of paid employment.
3. *Routed wages*: direct payments to care users. These payments, Ungerson (2002) identified, are increasingly part of the care system in many European countries can be used by care users to purchase their own services including the direct employment of care assistants. Routed wages, Ungerson contends "constitute the sharp end of commodified care and marketised intimacy". (p. 354)
4. *Symbolic payments*: paid by the care users to kin, neighbours and friends. People in receipt of state benefits may transfer some of this payment to others within their household. These transfers are unregulated and informal and, Ungerson warns, can end with "difficulty and embarrassment – if the participants are unhappy with caring aspects of their extant relationship". (p. 355)
5. *Paid volunteering*: paid by voluntary organisations and local authorities to volunteers. Ungerson identifies that paid volunteering is probably unique to Britain

and involves the payment of symbolic wages to strangers to work in the private domain. (Ungerson 2002).

Colombo *et al.* (2011) reported that less than half of OECD countries provide a payment to informal caregivers; this figure includes Nordic countries wherein informal caregivers are effectively employed by municipalities. Some other countries provide a payment to care recipients which they may use to purchase care and around 20% of OECD countries do not have any specific care payment.

3.3.2 Employment related provisions

The issue of employment is an important one for caregivers. Working age carers are at a higher risk of poverty than non-caregivers (Colombo *et al.* 2011). Such caregivers may have to reduce working hours or withdraw completely from paid employment (Larkin & Milne 2014, Colombo *et al.* 2011); family caregivers miss more days at work, work fewer hours and take more unpaid time off work than non-caregivers (Lai 2012). Carers in paid employment may be at risk of poorer health and high stress levels (Eurofound 2015). International evidence indicates that carers in paid employment work reduced hours (Lilly *et al.* 2007, Van Houtven *et al.* 2013, Kotsadam 2011). Caring can have significant impact on career opportunities and progression (Bauer & Alfonso Sousa-Poza 2015) and many carers use their holiday entitlement for caring tasks including responding to crises or attending medical appointments with the care recipient (Hoff *et al.* 2014).

It is argued that individuals with poorer employment opportunities may self-select into the caregiving role (Alpass *et al.* 2017). Carmichael *et al.* (2010) in their analysis of 15 waves of the British Household Panel Survey concluded that individuals who are not in employment or who are badly paid employment are more likely to provide care (Carmichael *et al.* 2010). Therefore caregivers may enter the caregiving role already at an economic disadvantage. Carmichael & Ercolani's (2016) subsequent analysis of twenty waves of the combined British Household Panel Survey and follow-on Understanding Society (BHPS-US) prompted their conclusion that

... early decisions about employment and caregiving can shape lives for many years to come. The implications of such decisions can be far reaching for persistent caregivers who can end up poorer, unhappier and less healthy. However, the results also suggest that the burden of caregiving is potentially reduced when a balance can be struck between paid work and unpaid caregiving.

Further research is needed to establish how policies such as flexible work practices can be better designed to support caregivers to maintain such a balance. (Carmichael & Ercolani 2016, p. 10).

The authors also note the difficulties caregivers may experience when trying to return to the labour market.

Importantly however, employment outside the home may also have a protective effect of a carer's wellbeing. Working outside the home may ease financial pressures, enhance self-esteem and the social interaction which employment may provide essential support to sustain the carer's capacity to care (Hoff *et al.* 2014). Joseph & Joseph (2019) argue that employment is an important space for caregivers and a contributor to well-being. Reporting on data from the European Quality of Life Survey, the European Foundation for the Improvement of Living and Working Conditions. (2017) reported that carers who were not in paid employment were more likely to agree or strongly agree (26%) with the statement that "people look down on me" than carers in paid employment (16%) or non-carers (17%). Likewise, they were more likely to endorse the that they felt "left out of society" (26%) than were carers in employment (16%). The 2017 report concluded:

The difficulties of reconciling work with care are not generally associated with outcomes as negative as those for non-working carers: that is, poorer health, less income and more difficulty making ends meet, greater feelings of social exclusion and lower life satisfaction. (European Foundation for the Improvement of Living and Working Conditions 2017, p. 45)

A similar conclusion was drawn by Eurofound (2015) in the statement:

Maintaining a professional life is important for carers: work gives them access to vital social networks, gives them a role other than the caring role and helps them to retain a perspective on their career, learning and experiences so that they feel included in society. The research shows that carers who are in a position to combine work and care have a better quality of life and higher self-esteem, as well as being able to maintain a career, contribute towards their own pension and social protection entitlements and be productive in the economy. (p. 2)

The issue of combining work and care has been increasingly forced onto the agenda of policy makers by a combination of pressures including an aging population, increased female participation in the workforce, increases in the age of retirement and the costs of long-term care provision (Eurofound 2015). Hoffman & Rodrigues (2010) describe as a "key policy challenge" the European drive to expand the workforce by increased female and older person participa-

tion and the importance of also “trying to avoid a ‘drying out’ of the family care pool” (p. 4). Unpaid care labour is a barrier to female participation in the paid labour force and therefore a hinderance to nation’s economic expansion (International Confederation of Trade Unions 2019). On June 13th 2019 a new EU Directive on Work Life Balance came into effect. Most provisions of the Directive are focussed towards parents (mainly mothers) and aim to reduce gender inequality in the workplace and minimise the economic wastage of “inactive” women:

Caring responsibilities are reasons for inactivity for almost 31% of inactive women, while this is only the case for 4.5% of men. Taking action is not only a question of fairness, but it is also an economic imperative: we estimate the economic loss due to the gender employment gap amounts to around €370 billion per year. The new Directive will help working parents and carers by not obliging them to make a choice between their family lives and their professional careers. (EU Commission 2019, p. 1).

The provision for carers in the Directive is an entitlement to five working days of carers’ leave per year. Member states can decide whether to introduce a payment or allowance for workers who avail of the five days leave.

3.3.3 Neo-liberalism, employment and social policy

In response to the demographic and family structure changes many welfare states across Europe have reduced benefits and pensions and increased the conditionality attached to these (McCashin 2012). Isin and Turner (2007) argue that the Anglo-American neo-conservative “revolution” of the late 70s marked a retreat from politics committed to universalistic principles of social rights, an encompassing welfare state and full employment. These were replaced with strategies which deregulated financial and labour markets, reduced state intervention and promoted welfare for work (Isin & Turner 2007). The world of work has undergone a transformation from that upon which welfare states were built wherein “a Fordist economy guarantees decent pay and secure employment” (Lister 2001 p. 93). A shift away from a breadwinner model towards an adult worker model forms part of the wider trend towards active rather than passive welfare with an emphasis on responsibilities rather than rights (Orloff 2002). Raffass (2016) cites Plant’s (2003) assertion that Tony Blair’s New Labour was internationally influential in its emphasis on citizen’s obligations rather than entitlements and its reframing of citizenship as a status to be achieved

Social rights were to be enjoyed in the form of opportunities to work, which New Labour promised to extend and at the same time to ‘take tough measures to ensure that chances that

are given are taken up' (Blair cited in Morrison, 2004: 171). Thus, in the Third Way conception, social inclusion occurs and social citizenship is realised through the fulfilment of the obligation to participate in the labour market . (Raffass 2016, p. 424)

Linking social welfare provision to labour market activation reframes unemployment as job-seeking or economically inactive and as a matter of individual responsibility and personal failure (Raffass 2016). Dukelow & Considine (2017) note how the shift from income maintenance to employment activation has included people who were previously exempted from an expectation of participation in the labour market

blurring the boundaries between social protection traditionally associated with the unemployed and other social protection programmes, and between social insurance and social assistance. (p. 185)

Provision of, or payment to purchase, childcare was conceptualised as liberating women to enjoy equality in the labour market. However, Razavi (2007) notes the more recent reframing of childcare as an element of “productive welfare” and an investment in children and raises concerns about the implications of this policy framing on the care of “unproductive” elderly or disabled people (Razavi 2007, p. 31)

Lewis (2007) argues that the assumption that all adults will be financially independent and active in the labour market is paralleled in the restructuring of welfare states to an extent that it constitutes a “new social settlement” (p. 272). However, it is unclear how care can be accommodated into this new economic model (Lewis & Giullari 2005). Wrenn and Waller (2017) argue that neoliberalism crowds out an ethic of care with its emphasis on autonomy and personal responsibility and has, in effect erected a wall between the individual and the state. Care, as a response to dependency, is incompatible with the neoliberalist focus on autonomy and independence. Care then is without value and invisible and those who provide care are without economic, social and political power (Glenn 2000). Singleton & Fry (2015) argue that measures to encourage caregivers to combine paid employment with their care responsibilities may serve to reinforce the perspective that full citizenship is attainable only through being a member of the workforce and denigrates caregiving as a key attribute of citizenship. Thus, they suggest, carers may exist as just “partial citizens” (p. 561)

3.3.4 Formal services

Formal services are a social policy response to care need. However, the relationship between caregivers and service providers is a fuzzy one as its existence is entirely a consequence of the client-provider relationship which exists between the care provider and care recipient. Thus, service providers may view the needs of caregivers as outside their service remit. Julia Twigg (1990) suggested that caregivers exist in an ambiguous position within the social care system as both part of the taken-for-granted background to provision and as by-products of a system whose focus is elsewhere. In the 1990s Twigg (1990) and Twigg & Atkins (1994) proposed a framework conceptualising the relationship between formal services and caregivers

- a. carers as a resource: carers are perceived only in relation to their ability to provide care to the care recipient. Carers form 'the given', 'the taken-for-granted' or the 'out there' backdrop to a residualist formal service provision.
- b. carer as co-worker: carers are perceived as working alongside the formal care service and there is a concern to support the well-being and morale of the carer in order to sustain the caring relationship who are brought into the orbit of the formal system.
- c. carer as co-client: the needs and well-being of the carer are recognised and supported through, for example, respite services for the care recipient. However, Twigg & Atkins (1994) raise the query about the appropriateness of attaching the label of client to a carer: "To regard carers as co-clients, therefore, threatens, on the one side, an imperialistic take-over of what are normal processes of life; and on the other, a swamping of the social care system with 'ordinary misery'" (p. 60)
- d. superseded carer: the independence of the care recipient is maximised and the need for informal care is obviated (Twigg & Atkin 1994)

Hussein (2010) argues that the relationships between the provision of formal and informal care exists on a continuum between substitution and complementary (Hussein 2010). She notes the contrasting arguments that the introduction of formal care results in the replacement of informal care and that formal and informal care can co-exist and complement each other. In the current era of retrenchment in the financing and provision of health and social care services, Verbakel (2017) used data from Round 7 of the European Social Survey (n = 32,894 respondents; n = 19 countries) to test the assumption that reduction in the state provision of care results in a greater level of informal care or whether, in fact, greater state provided, formal care leads to an increase in lower

intensity, voluntary, informal care. The ‘crowding-in’ theorists argue that care is a joint responsibility of the state and family and that families are better able and more motivated to provide informal care in situations where formal care provision takes responsibility for the heavy caregiving tasks. Conversely, ‘crowding-out’ theorists posit that state provided formal care obviates the need for informal care and in times of retrenchment of provision, societal norms will change and families will become more inclined to provide informal care. Verbakel (2017) examined how the prevalence rates of informal caregiving and intensive caregiving (defined as providing at least 11 hours of care weekly) vary between European countries and the relationship of informal and intense caregiving to the countries formal long-term care provision and family care norms. Informal caregiving was most prevalent in countries with the most generous long-term care provisions but these countries had a low prevalence of intensive caregiving. Family care norms were found to be positively related to intensive caregiving but not to the likelihood of informal caregiving. The author concluded:

... less generosity of formal long-term care provisions was also related to fewer informal caregivers in total. Since especially intensive caregiving is burdensome, [25–27] low levels of formal long-term care provisions might bring risks. Overtaxed informal caregivers may provide lower-quality care, may dropout as caregivers, and may even become in need of care themselves. Therefore, a situation in which ‘many caregivers do a little each’ may be a more sustainable situation for the healthcare system. This study’s results suggested that such a situation is most common in countries with generous formal long-term care provisions. (Verbakel 2017, p. 10)

Da Roit, Hoogenboom and Weicht (2015), in the context of services for older people needing care in thirteen European countries, reported that the crucial factor in women’s participation in the labour market was the presence or absence of public services. Using European Union Statistics on Income and Living Conditions (EU-SILC) data from 2016, Privalko *et al.* (2019) identified significant deficits in the provision of formal care services in Europe concluding that most people needing formal care services were not getting the help they needed. They predicted that this will become increasingly acute due to an anticipated increase in demand of 66% by 2030. Using a typology that differed slightly from Esping-Andersen’s (1990; 1999), they categorised countries as either:

- **Social Democratic** with an emphasis on universalism and redistribution. Sweden, Finland and Denmark represented this type of welfare regime which is noted for its generous welfare and unemployment benefits

- **Corporatist** regimes within which less emphasis is placed on redistribution and entitlements are linked to employment history. Austria, Belgium and France represented this type of regime in the survey.
- Ireland and the United Kingdom represented **Liberal** regimes which were described as regimes which emphasise provision through the market with the state acting only where the market fails.
- The **Southern** regime was said to be characterised by undeveloped and selective labour market policies with most care provided by family. Italy, Spain and Greece were included in the survey as examples of this type of welfare regime

Levels of formal care provision to persons needing care due to illness, infirmity or old age was highest in countries with a Corporatist or Social Democratic welfare regime and lowest in Southern countries. Rates of access in Southern countries was 10- 12% and in Ireland it was 24% and, in all countries, older people were more likely to be in receipt of formal services than people with a disability or those in need through illness. Lone parents and working age families with a disability in Ireland were 2.6 times more likely to have an unmet need than those in Sweden.

3.4 Caregivers in Irish Social Policy

3.4.1 Introduction

Carer's needs are not widely addressed in Irish social policy however their lives may be circumscribed by a range of policies including, in the context of this thesis, disability policy and service provision. This section will start with an overview of the National Carers' Strategy followed by a consideration of the financial and employment provision which may be available to some caregivers. This will be followed by an overview of intellectual disability services in Ireland and an outline of recent, relevant disability-focussed policy measures. The issues raised will be considered in detail in a later section of this chapter.

3.4.2 The National Carers' Strategy

The National Carers' Strategy, published by the Department of Health in 2012, provides the strategic direction for future policies, services and supports provided by Government Departments and agencies for carers in Ireland.

A number of priority areas were identified within the Strategy which were formulated into four national goals and accompanying objectives:

Goal 1: Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person they are caring for

Objectives:

- 1.1 Strengthen awareness and recognition of the role and contribution of carers at national, regional and local level;
- 1.2 Include carers in care planning and decision making for those that they care for
- 1.3 Recognise the needs of carers by provision of income supports.

Goal 2: support carers to manage their physical, mental and emotional health and well-being

Objectives:

- 2.1 Promote the development of supports and services to protect the physical, mental and emotional health and well-being of carers
- 2.2 Support children and young people with caring responsibilities and protect them from adverse impacts of caring

Goal 3: support carers to care with confidence through the provision of adequate information, training, services and supports

Objectives:

- 3.1 Promote the availability of the user friendly and timely information and advice
- 3.2 Provide relevant and accessible carer training opportunities for carers
- 3.3 Promote the development of accessible living environments for all.

Goal 4: empower carers to participate as fully as possible in economic and social life.

Objectives:

- 4.1 Enable carers to have access to respite breaks
- 4.2 Enable carers to remain in touch with the labour market to the greatest extent possible.

The Strategy was published during a period of economic retrenchment and national austerity measures and the commitments made were designed to be cost-neutral (Oireachtas Library & Research Services 2019). This cross-departmental strategy was framed around 42 actions and responsibility for each of these actions was assigned to particular government department. The government publishes an annual progress report on the implementation of the strategy; and these progress reports are monitored by a monitoring group in Family Carers Ireland that assesses these progress reports to ascertain whether there had been any identifiable impact on the lives of family carers. The most recently published scorecard, published in 2018, awarded an ‘Objective Achieved’ score to only one action and this was the objective to: “Continue to convene an annual carers’ forum to provide carers with a voice at policy level” (1.1.4). Twenty-one actions received a “good progress score”, eight received an initial progress score, nine received a “no progress score” and three actions received a “regressive” score indicating that the situation has disimproved for family carers (Family Carers Ireland 2018b).

3.4.3 Carer’s Allowance

Cash transfers to carers in Ireland are in the form of Carer’s Allowance, Carer’s Benefit and the Carer’s Support Grant (previously the Respite Care Grant). The total expenditure on these schemes has grown by 78% between the years of 2008 and 2018 from €582 million to €1,038million (Boyle 2019). The rate at which the Carer’s Allowance and Carer’s Benefit is paid rose by €5 per week in the years 2017, 2018 and 2019 which accounts for some of the increase in total expenditure on the schemes but most of the increase is attributable to increased numbers of recipients (Boyle 2019). In 2018, 79,914 individuals were in receipt of the Carer’s Allowance which was an increase of 66% from the numbers in receipt in 2009 (Boyle 2019).

Doyle (2019) reported, in a spending review of carer support, that an average of 38% of those cared for by a person in receipt of Carer’s Allowance were receiving a pension, 33% were receiving a working-age illness or disability payment and 25% of the care

recipients were children benefitting from the Domiciliary Care Allowance which is payable in respect of qualifying children between the ages of 2 and 16 years. Considering the trend, Doyle (2019) notes

the growth in the working-age population in need of care puts considerable pressure on carer support expenditure as they have the potential to be in receipt of care for a longer period of time and into old age (p. 35).

Half the recipients of carers' support were aged between 40 and 59 years in 2018 and 20% were aged over 65 years (Boyle 2019). Boyle (2019) reports that the age profile of recipients changed only marginally between the years of 2008 and 2019. Across all the age groups, women represented over three-quarters of the recipients of Carer's Allowance in 2018. This percentage was as high as 87% for the age groups spanning 30 to 39 years and reduced to 63% in the over-80 years age group (Boyle 2019).

Since 2017, the GP of carers applying for the Carer's Allowance are required to provide an ICD-10 code in respect of the care recipient. Developed by the World Health Organization, the ICD-10 codes (International Classification of Diseases) are a classification of illnesses and disabilities. Doyle (2019) reports that since 2017, 37% of care recipients have a diagnosis relating to Mental and Behavioural Diseases. The top four diagnoses by prevalence between 2017 and 2019 were:

- Autism Spectrum Disorder: 11.8%
- Attention-deficit hyperactivity disorders: 3.8%
- Chronic obstructive pulmonary disease: 3.4%
- Dementia: 2.8%

The Carer's Support Grant is paid annually to carers in receipt of Carer's Allowance or Carer's Benefit and amounted to €1,700 in 2019; this grant accounted for 19.6% of expenditure of carers' support in Ireland in 2018. Carer's Benefit is a social insurance payment payable to insured people who leave employment to care for an individual or individuals in need of full-time care and attention. Carer's Benefit is payable for up to 104 weeks, either in one continuous block or in a series of shorter blocks totalling 104 weeks. Carer's Benefit accounted for just 3.7% of expenditure on carer's financial support in Ireland in 2018.

The Carer's Allowance is means-tested against both the caregiver and the caregiver's partner's income subject to a level of disregard, and it is paid at a rate to reflect income

support rather than a payment for caring (Murphy & Turner 2017). The current weekly payment is €219.

A single Carer's Allowance may be shared between two caregivers who provide care on an established part-time basis; carers can alternate weeks but must be providing care from Monday to Sunday and each carer is restricted in the hours they may work even during the week that they are not providing care. Family Carers Ireland (2018b) suggest that the fact that only 29 people were availing of the scheme in 2017 is evidence that it is an unattractive option for carers.

Carers in receipt of the Carer's Allowance are not permitted to engage in employment, self-employment, training or education for more than 18.5 hours per week. Carers who are receiving other social welfare benefits may qualify to receive a half-rate Carer's Allowance; the entitlement to receive other social welfare benefits alongside the Carer's Allowance is a unique aspect of the benefit. In 2018, 46.7% of recipients of Carer's Allowance were in receipt of the half-rate allowance; these recipients were also in receipt of other social welfare payments including the following:

- one-parent family payment: 19.5%
- contributory state pension: 15.6%
- disability allowance: 8.2%
- qualified adult dependants of disability allowance recipients: 8.8%
- non-contributory state pension: 7.2% (Doyle 2019)

A Home Care Tax Credit of €1600 is available to married couples of civil partners who are jointly assessed for tax and where one of the couple cares for a dependent person. The carer's own earned income must be less €7,200 for the full tax credit to be applied and will be subject to a reduced tax credit if the carer's income is between €7,200 and €10,200.

People who give up paid employment to care and who receive Carer's Allowance or Care's Benefit will be eligible to receive some social insurance credits. People who take unpaid statutory Carer's Leave will also be entitled to these credits if their employer completes as "application for carer's leave credit" form on their return to paid employment.

Carers in receipt of a Carer's Allowance or Carer's Benefit are eligible for a Medical Card entitling them to free GP consultations.

3.4.4 Employment and carers

Under the Carer's Leave Act 2001 employees are entitled to up to 104 weeks of unpaid leave to provide full-time care and attention to a dependent person. Employees must have worked for an employer for 12 months before the entitlement starts. Carers may take this leave in blocks of at least 13 weeks and up to 65 weeks and employers are obliged to keep their jobs open for them. Carer's must provide a medical assessment confirming that the care recipient is in need of full-time care and attention. Carers who take Carer's Leave may be entitled to Carer's Allowance or Carer's Benefit subject to the eligibility criteria.

3.4.5 Irish intellectual disability policy.

It is a unique feature of Ireland's social services that the majority of services to people with disability is provided by voluntary organisations. Historically, these organisations and religious orders were largely funded by the State which then distanced itself from the administration of the services. The social thinking of the Catholic Church was underpinned by the "fundamental", "unshaken" and "unchangeable" principle of subsidiarity which demands that care should be given by those closest to the individual who needed that care (Timonen & Doyle 2008). This principle of subsidiarity dovetailed neatly with the Irish State's reluctance to involve itself in personal and family issues and the primacy of the family is enshrined in the Irish Constitution.

This has resulted in a highly fragmented service (Linehan *et al.* 2014). Ireland's social services developed in a patchy manner with entitlements introduced piecemeal and in response to diverse pressures rather than as part of a coherent political outlook (Curry 1993, p. 6). Moran (2013) identifies the period of record economic growth starting in the 1990s and styled the "Celtic Tiger" period, as the time when Ireland made some progress towards the development of a welfare similar to that of other European countries (Moran 2013). The abrupt end of the boom heralded a new era of austerity leading to severe retrenchment of social policy spending with cuts across welfare, health, education and housing provision and the introduction of a range of levies and charges (Moran 2013).

Disability policy in Ireland, to the extent that it existed, was historically vested in the Department of Health and the agencies of the Department of Health and Doyle (2003) states that "the public policy approach in relation to people with disabilities was static until the 1980s" (p. 10). The Green Paper on Services for Disabled People and the National Disability Strategy published in 1984 marked the start of the policy orientation towards mainstreaming service provision for people with disabilities (Doyle 2003) and a number of key policies have been published in recent decades.

The National Disability Strategy (2004) had the stated aim of underpinning the participation of people with disabilities in Irish society and built on previous equality policy and legislation including the Employment Equality Act, 1998, the Equal Status Act, 2000, and the Equality Act, 2004. *Needs and Abilities: A Policy for the Intellectually Disabled* (1991) represents the only intellectual disability-specific policy document published in Ireland and it recommended a move away from large residential centres to support people with intellectual disability to “live to their full potential within the community” with residential provision in small clusters of 3 or 4 houses. Most people (69%) with intellectual disability in Ireland live at home with parents, siblings, relatives or foster parents including almost one-third (31.6%) of those aged 35 years or older (Hourigan, Fanagan & Kelly 2017). There also exists an unknown number of older people with intellectual disability living in the community who have never been in receipt of any services and their level of need and that of their family member cannot be quantified (Ryan *et al.* 2014).

In 2011 the Health Service Executive report “A Time to Move On from Congregated Settings” recommended that people with a disability living in congregated settings be moved into their own homes in a community setting within a timeframe of seven years. At the end of December 2016, the Health Service Executive (HSE) reported that 2,579 people were still living in congregated settings; approximately half of these people were aged between 40 and 60 years of age and 30.6% were aged over 60 years of age. Almost 57% of people with an intellectual disability living in congregated settings at the end of 2016 were classified as having a moderate or profound level of disability (HSE 2016).

Funding for disability services has traditionally been provided to services based on the number of people using that service and in the form of a block grant and is not calculated on the needs of each person attending the service or the cost of providing the service to individuals. This model of funding, it is argued, has resulted in funding becoming distant from the needs of individuals (Department of Health 2012, Power & Kenny 2011). In recent years a number of policy reviews and reports have recommended fundamental changes in the provision of services to people with disability (Mulkeen 2016, Keogh 2011, Department of Health 2012). The Expert Review Group on Disability (Department of Health 2012) proposed, *inter alia*, the introduction of personalised budgets with which people with disability will commission their own personalised support services to be delivered, as far as possible, through mainstream services. Likewise, the Value For Money Report called for a reorientation of funding to people rather than to places and further recommended that services should be commissioned through a process of competitive tendering rather than the current block grant system (Keogh 2011).

Personalised budgets and individualised services

In the Programme for Government 2011-2016 the new Government committed to moving a proportion of public spending to a personal budget model so that people with disabilities or their families have the flexibility to make choices that suit their needs best. (p. 53). To this end a Task Force comprising a strategy group and an Advisory and Consultative Group was established. A public consultation on the introduction of personalised budgets for people with a disability opened in October 2017 with a deadline to make recommendations to the Minister of State with Special Responsibility for Disability by the end of 2017.

The policy shift towards personalised or individualised budgets reflects a similar shift that has already occurred in other countries (Leahy 2018) and is consistent with the United Nations Convention on the Rights of Persons with Disabilities (2006). Hamilton *et al.* (2017) describes the personalisation agenda as an attempt to fundamentally change the relationship between the state and the individual and a “move away from a system with values rooted in institutional care” (p. 288) which provided individuals with a one-size-fits all service (Hamilton *et al.* 2017, Lloyd 2010). That personalised budgets requires the “adoption of personcentred practice, thinking and planning, promoting service user empowerment, choice and control” (p. 5) was one of the key messages from a review of the practice of personalised budgets for people with disabilities in a number of jurisdictions commissioned and published by the National Disability Authority in 2012. The review reported it was difficult to draw strong conclusions about the implementation, management and impact of personal budgets due to the limited evidence base, however the findings of qualitative studies indicated a generally positive response from service users (Hatton & Waters 2013, Glendinning *et al.* 2008). However, a number of authors are less convinced of the benefits and appropriateness of the funding model for all in need of support and suspicions have been raised about whether the implementation of personalised budgets is driven by a retrenchment agenda (Needham 2014, Harkes *et al.* 2014) and a view to cost saving benefits including those achieved by transferring the responsibility of recruiting, training, employing and managing staff onto the budget holder (Scourfield 2005, Ferguson 2007). People with intellectual disabilities may have difficulties with the financial complexities of managing their own budget (Abbott and Marriott 2013) and their reliance on others for support may, in fact, limit their autonomy and control. People with intellectual disability may also be particularly vulnerable to abuse and exploitation in situations where they hire and employ their own personal assistants (Sims & Gulyurtlu 2014, Manthorphe *et al.* 2011). Following a systematic review of the published research evidence on self-directed support and people with learning difficulties, Harkes, Brown & Horsburgh (2014), itemised

15 challenges or barriers to the success of such policies including: cost and complexity of implementation; difficulty integrating a variety of funding streams; lack of accessible information and confusing terminology; lack of support organisations; volume and complexity of required paperwork; risk of abuse; user/caregiver concerns about managing budgets and employees and a failure to account for the diversity of people including their readiness for or understanding of self-determination (Harkes *et al.* 2014).

Personalisation may also have significant implications for caregivers. Yet there is little research about these implications and a paucity of policy consideration of its impact on the choice or control in relation to family caregivers (Larkin & Mitchell 2015). The extant research does suggest that caregivers may have more time to spend on activities of their own choosing resulting in improved quality of life and a more positive attitude towards caregiving. However, caregivers also report stress as a result of the personalisation of the care recipients budget (Hatton & Waters 2013). Petriwskyj (2016) argues that individualisation assumes a high degree of agency and power on the part of service users and caregivers and the success of the policy of individualisation depends on this agency being enacted (Petriwskyj *et al.* 2016). Caregivers may play a pivotal role in facilitating care recipients to take up and manage their personal budget (Newbronner *et al.* 2011) and the tasks associated with employing personal assistants may fall to caregivers (Moran *et al.* 2012) resulting in increased time spent on administrative rather than hands-on caring tasks (Rosenthal *et al.* 2007). Personalised budgets may also change the interpersonal relationship between caregiver and care recipient in situations wherein the budget is used to remunerate the caregiver (Larkin & Mitchell 2015, Duncan-Turnbull 2010). In their evaluation of the implementation of Self-Directed Budgets in Scotland (SDS), Manthrope *et al.* (2011) identified a number of potential issues including:

- The use of family carers to compensate for a lack of services; this can institutionalise a system of low-paid care and make family members dependent on the service user for whom they are caring.
- Family carers may ask for more money than is realistic within the SDS budget.
- Paying family members through SDS might impact on benefits and make the family worse off overall.
- An emphasis on family recruitment might discriminate against users without strong social networks.
- Social expectations that family care is a duty can create suspicion or disapproval about paying for this kind of care or treating it as a commodity. Carers may feel that they are being harshly judged for accepting payment.

- Users might prefer the authority of an employee/employer relationship rather than the complications of paying family members and transgressing social norms. (Jill Manthorpe *et al.* 2011, s4.32)

A qualitative study in the USA with twenty-six family carers of adults with intellectual disability reported that twenty-four experienced barriers and challenges to person-centred supports for their adult child in self-directed budget programmes (Brown, Harry & Mahoney 2018). Among the challenges were those involved in recruiting, retaining and scheduling workers. Many of the carers considered that the budget allocated to their child was inadequate and prone to change and restrictions on the use of the budget resulted in parents supplementing the budget in order to meet needs of their child. The study authors concluded that it was not surprising that participation in a self-directed programme did not reduce caregiver strain given the level of work it generated for the family and the barriers which they faced in managing the programme.

An evaluation of four initiatives piloting individualised funding for people with intellectual or physical disability in Ireland was published in 2016. All four initiatives were challenged by access to funding either directly from the HSE or from the ‘bundled’ funding given to the service providers and indicated the necessity of a national resource allocation if the reality of individualised funding is to be realised. The evaluation identified many other barriers and frustrations to the implementation of an individualised funding model of supports including intrapersonal, organisational, and familial barriers. However, the evaluation reported “substantial” and “often unexpected” benefits to the pilot participants. The evaluation identifies the principles underpinning individualised funding “as based on self-determination, choice, control and, very often, person-centred planning” (Fleming 2016, p. 4). These principles are similar to the core values and supports envisaged in the New Directions model of day services policy published in 2012

Day services are a key component of services availed of by people with intellectual disability. McConkey *et al.* (2019) reported that up to 90% of adults with an intellectual disability (known to service providers) attended some form of day service and also noted that day service provide “an equal if not more important” function in providing breaks for family carers. The publication of the New Directions policy followed a review of day services in Ireland which identified that the current provision to the 25,000 individuals who attended day services experienced “segregated services, separate from local

communities and offering limited options, experiences and choices.” (HSE 2012, p. 3). New Directions, as envisioned by the HSE, would

...involve a radical shift from provider-led programmes to individualised, user-led supports. In the new approach, each adult will have access to flexible and outcome-driven supports to enable them to live a life of their choosing that meets their own wishes, aspirations and needs. The core purpose of the supports will be to enable people to participate as equal citizens in their community and to contribute to that community. (p. 20)

An evaluation of the first year of implementation of New Directions in a regional intellectual disability service was published by the NDA in 2017 (Lydon *et al.* 2017). The evaluation found that, overall, the implementation of New Directions was a positive experience for service users, parents and staff. Service users enjoyed the activities that they engaged in on a daily basis and which were activities chosen by themselves and parents identified valued the individualised and person-centredness of the new service. New Directions was intended to adopt “a flexible and seamless approach to the provision of supports that is not constrained by traditional nine am to five pm service boundaries” (HSE 2012, p. 22). The review of day services (HSE 2012) that informed New Directions recommended that services users should be supported to do ordinary things in ordinary places. For some parents consulted for the evaluation that included that their adult son or daughter could attend concerts, go bowling or go to the pub in the evenings alongside other people of their age and therefore in an age appropriate way. However, limited funding required that support hours used outside “nine to five” resulted in reduced hours between “nine to five”. This impacted on caregivers’ ability to work outside the home, attend to other duties or enjoy leisure activities.

The Profile of Intellectual Disability in Ireland

The National Intellectual Disability Database (NIDD) was established in 1995 and provides a longitudinal demographic profile of people with intellectual disability, the specialised services which they receive and those which they require currently or within five years. Information recorded in the database is provided by service providers therefore it does not capture data about the circumstances or needs of those not in receipt of such services. It is reasonable to assume that individuals with intellectual disability who are not known to services have a milder level of intellectual disability and it is estimated that only one-third of people with mild intellectual disability are on the NIDD. As these

individuals and their parents age, needs and capacities change and these may represent a very vulnerable, though unquantified, cohort in need of support but inexperienced in accessing such.

At the end of December 2016, 28,275 people were registered on the Irish National Intellectual Disability Database representing a prevalence rate of 6.16 per 1,000 population. The prevalence rate for mild intellectual disability was 2 per 1,000 and that for moderate, severe or profound disability was 3.59 per 1,000. There was a greater proportion of males (58.8%) to females (41.2%) registered on the database, a ratio of 1.43 to 1. A breakdown by gender and age group is presented in Figure 2 below:

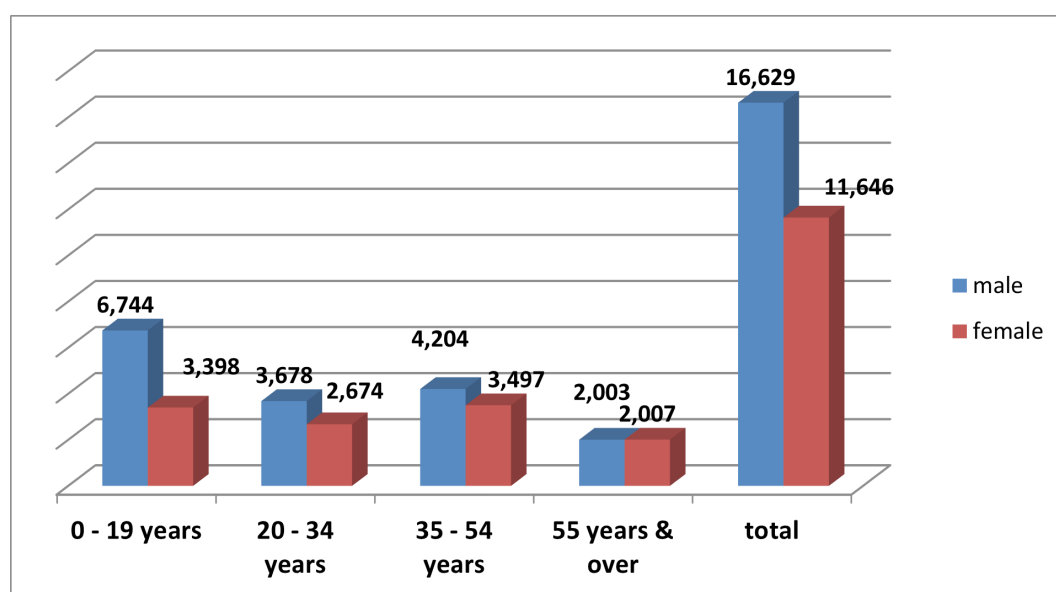


Figure 2: The prevalence rate for intellectual disability by gender and age group

Most people (68.7%) registered on the database lived at home with parents, siblings, relatives or foster parents; including almost one third of people (30.9%) aged 35 years or over with moderate, severe or profound intellectual disability (Hourigan *et al.* 2017). The vast majority (98.5%) of people on the database were in receipt of services, 0.8% were identified as in need of services but not availing of such.

3.4.6 A Critical Analysis of caregiving for older people with intellectual disability in Irish Social Policy

3.4.6.1 Introduction

This section will use What's The Problem Represented To Be? (WPR) approach to examine Irish social policy as it relates to carers of older people with intellectual disability through a critical lens. WPR is an interpretative, Foucault-influenced post-structural analytical approach developed by Carol Bacchi. Rejecting the notion that government practices and policies address problems that independently exist, Bacchi (2016) argues that all policies contain an implicit representation of the "problem"; the problem representation determines what gets done and what is ignored or downplayed. Bacchi (2009) argued that every postulated 'solution' to a problem intrinsically incorporates a particular representation of that problem and that this representation and its implications should be interrogated.

Problems, Bacchi proposes are constructed, that is they are "problematized", within policies and in this way policies shape "what it is possible for people to become" (Bacchi 2016, p. 50). Drawing on Foucault, WPR looks at the conceptual logic within problem problematisations, at pre-conceptions and assumptions and at the "unexamined ways of thinking." The purpose of a Foucauldian analysis is not to expose vested interests or to undermine but to examine the assumptions upon which problems are based

A critique does not consist in saying that things aren't good the way they are. It consists in seeing on just what type of assumptions, of familiar notions, of established and unexamined ways of thinking the accepted practices are based... showing that things are not as obvious as people believe, making it so that what is taken for granted is no longer taken for granted. To do criticism is to make harder those acts which are now too easy. (Foucault 2003, p. 172)

WPR does not focus on problem solving, rather its concern is with problem questioning (Bacchi 2009). Bacchi rejects the notion that the formulations of problems which social policy seeks to address are wholly objective, arguing that the representations of a problem is contingent on the knowledge and understandings that underlie the representation. Thus problematisations "make a problem exist as a particular type of a problem" (Bacchi 2009, p. 263). Although WPR can be used to recommend changes to policy or practice (Pringle 2019), its concern is not with the effectiveness of a policy and does not examine a policy's ability to solve a problem but examines the way policy formulates the problem and the assumptions and accepted norms that underpin it. However, it is

also the case that because problems are created, they can be re-created. Johnson (1981) describes this form of analysis as one

... that focuses on the grounds of the system's possibility. The critique reads backwards from what seems natural, obvious, self-evident, or universal to show that these things have their history, their reasons for being the way they are, their effects on what follows from them, and that the starting point is not a (natural) given but a (cultural) construct, usually blind to itself (p. 15)

Bacchi's WPR has been used extensively in policy areas including health policy, welfare policy, education policy and drug and alcohol policy. In the Irish context the application of WPR includes Van Aswegen's (2019) examination of the Irish Comprehensive Employment Strategy for People with Disabilities (2015 – 2014) and Fitzgerald and McGarry's (2015) problematisation of prostitution in Irish Law and Policy.

Other approaches to social policy analysis could have been utilised for this analysis including those that focussed on policy development or implementation or effectiveness. However, the WPR approach to policy analysis is particularly suited as the way in which carers are defined and understood in Irish social policy determines the parameters of the social policy response to the "problem" of carers. WPR supports an examination of how the problematisation of carers frames the policy response to the problem. Bacchi (2009) suggests that different groups of people are impacted differently by problem representations; this analysis will focus specifically on carers of older people with intellectual disability.

WPR's critical analysis approach is framed around the following 6 questions.

1. What's the 'problem' represented to be in a specific policy?

This covers the conceptual underpinnings of the problematisation

2. What presuppositions or assumptions underpin this representation of the 'problem'?

This question considers the assumptions and presuppositions which underlie a problem representation and the different forms of knowledge on which these assumptions are based. The underlying assumptions of a problem determine the boundaries about what can and cannot be said about the problem and highlight the rationales that operate the representation.

3. How has this representation of the ‘problem’ come about?

This question looks to understand the development of a problem representation providing an account of the current representation.

4. What is left unproblematic in this problem representation? Where are the silences? Can the ‘problem’ be thought about differently?

This question looks to what is left unproblematic about the representation. It asks: where are the silences? And how could the problem be thought about differently? This interrogation opens the possibility to “think otherwise”.

5. What effects (discursive effects, subjectification effects, lived effects) are produced by this representation of the ‘problem’?

Question 5 turns attention to the effects and implications of the problematisation. Bacchi (2009) advises that there may be three interconnected kinds of effects: discursive effects, subjectification effects and lived effects. Discursive effects look at the way in which the representation sets the terms of reference for the problem and limits what can be thought and said about the problem. Subjectification effects are those that shape the “subjects” of the representation with policies defining what it is possible for people to become. Practices are seen as enacting people. The lived effects are the consequences of the discursive and subjectification effects on the lives of the subjects of the policy.

6. How/where has this representation of the ‘problem’ been produced, disseminated and defended?

Policy documents are one of the “technologies” of government through which the representation of the problem is disseminated. The representation within policies creates the reality which the policy proceeds to address; policy documents, according to Bacchi (2009), serve to make representations “stick”. The problematisation of a problem is also key to the employment of other technologies of government including models of funding and the role of experts. Question 6 also includes a reflection on how the problematisation could be questioned, disrupted and replaced. This part of the framework questions that which is taken for granted in the problematisation and explores alternatives.

WPR is a flexible framework which can be adapted to individual studies and, as the questions are interrelated, Bacchi (2009) also suggests that they can be integrated in practice to avoid repetition and that all questions do not necessarily require the same level of attention in each study

The point of the analysis determines which questions are foregrounded. ... As a consequence, every question need not always be addressed in every analysis, although it is useful to keep the full set of questions in mind. (Bacchi 2009, p. 101)

The intention of the following analysis is to explore how Irish social policy addresses the needs of caregivers of older people with an intellectual disability. These caregivers are a unique subset of Irish caregivers and Bacchi's framework will be used, flexibly, to explore the extent to which the problematising of carers in Irish social policy resonates with and supports their lives as reported in the extant literature. Thus, the analysis is not presented by a working through of WPR's questions 1 – 6, rather the questions are integrated and worked through in accordance with the key objectives and themes of the policy. The National Carers' Strategy is the technology of the Irish government through which the reality of family caregiving in Ireland is created and this, therefore, will be the main reference point for the analysis.

3.4.6.2 Analysis

The representation of the "problem" of informal care in Ireland is formalised and disseminated in the National Carer's Strategy. Launched in 2012, the National Carers' Strategy represents the State's acknowledgement of the contribution made by carers to the well-being of others. The Strategy states that carers are vital to the achievement of a "key" Government policy objective "to support older people, children and adults with an illness or disability to live in dignity and independence in their own homes and communities for as long as possible". (p. 4)

The Strategy is described as a response to the "challenges and demands" experienced by some carers including emotional or psychological difficulties, physical ill health and adjustments to family and/or work life. The Strategy notes that carers may have to forgo opportunities that others take for granted and that lack of recognition may result in some carers feeling disconnected from society. However, austerity was said to preclude

any commitment within the Strategy to extra services or supports for carers but the Strategy would serve to place

carers firmly on the national agenda and [set] the strategic direction for future policies, services and supports provided by Departments and agencies for Irish carers. (p. 5)

The Strategy draws a distinction between carers who engage in “helping” others and those “heavily involved in caring” (p. 8) and asserted that the Strategy’s focus was on the latter group although some aspects of the Strategy may address some carers who do not fit the primary definition:

A carer is someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty. (p. 8)

The underpinning assumption of the problematisation of caregiving is that care is rightly provided by family and friends. While acknowledging the important, often unrecognised, contribution which carers make to the economy of the country, the Strategy nevertheless positions informal care as normative

Every day in this country, tens of thousands of family members, friends, partners, parents, children or neighbours, provide care for someone, who through a variety of circumstances, needs it. (p. 4)

This assumption is consistent with Ireland as a Liberal welfare state with historic allegiance to the principles of subsidiarity. Support for carers is not conceptualised as rights-based but is restricted to those deemed to give a significant level care and who met the rigid entitlement criteria.

3.4.6.3 Goal 1 of the National Carers Strategy

Goal 1 of the National Carers’ Strategy is to “Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for” (p. 10). The first objective of this goal refers to strengthening awareness and recognition of the role and contribution of carers at national, regional and local level. This goal is of limited relevance to this study and will not be addressed further in this analysis. Family Carer’s Ireland (2018b) note progress towards this goal through indicators including the embedding of the voice of carers within the National Patient Experience

Survey Programme, the establishment of Mental Health Area Leads in each Community Healthcare Organisations (CHOs); the continued funding of The Irish Longitudinal Study on Ageing (TILDA) and the efforts of Workplace Relations Commission to support carers in the workforce.

The second objective is to “include carers in care planning and decision-making for those that they care for” (p. 12). This objective is inconsistent with, and silent on, the direction of disability policy over recent decades which is promulgated on maximising choice and autonomy for those previously deemed in need of care and protection. Disability activists rejected the concept of care as infantilising and disempowering and the notion of care is increasingly replaced by those of support and assistance (Hughes *et al.* 2005). In keeping with international trends, the National Disability Inclusion Strategy 2017-2021 (Department of Justice 2017) commits to “strengthen the focus on culture change from the ‘care’ to the ‘support’ model” (p. 33). Indeed, a review by Care Alliance Ireland (2017) of the language used in the National Disability Strategy Implementation Plan (National Disability Strategy Implementation Group 2013) indicates an airbrushing of family carers from Irish disability policy. The review found that the word “supporter” was used 74 times in the policy, the word “staff” was used five times whereas there was zero use of the words “family”, “carer”, “advocate” or “caregiver”. Care Alliance (2017) notes the incongruity of excluding family carers from disability policy conversations when almost 70% of people with intellectual disability live at home with family members.

The National Carer’s Strategy pre-dates the Assisted Decision-Making (Capacity) Bill 2013 which was signed into law by President Michael D Higgins in December 2015, replacing the Lunacy Regulation Act of 1871. However, enactment of the legislation was a requirement under Article 12 of Convention of the Rights of People with Disabilities and was in the process of enactment for very many years prior to 2015. It places a legal requirement to comprehensively enable a person to make a decision through the provision of a range of supports and information appropriate to their condition. Although it lacked a legal basis, family members historically made decisions with and/or on behalf of their family member with intellectual basis and such decisions ranged from day-to-day choices to major life decisions on issues involving health, finances and living arrangements (Curryer 2020). Under the Assisted Decision-Making (Capacity) Bill family members may take on the role of decision-making assistant or be appointed to the more formal position of decision-making representative, therefore the objective of the Carer’s Strategy for the inclusion of carers in decision-making must be done within the requirements of this legislation.

The problematising of care in Irish social policy is also silent as to the other tensions which exist between a family-focused approach and a rights-based approach (Bigby & Ozanne 2004). Recent policy developments in Ireland such as personalised budgets and the New Directions model of day services have been shown to have the potential to impact negatively on caregivers. Family members in Ireland have expressed concern that the drive to promote autonomy may restrict the level of support which they have heretofore giving their family member with intellectual disability (McCarron *et al.* 2018). In a study of mothers supporting their adult son or daughter with intellectual disability's self-determination, Curryer (2020) noted that

The mothers' experience was dominated by a sense of tension, and an attempt to balance values and rights with concerns and consequences. (p. 383).

Thus, a rights-based framework supporting choice and self-determination may sit uneasily with family-focussed approaches which acknowledge the important role that families often play in the lives of adults with an intellectual disability.

3.4.6.4 Objective 1.1 of the National Carer's Strategy

Objective 1.1 also refers to the critical importance of identifying carers as early as possible in order to maximise their longevity as informal caregivers.

if they are to be supported to maintain their caring role, particularly as some do not readily identify themselves as being a carer" (p. 12)

The point of diagnosis or the onset of a condition are frequently the moments in time during which caregivers are identified and the provision of information and linkages with support services to begin. However caregivers of older adults with intellectual disability are, according to Henwood *et al.* (2017)

less likely to identify themselves as carers because of the context of their relationship which is characterised by long-term reciprocity, mutuality and interdependence (p. 88-89)

Caregivers of older people with intellectual disability have had a lifetime of caring and are embedded in a familial relationship wherein their primary identity may not be that of "carer". Thus, the National Carer's Strategy is silent to the centrality of love

labouring to the personal identities of caregivers and the extent to which love labouring “leaves such carers vulnerable to the lack of respect and material supports” (Lynch, Baker and Lyons 2009, p. 11).

3.4.6.5 Objective 1.3 of the National Carer’s Strategy

Objective 1.3 of the National Carer’s Strategy pledges to recognise the needs of carers by provision of income supports. The Carers’ Allowance is a means-tested social assistance payment and is the main direct income support of Irish caregivers accounting for 76.6% of expenditure on carer financial support in 2018 (Boyle 2019). A key eligibility criteria for Carer’s Allowance “is to be living with, or in a position to provide full-time care and attention to a person in need of care” (Citizensinformation.ie) thus identifying the role of carer as a full-time one. When it was introduced, the allowance represented a significant development from the State’s historic position wherein it did not recognise that it had a responsibility for family care. However, Family Carers Ireland, a national support and advocacy organisation, report that 80% of Irish caregivers are not in receipt of the allowance due to eligibility restrictions (Family Carers Ireland 2020). The Carer’s Allowance is means-tested against both the caregiver and the caregiver’s partner’s income subject to a level of disregard. The current weekly payment is €219 whereas the Central Statistics Office reports the average weekly income in the third quarter of 2019, for an average 32 hour working week, as €768.14.

Irish households that include an adult, or adults, with a disability are amongst those with the highest poverty levels (Watson & Nolan 2011, Russell *et al.* 2010, Emerson 2007). Families of people with intellectual disability may be financially impacted by the restrictions on the caregiver’s ability to work and/or by costs associated with disability (Heller, Gibbons & Fisher 2015). Emerson (2007) reports that the health and social inequalities experienced by people with intellectual disability and their families is associated, at least in part, with their increased risk of living in poverty. The lived experience of carers may be lives of financial struggle and the subjectification of carers as welfare recipients. Carer’s Allowance, Carer’s Benefits and other social welfare entitlements are not rights-based and as such the payments may have a stigmatising or demeaning effect of the recipients of the payment and the lack of a legal underpinning of any support leaves carers vulnerable in times of economic retrenchment (Dukelow & Considine 2017, Care Alliance 2016, Singleton & Fry 2015). The low level at which these cash transfers are made to caregivers tend not to attract men to caregiving thus reinforcing the gender imbalance in family caregiving (Daly 2002).

Carers in receipt of Carer's Allowance may also be penalised with respect to the allocation of other resources (Oireachtas Library & Research Services 2019). In their submission to the Department of Health in 2019, Family Carers Ireland (2019) assert that home care support hours are commonly rationed when a family member receives Carer's Allowance. In its reflection on this, the Oireachtas Library & Research Services Report (2019) stated firmly

In addition to undermining an understanding that Carer's Allowance is an income support rather than a payment for services, this practice seems to indicate a view in certain segments of the health service of carer's needs as marginal (p. 32)

Advocates of Basic Income propose a rights-based alternative to support all citizens including care-givers in the form of basic income. Unconditional or universal basic income provides an income to all citizens; the income is set at a level that will meet all basic needs and enable the recipient to live a life outside poverty. In a presentation to the Carers Association in (nd) Baker & Ryan argued that basic income would be evidence of a caring society which shared responsibility for meeting basic needs as a fundamental right of citizens. Basic income would provide citizens with financial security, a greater quality of life, eliminate poverty traps, support full and part-time education, and provide certainty and security for people working on part-time or short-term contracts, self-employed people and start-up entrepreneurs and reduce bureaucracy and costs. Basic income, as they envisage it, would replace all existing social welfare payments and people with special needs would receive a top-up to the standard payment. All earned income would be taxed, subject to some exceptions. While acknowledging that the Carer's Allowance system may work well for those for whom it works well, they suggest that it is failing many family carers whose valuable role in society goes unacknowledged. Basic income would obviate the difficulties some carers experience when applying for the Carer's Allowance particularly if taking on the role of carer is precipitated by a sudden crisis; in such circumstances the new carer can be without income for some time. New carers will already be in receipt of basic income and therefore there will be no stressful transition period. Likewise, there will be no potentially stressful transition when caring ends. Currently carers are entitled to receive the Carer's Allowance for up to ten weeks when the care recipient dies or moves into residential care. During this period, the former carer has to either find employment or apply for unemployment payments. Carers would no longer have to prove that the care recipient was sufficiently in need of care to meet the eligibility criteria of the Carer's Allowance. They would have more security to reduce

their paid working hours or take breaks from employment. Carers will have greater choice and greater flexibility to accommodate paid employment and care responsibilities, including their capacity to share care responsibilities with others.

3.4.6.6 Goal 2 of the National Carers Strategy

3.4.6.6.1: Goal 2 of the National Carers' Strategy is to "support carers to manage their physical, mental and emotional health and wellbeing" (p. 11). Ireland does not have a system to identify caregivers except via the care recipient. Caregivers are not entitled to an assessment of their own needs, as distinct from those to whom they give care (Courtin *et al.* 2014). Carers, particularly as they age, may have support needs notwithstanding that their experience of caregiving is a positive one (Gant & Bates 2019). Without an assessment of need, it is difficult to appropriately meet needs (Henwood *et al.* 2017), nonetheless it is also the case that legislative or policy provision for an assessment of carer need does not necessarily translate into either widespread uptake or availability. Carer assessments in the UK were provided for in the Care Act 2014 but in a survey by Carer's Trust (2016) 65% of respondents had not received an assessment and 34% of those that had, had not found the assessment helpful. Henwood *et al.*'s (2017) scoping review identified that take up of assessments have been both low and variable between local authority councils. They reported evidence of ambivalence and ambiguity on the part of professionals tasked to undertake the carer assessment and quote Seddon & Robinson's (2015) suggestion that such ambivalence stems

largely from the perceived lack of new types of support for carers following the completion of a separate carer assessment. The continued reliance on traditional social care provision, including home care and respite care, means that practitioners remain cautious about raising carer expectations and identifying support needs, which traditional services do not address. In particular, they are hesitant to discuss the emotional and relational aspects of caring, and explore carers' associated support needs." (p. 17) (Henwood 2017, p. 74)

Interventions designed and evaluated to support informal caregivers of older adults rarely include older adults with intellectual disabilities (Heller *et al.* 2015). Resources are usually standardised and therefore may be mismatched to the particular, self-identified needs of individual caregivers (Milliken *et al.* 2019). Caregiving is inherently unpredictable and standardised responses may be of little value to caregivers

The unpredictability of many caregiving challenges led to unique needs in terms of the content and timing of interventions, which was exemplified in the “supportive support” category. In other words, supportive support involved meeting the caregiver where they were at any given moment, and just because something is available as a support does not mean that it is supportive. (Milliken *et al.* 2019, p. 166).

3.4.6.6.2: The National Carer’s Strategy identified that “The positive role of telehealth-care (telehealth, telecare and telemedicine) in supporting carers is increasingly being recognised” (p. 14). The NDA defines telecare as social services delivered from a distance using technology and report that the emphasis of telecare tends to be on “risk management/mitigation and user safety, remote monitoring, and supporting independent living” (NDA 2018, p. 13). The National Disability Authority conducted a study, published in 2018, to explore how international best practice in telehealth/telecare could contribute to a blueprint for effective implementation and monitoring of telehealth and telecare in Ireland (NDA 2018). The study reported that telecare may have a role in providing reassurance to carers about the safety of the cared-for person when they are not in their presence but also reported that there may be more downsides than benefits where frequent responding to alerts is required. A systematic review of the informal caregiver effects of telecare provided for a person with social care needs (Davies *et al.* 2013) included seven evaluations. No evaluation focussed on carers of older people with intellectual disability, one specifically excluded participants where the care recipient had a cognitive disability. The review tentatively identified a positive effect on carer stress and strain but none on burden or quality of life. It further found conflicting evidence on whether telecare had an effect on the amount of time carers spent caring or on the relationships between caregivers, care recipients and other family members. Heller *et al.* (2015) identified the potential of technology to reach caregivers of adults with intellectual disability living in remote geographic areas and in 2019 Caton *et al.* (2019) reviewed the eight published articles on the use of the internet by carers of people with intellectual disabilities and/or autism noting that five of the articles focussed specifically on carers of people with Autistic Spectrum Disorder (ASD). The dominant themes identified in the review was the internet provided a convenient and valuable source of information and support for family carers. Family caregivers reported finding solidarity online and having an enhanced sense of agency and empowerment from both giving and receiving support and information online. However, Caton *et al.* (2019) noted that, overall, evidence about the internet use of caregivers of adults with an intellectual disability was very limited.

3.4.6.6.3: The National Carers' Strategy noted that it was important

“to have regard to the range of supports and services that are already available for carers so that proposals emerging from this Strategy build on, rather than duplicate, existing arrangements. Some support services are specifically targeted at carers but carers can also benefit from the supports aimed at those for whom they are caring”. (p. 4)

This provision in the Strategy gives rise to an important silence about the extent and focus of existing supports. Twigg & Atkin (1994) proposed that formal support for carers could be divided into “direct” support, (typically small-scale support and targeted directly at carers) and in-direct supports (typically targeted at care recipients). Ireland has a high prevalence of informal caregiving and a very high prevalence of intensive informal caregiving (Verbakel 2017). Successive Irish Government policies have emphasised a shift to community based services but have been accused of failing to adequately fund community based services. Timonen & Doyle (2008) note the conflict between the government’s espoused policies and the inadequate funding provided to support home-based care. Reporting on data from the CSO’s Survey on Income and Living Conditions, Grotti, Maître & Watson (2019) found that the rate of unmet need for formal home care support among people with an illness or disability was 83%. In a report on long-term care for older people in Ireland, Browne (2016) identified that family caregivers, of older people and people with disabilities are undermined by a community care service that is characterised by fragmentation, inadequate needs assessment and arbitrary allocation of resources, geographical inconsistency and low levels of provision. Family carers of people with intellectual disability may be strongly reliant on formal supports, particularly day and respite services, to sustain their ability to care (Brennan *et al.* 2016). Fergusson & O’Brien (2005) argue that services providers must move from giving a service to being of service to people with intellectual disabilities and their families (Fergusson & O’Brien 2005). However, in accordance with the way in which they are funded, the priority of intellectual service providers in Ireland, mainly voluntary or not-for profit organisations, has been to provide care for the person with intellectual disability rather than providing support for their carers (Barron *et al.* 2006). Within Twigg & Atkin’s typography (1994) carers position vis a vis the intellectual disability services is that of “resource”. Positioning caregivers as co-clients of the intellectual disability services may swamp the services but would also contradict the Strategy’s characterisation of them as “key partners in the caring process” (p. 9). A review of forty-six studies about the relationships between caregivers of people with intellectual disabilities and intellectual

disability service providers identified six key themes expertise and knowledge; trust and respect; information provision; communication; involvement of clients and families and co-ordination of services (James 2014). The findings also highlighted the extent to which the quality of the relationship between family caregivers and professionals was impacted by the caregivers' perception of the extent to which families felt that the professionals recognised and valued their knowledge and expertise. Caregivers can feel judged and disempowered by professionals but may be reluctant to speak out in case their criticism impacts negatively on the services received.

The proposal that intellectual disability services should provide a range of supports and services to caregivers is silent to the issues that services can also be a major source of stress to parents (Unwin & Debs 2011) and a generator of increased workload. A meta-synthesis of qualitative research on caring for a family member with intellectual disability and challenging behaviour focussed in particular on the families' experiences of support services (Griffith & Hastings 2014). The meta-analysis included seventeen studies and the authors noted a 'striking' consistency within the studies that support services "often caused additional problems for families, rather than alleviating the burden of care" (p. 416). The studies documented a 'them vs us' perception with little evidence of collaboration or partnership between caregivers and service providers and a perception by caregivers that their views were marginalised. Studies reported that caregivers battled for services and were often met with a wall of bureaucracy. Some caregivers mistrusted the expertise and ability of service providers to deal with challenging behaviour resulting in the withdrawal of the person with intellectual disability from the service.

Chadwick *et al.* (2013) conducted ten focus groups with seventy parents and siblings of people with intellectual disability during which much of the discussion concerned services and family members described a continuous fight to advocate for supports and entitlements. Families acknowledged instances of high quality and appropriate services:

For families, 'appropriate' meant services where staff were committed and inspiring, and that were provided in a timely, well co-ordinated, flexible manner and which were responsive to the family's changing needs. (p. 124)

However, families largely felt unsupported by services and identified, in particular, a lack of respite, home based and therapeutic services (Chadwick *et al.* 2013). Some caregivers were reluctant to complain or advocate for more or better services for fear of repercussions from the service providers. Family members also related experiences of poor communication on the part of the service providers leading to a lack of trust on

the part of caregivers and some resentment because they believed that they were made to feel ungrateful and unappreciative of the service which they were given. These findings by Chadwick *et al.* (2013) reflect those of other Irish studies who report Irish families struggling with unmet needs and unresponsive service (McConkey 2005, Kenny & McGilloway 2007, Power 2009). Power (2009) reported a perceived mismatch between the service that is given to Irish people with intellectual disability and their families and the actual requirements of the family and a belief on the part of families that “the system works for the system” (Power 2009). These findings indicate that the objectives of the National Carers’ Strategy with regard to service-provided support for caregivers of adults with intellectual disability may be difficult to achieve.

3.4.6.7 Goal 3 of the National Carers Strategy

Whereas the focus of Goal 2 is to support the health and wellbeing of carers, Goal 3 focuses on their ability to provide care with confidence: “Support carers to care with confidence through the provision of adequate information, training, services and supports”. (p. 11). The Strategy further states that

Learning new skills or improving existing knowledge can make life as a carer much easier. Knowledge and training empower carers and benefits for carers include increased confidence, improved health and well-being and fewer injuries relating to their caring roles” (p. 16)

This goal may have limited relevance to family caregivers of older people with intellectual disability.

Following a systematic review, Larkin *et al.* (2019) identified that although a substantial amount of research has sought to identify what constitutes effective support for caregivers much of the extant research is methodologically weak producing results that are “equivocal, contradictory and often inconclusive” (p. 63). Most research focus and the strongest evidence about the effectiveness of caregiver interventions relate to specific groups of caregivers such as those caring for people with dementia, cancer or stroke survivors (Aksoydan *et al.* 2019, Larkin *et al.* 2019). Larkin *et al.* (2019) noted that the types of interventions which have been found to be effective include

caregiver support groups; telephone counselling; educational programmes; art therapy; meditation-based interventions; computer-mediated interventions; cognitive reframing; couple-based interventions; and psychosocial interventions. (p. 63)

Older caregivers, in general, are generally neglected in research despite that they may provide an intensive level of care according to Greenwood *et al.* (2019). Although family carers of older people with intellectual disability may increasingly require support interventions (Heller *et al.* 2007) few such interventions exist (Heller *et al.* 2015). Heller *et al.* (2015) note that the increasing intersections between ageing and disability are not being reflected in research or policy literature

.. it is important to bridge the IDD and gerontology literature because many families are caring for both adults who are ageing with lifelong disabilities, as well as adults ageing into disability. Thus these two fields have much to learn from each other. The IDD and ageing caregiver literature have created a dichotomy in caregiving and both fields need to need to break down the silos to partner and collaborate. (p. 338)

In 2000 the World Health Organization characterised older people with intellectual disability and their ageing family carers as two joint vulnerable groups as they age together. The needs of older carers may often go unrecognised and therefore unaddressed particular when the roles of the designated caregiver and care recipient become blurred (Manthorpe *et al.* 2015). Older family caregivers are also less likely to avail of interventions and to use statutory services than younger caregivers as a consequence of previous negative experiences with services and resultant low expectations of interactions with services (Walker *et al.* 2020, Ryan 2014, Bigby & Ozanne 2004). Little evidence is available to indicate that progress in being made towards the implementation of the recommendations of the International Association for the Scientific Study of Intellectual Disabilities to improve services for ageing carers by combining expertise from different sectors (Ryan 2014).

3.4.6.8 Goal 4 of the National Carers' Strategy

Goal 4 of the National Carers' Strategy is to “empower carers to participate as fully as possible in economic and social life” in recognition of the reality that many “be unable to do the day to day things that most people take for granted – to relax, to socialise or to work” (p. 18). The Strategy identifies respite as a key facilitator of caregivers' participation in economic and social life and Objective 4.1 states that carers:

Need access to a range of flexible (in relation to timing and type) and responsive respite care services, including in-home, residential and emergency respite. The quality of the respite services should also be of a standard that does not deter the carer from using them – carers need to be

confident that the person that they are caring for is well cared for in their absence. (National Carers' Strategy 2012, p. 18)

Eurocarers (nd) report that respite is “often perceived as the most important and common form of support to alleviate caregiving burden and stress” (npn). However, the provision of respite services in Ireland is limited and patchy (Hourigan *et al.* 2017, McConkey *et al.* 2012, McConkey 2005). Despite its importance as a support to families, no national policy on respite services exists and provision is dependent on the policy and resources of local service providers (Gadd 2019). McConkey *et al.* (2012) documented a parallel trend of increasing need for respite services alongside an apparently diminishing provision of such services. Family caregivers have suggested that respite is less available to those with more complex or challenging needs; services were said to be content to fill their respite places with individuals who placed fewest demands of the service providers' staffing and resources (Griffith & Hastings 2014)

The second objective of Goal 4 of the National Carers' Strategy is to “Enable carers to remain in touch with the labour market to the greatest extent possible”. Carers will have different preferences, capabilities and aspirations about combining paid employment and caregiving. Paid employment is largely structured around men's traditional work patterns and do not accommodate women workers with care responsibilities (Orloff 2002). Ireland's strong male breadwinner model has given way in recent decades to a dual-breadwinner model or adult-worker model) however mothers of older adults with intellectual disability may have withdrawn from the paid workforce well before retirement age. Female participation in the workforce in Ireland was traditionally low before it was “revolutionised” in the 1980s (O' Sullivan 2012). In 1993, just 39 percent of Irish women were in paid employment; this percentage was 59.5 in 2016, slightly short of the EU average of 61.4 percent. Since the 1990s in Ireland the State has encouraged women to enter the paid workforce and this gained increased impetus in the era of the Celtic Tiger. In order to support mothers of young children to work, creches and other childcare facilities were financially incentivised, however no such structural supports are available to carers who wish to join or remain in the labour force. Yet the availability, accessibility and affordability of an appropriate and supportive care infrastructure are central to the feasibility of carers joining or staying in the labour market. A Eurofound (2015) report on reconciling care and employment highlighted this discrepancy:

In sharp contrast to the progress made in raising awareness of the rights of workers with care responsibilities for children, public awareness and policies relative to workers with care respon-

sibilities for adults and elderly relatives have been extremely limited. ...A double approach is needed to improve the situation of working carers: more publicly funded support infrastructures and improving the rights of workers with care responsibilities, including receiving compensation for the foregone earnings. (Eurofound 2015, p. 85).

The National Carers' Strategy envisions carers being supported in the labour market by flexible and responsive respite services, and through part-time and flexi-time working, job-sharing and tele-working. However, employers are not legally obliged to offer flexible work structures which many carers require. Part-time work and job-sharing are likewise at the discretion of employers and may not generate sufficient income to ensure a standard of living for the carer or their family and, as previously highlighted, respite services in Ireland are not generally characterised by caregivers as flexible and responsive.

In a review of the national policies of the EU 28 countries to reconcile care and work, Eurofound (2015) ranked countries by their generosity level of legal entitlements for the reconciliation of work and care. The ranking was presented with a number of important caveats including the limitations of the information available, the dimensions included and the welfare context within each country. Thus countries such as the Netherlands may not require a high number of work and care reconciliation measures because the infrastructure and the long-term care policies provide a high level of support to those who care and work in paid employment. The study used a cluster analysis to divide the 28 countries into three clusters. Cluster 2 comprised countries with '*partial care*' regimes which provided a combination of short-term leave, with or without income replacement, and employment protection for working carers; countries in this grouping included Croatia, Norway, Italy, Luxembourg and Slovenia. Cluster 3 comprised countries that only have low-level leave entitlements, if any at all, and which largely rely on flexible working arrangements; this cluster included Bulgaria, Slovakia, Greece, Latvia, Hungary and Poland. Ireland was listed, alongside the UK, Denmark, Germany, Finland, Belgium, Sweden, France, Austria in the first cluster which represented "countries that have a fully developed policy regime for the reconciliation of work and care" in the fields of working time flexibility, emergency leave and a high level of employment protection for carers (p. 39).

The "generous" legal entitlements noted by Eurofound (2015) included those legislated for in the Parental Leave (Amendment) Act 2006, the Protection of Employees (Part-Time Work) Act 2001, the Employment Equality Act 1998, the Equal Status Act 2000 and the Carer's Leave Act 2001. The Equal Status Act prohibits discrimination in employment, training or work experience, vocational training, access to employment,

conditions of employment, the provision of accommodation, service provision and educational establishments. The Act identifies nine grounds of discrimination including family status and defines family status as being pregnant or having responsibility:

- a. as a parent or person in loco parentis in relation to a person who has not attained the age of 18 years, or
- b. as a parent or the resident primary carer in relation to a person of, or over that age, with a disability which is of such a nature as to give rise to the need for care or support on a continuing, regular or frequent basis.

The Carer's Leave Act is considered to be a progressive benefit yet there is a low level of take-up of the entitlement (Oireachtas Library & Research Services 2019). The Oireachtas Library & Research Services, (2019) state that this may be due to a lack of awareness about the scheme, a poor fit between what the scheme offers and what caregivers need, potential negative career consequences of availing of the leave and the economic, social and psychological consequences of withdrawing from the paid employment. Smith (2012) argues that the provisions of Carer's Leave reinforces the hard division between work and care as it demands a withdrawal from the labour market whereas a more flexible entitlement could work to support individuals to combine care and paid employment.

Cullen, Delaney & Duff (2002) contend that care and employment should be conceptualised in terms of two interacting continua. The care continuum ranges from intensive 24-hour care giving to casual or discretionary care provision and the employment continuum ranges from permanent inactivity to full time employment in their conceptualisation. They identified that the implications for the labour market of this continuum perspective was that a range of rights were required including for positive action and reasonable accommodation provisions by employers, the right to balance working and caring preferences and needs in a way that best suited to a carer's circumstances and the right not to be discriminated against because of one's caring status (Cullen, Delaney & Duff 2004). Cullen *et al.* (2004) also included the "opportunity to discontinue working or not to seek work, if desired and/or necessary" (p. 51). Without adequate formal services the momentum to increased female participation in the labour market fits badly with policies to locate most care in the community:

Put crudely, current employment policy is oriented towards increasing participation rates for all groups, including carers, and current health policy is predicated on continued availability of informal carers to provide the vast bulk of care and support in the community. (Cullen *et al.* 2004, p. 19)

The National Carer's Strategy states that to achieve the goal of "enabling carers to remain in touch with the labour market to the greatest extent possible" (p. 18), "the care recipient's access to home care services and to day care in the community will be ... important in this regard" (p. 18). However, as noted previously, community and day care services have been subject to retrenchment in recent years and research has indicated that families do not, in general, find services flexible to the needs of families.

The intensity of care provided has been demonstrated to impact on employment; the OECD reported in 2011 that an increase of 1% in hours spent caring results in carers being more likely to stop working by 10% (Colombo *et al.* 2011). Likewise, the 2016 Irish Census results indicate that carers who spend the fewest hours per week caring (less than 28) were not less likely to be in paid employment than non-carers. In their analysis of the 2016 Census results Family Carers Ireland (2017) report that:

- carers proportionally occupy a significantly higher number of roles in 'Caring personal service occupations'
- there is a noticeably higher percentage of carers in administrative and secretarial occupations, and among teaching and educational professionals, health professionals and health and social care associate professionals and
- carers are comparatively underrepresented in the category of science, research, engineering and technology professions. (p. 9)

The Family Carers Ireland's (2017) analysis also demonstrates that although the socioeconomic status of carers shows a similar proportional spread, overall, to that of non-carers disparities are apparent for the high intensity carers. Thus there are disproportionately fewer high intensity carers in the "professional workers and managerial and technical" categories and a higher percentage in the semi-skilled, unskilled and 'All other gainfully occupied and unknown'.

3.4.6.9 Empowerment and choice

The National Carers' Strategy identifies empowerment as one of the guiding principles which underpin the Strategy. It asserts that

Carers will feel empowered to make decisions about how they choose to live their lives as individuals in their own lives. (p. 9)

This principle resonates with Henwood *et al.*'s (2017) assertion that:

Support for carers has increasingly come to mean more than recognising carers' existence and helping them to continue caring; it is also about supporting them to live a fulfilled life outside caring, (p. 73)

Lynch (2013) argues that carers are both disempowered and impoverished in cultures where care is not recognised or rewarded and that family caregivers, in particular, often have little power to control the conditions under which they provide care.

Choice is an important principle underpinning recent disability policy resulting in "greater visibility on the policy stage, a louder voice in discourse about welfare services and an increase in legally based enforceable rights in a number of key areas" (Larkin & Milne 2014, p. 26), however little scope exists for Irish caregivers to exercise choice about whether or not to care and about the extent to which they are able to provide care. Choice and independence do not have the same legitimacy in Irish social policy for caregivers as it does for care recipients. Lack of choice for caregivers may be seen as a consequence of the way informal carers are problematised in social policy:

However, as long as the Government continues to view carers as a free resource, the reality of the choice agenda for carers is highly problematic – especially in relation to choices that are likely to impact on their unpaid care-giving roles. (Arksey & Glendinning 2007, p. 173)

The exercise of choice, Arksey and Glendinning (2007) point out, presupposes at least two alternatives from which to choose. Irish carers of older people with intellectual disability have limited opportunities to choose between alternatives either in respect of supports to themselves as carers or in respect of the services received by the care recipient.

3.4.6.10 Empowerment and mutuality

The National Carers' Strategy makes explicit that the state predicates support for caregivers on the maintenance of the caring relationship in order to prevent or postpone the need for the more costly alternatives. This goal of caregiver support has been decried by Nolan *et al.* (2001) as exploitative and morally, ethically and pragmatically indefensible. Nicholas (2003) argues that

... choice and independence are as valid for carers as they are for users of services" (p. 33)

Policy and practice developments for care recipients and caregivers often happen in parallel to each other without acknowledgement of their interdependencies (Mitchell *et al.* 2015). Arksey & Glendinning, (2007) contend that caregiver and care recipients' needs are frequently conflated into a single, and implicitly harmonious, unit, ignoring the complexity of the relationships and sometimes contradictory interests between caregiver and care recipient (Henwood *et al.* 2017).

However, Calderbank (2000) argues that the needs of carers are a symptom of service users' unmet needs and undoubtedly caregivers benefit from services and supports provided to the people for whom they care. It has been argued that the unrecognised needs of 'carers' are only such because the people they care for are marginalised and that the needs of carers are a symptom of service users' unmet needs (Calderbank 2000, Molyneaux *et al.* 2011, Barnes 2011). Yet caregivers and care recipients rarely mobilise together to influence government policy (Lloyd 2006) or to advocate for an approach that accounts for the common needs of both caregiver and care recipient (Parker & Clarke 2002); this overlooks the reciprocal and mutuality of care.

The interdependence and mutuality of the lived reality of the relationships between caregivers and care recipients is an important silence within Irish social policy. Mutuality and reciprocity of care may be a particularly important feature of the lives of parents of older people with intellectual disability as they age (Gant & Bates 2019, Ryan *et al.* 2014, McKenzie & McConkey 2016, Knox & Bigby 2007). The UK Care Act 2014 places a legal obligation on local authorities to meet the needs of both care giver and care recipient and acknowledges the significance of the family unit within which people with an intellectual disability may live (Gant & Bates 2019). Gant & Bates (2019) contend that

The reciprocal care alluded to and articulated by participants needs to be recognized as something to celebrate alongside the use of comprehensive assessments that are person centred and build on the strengths of an individual and also that of their family and carers. ... Recognizing the

role of older carers and the presence of reciprocal caregiving also allows practitioners and policy makers to respond more pragmatically to real need, rather than assuming that such relationships are normative and therefore not requiring of support and maintenance. (p. 439)

Tomkins and Eatough (2015) argue that an increased focus on the care relationship itself, will reduce the unhelpful distinction between care givers and care recipients and other theorists such as Williams (2001) suggest that a universalist concept of care recognises the interdependence and mutuality that are fundamental to a care relationship.

3.4.6.11 How could it be different?

The way that carers are problematised in Irish social policy restricts the policy responses to achieve the stated vision of the Irish National Carers' Strategy to empower carers who chose to care "to do so without detriment to their inclusion in society and to their health" (p. 9). Question 6 of the WPR approach requires us to consider how it could be different; in response to this the following section considers care as embedded in a concept of citizenship. Lynch (2013) contends that Western political theorists have ignored the reality of human dependency and have idealised the non-attainable concept of the autonomous and independent individual. The absence of attention in socio-political analysis to the importance of emotions and affective realities results in a limited conceptualisation of citizenship and perpetuates (gendered) inequalities (Lynch 2013).

Despite the existence of advocacy groups for carers at national and European level, the carers' movement has not achieved political voice comparable to that achieved by the disability movement (Larkin & Milne 2014). The disability movement is cited as a precedent for rights-claiming that could be emulated by caregivers. The disability movement established the right of people with disability to the accommodations and resources that would enable them to participate as meaningful citizens and not simply as objects of policy (Lister 2001, Glenn 2000). Lister (2001) described that the disability movement used a universalistic discourse of equal citizen rights and social justice to achieve welfare provisions that reflect the social rather than the medical model of disability. Larkin & Milne (2014) suggest that the carers' movement is limited by a lack of a strong theoretical foundation equivalent to the social model of disability which drove that movement to political and legislative success. An inclusionary model of citizenship, it is argued, may provide an effective framework through which to gather some momentum behind carer advocacy (Larkin & Milne 2014).

In his influential theory of citizenship, TH Marshall (1964) conceptualised citizenship as a status belonging to those who are full members of a community; all citizens are equal and equal in respect of their rights and responsibilities. Marshall divided citizenship into three parts: civil, political and social. Social citizenship was characterised as the right to live as a civilised life according to the standards of the time. Social citizenship rights included the right to housing, employment, pensions and education and, in return, the citizen contributed to the state through work or military service. Thus, social rights were contributory rights (Isin & Turner 2007). Citizenship has historically been a reward of paid employment and in return for fulfilling citizenship responsibilities, citizens become entitled to old age pensions, unemployment payments and health and safety protections. These outcomes were primarily relevant to adult male breadwinners, protecting them from poverty, particularly in old age and unemployment (Ferragina 2017). Most countries do not define people working full-time as carers in the home as “workers”. Family caregivers, working in the private realm, are not deemed to fulfil the responsibilities of citizenship and are therefore not accorded that status or the entitlements accruing (Glenn 2000).

Thus the social rights identified by Marshall did not include the right to give or receive care, the responsibility for which was considered to be that of family and social networks. This exclusion of care from citizenship rights located care firmly in the domestic sphere enforcing male individualisation and de-individualising women. When citizenship is closely bonded to paid employment, unpaid work is denigrated as is the value of this contribution to society and to the economy (Becker 2003, Knijn & Kremer 1997). Despite its crucial importance to the economy, informal care does not feature in national accounting (Russell *et al.* 2010, Hanly & Sheerin 2017). Informal care is politically and socially invisible because it “falls outside the market economy” (Parks 2002, p. 19; Weicht 2010) and dependence, as a social risk, is an unmet challenge for most welfare states (Pavolini & Ranci 2008). However Kremer (2005) and Knijn & Kremer (1997) propose that social citizenship should be inclusive citizenship recognising the right and obligation to participate in the labour market but equally recognising the right to give and receive care and that (Knijn & Kremer 1997) such rights would be both an entitlement and an obligation of citizenship and those who give care would enjoy the entitlements of citizenship

Investment in childcare is increasingly framed as social investment to improve the welfare of children as citizens-in-becoming (Dobrowolsky & Lister 2005) and an investment which will result in important rewards; however, care for older people or people with disabilities do not fit the social investment model in the same way (Lewis 2007, Razavi 2007). The social investment model excludes and marginalises adult care

recipients and those who care for them, Lynch & Lyons (2009b) contend that they “are seen as unproductive, vulnerable and even ‘wasteful’ in a strongly capitalist society”

Care recipients are clearly not citizens in the politically engaged sense, especially where they have severe intellectual disability Carers are also invisible in this politically engaged definition as their care work controls their time, forcing them to disengage from political action and indeed from employment when they lack care support services. Revaluing care thus requires a reconceptualization of citizens as interdependent. (Lynch & Lyons 2009b, p. 79)

Kremer (2005) suggested that caregiving should be the basis for full citizenship rights with carers given the status of citizen-carers and Glenn (2000) argues that giving care fulfils an obligation of citizenship:

If citizens have a right to care, then there is a corresponding responsibility on the part of the community to ensure that those who need care get it. Further, if care giving is a public social responsibility, then those who do care giving fulfil an obligation of citizenship and thus are entitled to societal benefits comparable to those accorded for those fulfilling the obligation to earn for example, social security, seniority, and retirement benefits (Glenn 2000, p. 88)

The desired objectives of welfare states are frequently itemised as providing autonomy to citizens; providing social stability in the event of risk and ameliorating poverty. While all welfare states accept some public responsibility for care, they differ in how this responsibility is assigned and differ in the underlying assumptions and conditions under which they undertake this responsibility (Knijn & Kremer 1997). Knijn & Kremer (1997) assert that the quality of care given is dependent on the conditions under which it is given and performed

do care receivers get the care they need, in the environment they choose, given by people who have enough time to pay attention to them? Do caregivers have enough time to care without becoming second-class citizens, are they well paid for caring and do they have enough resources for their work? (p. 349)

Lynch & Lyons (2009a) assert that “the individualised citizen in Western democracies is not a caring one” (p. 56) and when autonomy and independence are intrinsic features of citizenship, vulnerability, dependence and interdependence are devalued. Glenn (2000) argues that this conceptualisation of citizenship is based on two conceptual dichoto-

mies; that between the public and the private realms and that between dependence and independence. The ideal citizen conceptualised as “an autonomous individual who can make choices freely in the market and in the political realm” (Glenn 2000, p. 84). The idealised autonomous citizen is almost certainly male and reflects hegemonic conceptions of masculinity (Lynch & Lyons 2009b, Knijn & Kremer 1997). The care-less adult worker paradigm is reinforced by labour market structures and government policies which fail to recognise the need for and social value of care.

This conceptualisation of inclusive citizenship includes the right not to care or to relinquish care. Kremer (2005) warns of the possibility of citizens becoming trapped in a particular sphere and argues that inclusive citizenship includes the right both to care and to work. She argues that T.H. Marshall’s (1964) definition of citizenship as participation in the community can easily accommodate caregiving and suggests that

Including care in the concept of citizenship means that people, both men and women, have a freer choice as to whether they want to care or not. Citizenship then means the right to care and the right not to care, but without being locked into one activity. In other words, the right to give care as well as to receive care are important for modern welfare states. These rights indicate how welfare states care and under which terms care is given (Kremer 2005, p. 238)

Kremer (2005) echoes Pateman’s (1989) observation on the paradox of women’s lesser citizen status “whereas what they actually contribute to welfare states is welfare itself” (p. 28).

Carers will be powerless when they are not respected, recognised, rewarded or supported diminishing their capacity to enjoy the positive rewards of providing love, care and solidarity. Affective inequality, Lynch (2013) writes, occurs both when the burdens and pleasures of care and love are distributed unequally and also “when love, care and solidarity work is trivialised by omission from public discourse”(p. 8). Lynch and Walsh (2009) assert that the labour involved in care and solidarity is a public good and should be supported as such. Likewise Fineman (2001) argues that the work of care preserves and perpetuates society creating a social debt “that binds each and every member of society” (p. 1411).

3.4.7 Conclusion

As the body of carer research grew exponentially from the 1980s, much of its focus was on what Milne & Larkin called “Gathering & Evaluating” research. The emphasis of this focus on the negative impacts of caregiving reflecting the early feminist campaigns which stressed the burden experienced by (mainly) women whose lives were being constrained and negatively impacted by their caregiving in the invisible realm of the home. Ethic of care theorists reframed the discourse on care locating the concept within relationships and emphasising the universality of dependency and interdependency. Positioning care as a social debt “that binds each and every member of society” (Fineman 2001, p. 1411) requires that society responds to the debt it owes to carers and values them as full citizens.

The extent to which a society actually values carers is evidenced in its social policy response to the issues of care, dependency and interdependency. The National Carer’s Strategy is the cornerstone of the Irish social policy response to care and is underpinned by a vision to recognise, support and empower caregivers. The use of the “What’s the problem represented to be” approach in this chapter facilitated a problematising of the assumptions underpinning the Strategy and an examination of the relevance of the Strategy to the lived experiences of carers of older adults with intellectual disability in Ireland. This critical analysis made apparent that much of the focus of the Strategy is not inclusive of older carers of people with intellectual disability who experience a number of unique challenges including the longevity of the caregiving role and issues relating to mutual ageing (Ryan *et al.* 2014).

The identity of carer has been constructed through social policy and social policy responds to the identity of carer as constructed by social policy. The limited supports that are available to carers are available only to those who self-identify with the carer-as-constructed rather than those whose main identity is based within their relationship with the care-recipient. Eligibility for the Carer’s Allowance restricts the caregivers’ freedom to engage in paid employment and requires the caregiver to characterise the care given as burdensome. Molyneaux *et al.* (2011) argue that the term carer should be replaced by relational terminology that more coherently fits the experience suggesting that “carer” is “a mark of bureaucracy, turning what is a normal human experience into an unnecessarily complex phenomenon” (p. 422). Guest & Corrigan (2018) propose that the co-existence of everydayness and complexities of caring can be understood as an experience of ‘extraordinary normalcy’ and argue that their concept acknowledges the changes and challenges that providing care can bring about whilst also recognising how these merge into everyday normalcy. O’ Connor (2007) describes that the family caregivers in her study had to transition from locating their activities within a framework

of their familial relationship to accepting the label of caregiver: “it simply did not occur to participants that they were doing something outside the bounds of their relational role” (p. 168). The transition from giving care to a child with a disability to giving care to an adult child with a disability is gradual making it more complex for parents to redefine themselves as caregiver. Caregivers of older people with an intellectual disability may therefore find it difficult to identify with the carer that is problematised by Irish social policy. It is a narrow, definition, unlikely to embrace the hidden carers. Fyffe *et al.* (2015) suggests that

As the understanding of care and caring has narrowed there is evidence that many family members do not relate to how their daily lives are described in policy, service provider and research circles (Stalker 2003). Families want their lives to be more accurately portrayed (Stalker 2003). Family carers are dissatisfied with being asked to identify with an artificial care concept. (p. 75)

Ireland compares relatively well in terms of the level of social welfare payments to carers and has a duration of carer’s leave that similar to other European countries such as Belgium and France. However, in other ways there exists an apparent inconsistency between the rhetoric of Irish policy makers about the importance and value of caregivers and the extent to which support is provided including services for care-recipients. By European standards Ireland has a low level of long-term care service provision Kautto (2002) and Ireland’s public expenditure on long-term care is lower than the European average (Lipszyc *et al.* 2012).

Deficits in services for care-recipients impact directly and indirectly on caregivers; that which the state does not provide is left to families to provide (Jenson and Saint-Martin 2003, p. 81). The Strategy positions caregivers as both “key care partners” (p. 12) with the formal care services and as co-clients of services: “carers can also benefit from the supports aimed at those for whom they are caring” (p. 4). However, the absence of formal services results in Irish caregivers providing a high intensity of care. In 2006 Fanning & Rush identified that Ireland suffered from a social care infrastructure deficit; and in 2020 the Disability Federation of Ireland state that disability services are “crumbling” with mounting sectoral deficits of more than €40 million (Disability Federation of Ireland 2020). Services which exist are crisis-driven and reactive rather than proactive and

supportive (Ryan *et al.* 2014). Dukelow and Considine (2017, p. 333) contend that the Irish welfare state lacks a vision for the place of care in contemporary society

Expectations of carers and of women in particular, remain deeply embedded in a largely implicit policy framework which preferences familial care but without adequate care supports. Where supports are available they remain a mix of limited state provision and increasingly market-based solutions, contingent on ability to pay. It is clear that carers, and by association the people receiving care, are still not adequately recognised or supported and affective inequalities are widespread. There is little robust public or political consideration of the consequences of these shortcomings.

The review of the literature highlighted the inconsistency of findings in caregiver research indicating the importance of focussed research. A pre-requisite to advocating for an adequate social policy response for carers of older people with intellectual disability is robust data on their specific lived experiences, health and well-being. The IDS-TILDA Carer's Study is a unique source of such data and the findings from Waves 1, 2 and 3 of the study are presented in the Chapter 5.

Chapter 4: Methodology

4.1: Introduction

This chapter describes the methodology used in this study. The research question, the research objectives and the methods used to achieve these will be described. The research paradigm and the researcher's positionality is outlined. A description of the data set upon which the study is based will be presented followed by an account of the process of data collection. An overview of quantitative and qualitative analysis will be described. Finally, the ways in which ethical issues were addressed in the design and conduct of the study are outlined.

4.1.1 Research question, aims and objectives

4.1.1.2 Research question

The key research question is how has the health status of the caregivers of adults with an intellectual disability involved in the IDS-TILDA study changed over time and what factors are associated with the health and wellbeing of the caregiver?

4.1.1.3 Objectives

1. To explore how 'care' has been conceptualised and theorised; and to consider the extant research about the impacts of caregiving on caregivers.
2. To identify social policy responses to 'care' across different welfare regimes
3. To identify the health and wellbeing status and changes in the health and wellbeing status of caregivers in the IDS-TILDA study over **Waves 1, 2 and 3**.
4. To identify changes in intrapersonal changes in seventeen caregivers who participated in both **Wave 1** and **Wave 3**.
5. To explore whether the experiences for siblings differ to those of parent caregivers and to consider whether these suggest a specific policy or service provider response in needed to support sibling caregivers of people with an intellectual disability.

4.2: Research paradigm

The Carer's Study utilised a mixed methods approach generating both quantitative and qualitative data. A mixed methods approach facilitates a more complex exploration of a phenomenon than can be achieved by the use of a positivist or interpretivist approaches in isolation (Shannon-Baker 2016). The study questionnaire is largely quantitative in design allowing for statistical analysis, however the strategic inclusion of text boxes allows carers to expand on their answers and provide contextual elaboration. As a methodological movement which has developed over recent decades, a mixed methods approach complements the existing, polarised traditions of the quantitative and qualitative movements and the opposing paradigms of positivism and post-positivism (Hall 2013).

4.3: Researcher positionality

Shannon-Baker (2016) argues that the conscious use of paradigms serves not just to provide a guiding framework for researchers but also to inform the audience of the beliefs of the researcher and, therefore, the potential influences on the research. Drawing from Teddlie & Tashakkori's (2009, p. 84) view of paradigms as a worldview together with the various philosophical assumptions associated with that point of view, this researcher would locate herself in the post-positivist philosophical perspective of critical realism which assumes a reality but accepts that it cannot be perfectly understood and that differences exist between reality and individuals' perception of reality (Bisman 2010). The choice of methods employed by critical realists is determined by the nature of the research question but, most frequently, these are a combination of qualitative and quantitative methods (McEvoy & Richards 2006).

As the mother of an adult daughter with a significant physical disability, I share many of the experiences that are identified, measured and analysed in caregiver studies. The development and design of the questionnaire was complete pre-dated my involvement in the IDS-TILDA Carer's Study. However, my choice of framework through which to analyse Ireland's social policy response to caregivers was undoubtedly influenced by my own experiences, values and belief. A reflexive approach was taken to the analysis and write-up of the data to check for subjective biases or preferences and multiple quotes have been used to evidence the qualitative findings to ensure its credibility.

4.4: Caregiver and social policy literature

Objectives 1 and 2 were addressed through an extensive literature review which aimed to provide an analytic synthesis of the extant literature on caregivers in general, caregivers of older people with an intellectual disability and social policy responses to caregiving. A narrative literature review was chosen over a “systematic literature review” for a number of reasons. Systematic literature reviews have their roots in medicine where the purpose was to comprehensively identify and summarise the evidence for specific medical treatments (Boell *et al.* 2015). Thus the scope of a systematic literature reviews, as originally developed, is extremely narrow focussing on “what works” and “what works best”. Outside the field of medicine, the rigour of the search process has become the benchmark of the quality of the review (Boell *et al.* 2015) with protocols and inter-rater reliability ensuring that the literature included in the review met the inclusion criteria and with less regard to analysis or interpretation (McClure 2007). By contrast, a narrative review allows the researcher to investigate the scope the breadth and depth of a field of knowledge while developing a critical and reflective understanding of the importance of the literature (Boell *et al.* 2015). Fine and Glendinning (2005) describe “a stream, then a torrent” (p. 603) of carer research dating from the 1980s and the literature output from this torrent emanates from a diversity of disciplines. Unshackled by a protocol and inclusion/exclusion criteria to restrict the literature search, the aim of producing a narrative review for this thesis allowed for a systematic approach to the discovery and inclusion of both peer reviewed and grey literature unimagined at the start of the process. The literature included in the review included quantitative, qualitative and mixed methods studies, reports and published theses.

The search strategy used

- Academic databases including Scopus, PsychINFO, Embase, CINAHL
- Google Scholar

Key search terms included: carers/caregivers, parent carers/caregivers, sibling carers/caregivers, intellectual disability, male caregivers, feminism, care and citizenship.

The references of key documents were hand searched and their citations were followed up. No time restrictions were imposed on the searches; however the reviewed literature was limited to those in the English language.

4.5: IDS-TILDA

4.5.1: Carer's Study:

The data used in this study to address Objectives 3, 4 and 5 is from Waves 1, 2 and 3 of the IDS-TILDA Carer's study. This Carer's study is nested within the IDS-TILDA study and is a unique source of longitudinal data focussing on the lives of family carers of older people in Ireland with an intellectual disability in Ireland and, therefore, offers an exceptional perspective on an under-researched cohort of people. As the design and protocols of the Carer's Study are embedded in the IDS-TILDA study an overview of the IDS-TILDA study will be described followed by a similar overview of the Carer's Study.

4.5.2: IDS-TILDA

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing was launched in the School of Nursing and Midwifery in Trinity College, Dublin, on 3 December 2008. IDS-TILDA is a nationally representative longitudinal study of people aged 40 years and older with an intellectual disability in Ireland. The main aim of IDS-TILDA is to identify the principal influences on successful ageing in people with intellectual disability and to determine whether they are the same or different from the influences on successful ageing for the general population. The data from IDS-TILDA is also used to track the impact of key Irish policies including Healthy Ireland – A Framework for Improved Health and Wellbeing 2013-2025, the National Dementia Strategy 2014 and Time to Move on From Congregated Settings 2011 (McCarron *et al.* 2017).

IDS-TILDA provides data on the health, social, economic and environmental circumstances of older people with intellectual disability, and was designed to facilitate direct comparison with the circumstances of the general population (McCarron *et al.* 2014). A key comparator for IDS-TILDA is The Irish Longitudinal Study on Ageing. The Irish Longitudinal Study on Ageing (TILDA) is a prospective cohort study of a population-representative sample of community-dwelling individuals and households aged 50 years and older. Participants were sampled in geographic clusters and 8,504 were recruited at the baseline assessment conducted between October 2009 and February 2011. Among the objectives of TILDA are to

- Provide comprehensive baseline data on older people in Ireland to inform policy and planning
- provide new insights into the causal processes underlying aging
- Add to the prominence of aging as a topic of public interest and allow the voice of older people to be heard (Whelan & Savva 2013)

Data for TILDA is collected on a two-year cycle through a computer-assisted interview questionnaire (CAPI), a self-completion questionnaire and a detailed health assessment which takes place either in the participant's home or in a dedicated health centre.

IDS-TILDA was designed to maximise comparability with TILDA and other international studies on ageing. An international scientific committee provided expert advice on the development of the protocols for the study and the intellectual disability-specific content and people with intellectual disability were involved in every stage of the design, implementation and evaluation of the study. IDS-TILDA is underpinned by the values of inclusion, person-centredness, empowerment, choice, promotion of best practice, promotion of people with intellectual disability and promotion of best practice.

The sample for IDS-TILDA was drawn from the Irish National Intellectual Disability Database (NIDD) which, since 1995, has collected demographic, service use and service need information about people with an intellectual disability who are registered with a service provider. At the time of recruitment to IDS-TILDA, the NIDD held information on 26,066 individuals and, applying an inclusion criteria of being aged over 40 years, the PIN numbers of 1,800 people were randomly selected. IDS-TILDA differs from its associate study, TILDA, in its use of the age of 40 years rather than 50 years as the point of inclusion because the evidence demonstrates that people with intellectual disability begin the ageing process at a younger age than the general population (McCarron *et al.* 2011). Previous research had suggested that the sample of 1,800 would achieve recruitment of between 750 and 850 individuals to the study. The NIDD release the PINs to regional disability database administrators who, after verifying that each individual was still registered on the database and that their information was correct, posted the information packs on behalf of the IDS-TILDA study team to the individuals, families and support staff. The identity of the invitees was not known to the study team unless and until a consent form was returned by or on behalf of them. An information and advice campaign was conducted during the recruitment period aimed at people with intellectual disability, families and service providers to people with intellectual disability and members of the IDS-TILDA team were available to answer queries or address concerns about the study.

Seven hundred and fifty-three consents to participate in the study were received representing a response rate of 46% and amounting to 8.9% of individuals aged over 40 years of age on the NIDD. Two hundred and eighty-five of the consents were provided by the individual with intellectual disability and 468 (62%) of the consents were provided

by family members or guardians of individuals with intellectual disability. The sample was geographically representative of the country and key characteristics included:

- 45% were male; 55% were female
- They ranged in age between 41 and 90 years with a mean age of 54.7 years.
- 24% were classified as having a mild level of intellectual disability, 46% a moderate level and 24% were classified as having a severe level of intellectual disability and 5% a profound level. The level of intellectual disability was not verified in 5% of the sample.
- 52% of participants lived in 52 week residential settings and 5.3% lived in either a 5-day per week residential setting or one where they lived or holidayed elsewhere for at least two weeks per year. 11% lived in their family home, 34.1% in community group homes; 5% lived independently or semi-independently; one participant lived in a psychiatric hospital and two in a nursing home.

The sample achieved at **Wave 1** was, largely, retained in **Wave 2** and **Wave 3** with the majority of attrition due to the death of the participant. **Wave 2** included 708 participants represented 94% of the **Wave 1** sample. **Wave 3** included 609 participants representing 86% of the original sample and a response rate of 95.5% of **Wave 2** participants who were alive at **Wave 3**. The sample was refreshed prior to data collection in **Wave 4**.

4.5.3: IDS-TILDA data collection procedures

IDS-TILDA data comprises a pre-interview questionnaire (PIQ) and a computer assisted interview (CAPI). The pre-interview questionnaire is posted to the participant at least seven days before the scheduled personal interview with a request that it is completed prior to this interview. The PIQ includes questions about medications, health service use and frequency, diet, and reported challenging behaviour. The CAPI includes questions about health, social and family circumstances, quality of life and inter-personal relationships; an overview of the CAPI questionnaire is presented in diagrammatic form below:

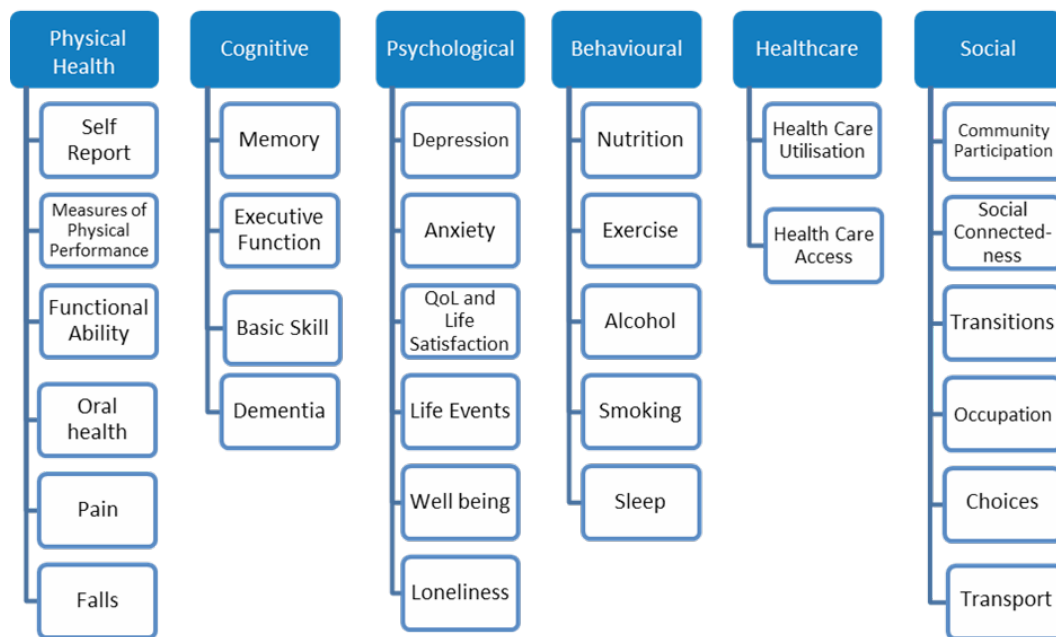


Figure 3: Overview of CAPI questionnaire.

From McCarron & McCallion (2012)

The questionnaires used in Waves 1, 2 and 3 of IDS-TILDA were fundamentally similar, however some modifications were made. The reasons for such modifications include the intention not to repeatedly ask questions, such as date of birth, for which the answer is constant, the desire to further probe issues that emerged from earlier Wave(s) or to further align IDS-Tilda to policy directions (McCarron *et al.* 2017). In **Wave 2**, 77 new questions were added, 16 were modified and 98 were removed; **Wave 2** also added a health assessment element to the data and an end-of-life interview with carers of participants who had died between **Wave 1** and **Wave 2**. In **Wave 3** a number of additional scales were added to the questionnaire focussing on the areas of physical activity, life satisfaction, personal well-being and social connectedness, mental health, behaviours

that challenge and dementia. **Wave 3** also collected objective data on weight, waist size and mid upper arm circumference.

4.6: Carer's Study

Eleven percent (83) of the seven hundred and fifty-three people with intellectual disability recruited to **Wave 1** of IDS-TILDA lived with a family member. Participants who lived with family members tended to the younger end of the age spectrum of the participants. Of these fifty-one lived with one or both parents, thirty-one lived with siblings and one lived with another relative. All eighty-three family were invited to participate in the Carer's Study and forty-seven took part in **Wave 1** of the study, seventy carers participated in **Wave 2** and forty-four in **Wave 3**.

At the start of each wave a field researcher makes telephone contact with the carers to confirm their interest in participating in the study. **Wave 1** and **Wave 3** carer participants received a Carer's Study questionnaire though the post. The completed questionnaire was either returned by post or collected by the field researcher who conducted the IDS-TILDA interview with the person for whom they care. All **Wave 2** carer questionnaires were administered by a researcher; one researcher carried out 40 interviews and a second researcher carried out the other interviews. This change in administration was made to facilitate a student conducting a Master's study.

There is a body of literature which indicates that the mode of administration of a survey affects the responses in a number of ways. Following a narrative review of the literature Bowling (2005) concluded that the mode of questionnaire administration affected the data quality and that the effect was most apparent between interview and self-administration modes. Face-to-face interviews tend to result in less missing data than self-administered surveys, possibly because of the interviewer's ability to motivate a participant to answer the questions or because of the opportunity to clarify questions (Christensen 2013, Bowling 2005). Interviewer administered questionnaires are also reported to produce more positive results than self-administered questionnaire particularly with questions involving subjective assessments (Croezen *et al.* 2016, Luong *et al.* 2015; Christensen 2013). Bowling (2005) or potentially sensitive behaviours (Tipping *et al.* 2010) suggests in face-to-face questionnaire administration, participants may fear embarrassment or appearing weak or to have failed whereas the more impersonal nature of a self-administered questionnaire may encourage participants to disclose more sensitive information.

The different mode of questionnaire administration in **Wave 2** appears to have had an effect consistent with those findings. The carers in **Wave 2** reported more positively than did **Wave 1** or **Wave 3** carers resulting in some quite stark and interesting differences in results across the waves. In acknowledgement of these differences, data from all three waves are presented in the results chapter, however comparisons of the responses to the questions are generally confined to those from **Wave 1** and **Wave 3**.

4.6.1: Carer's Study Questionnaires

The questionnaire evolved between the Waves. In **Wave 2** questions about health services satisfaction questions and a carer strain measure were added. In **Wave 3** additional questions relating to income and health were included in the questionnaire. The **Wave 3** questionnaire can be seen in Appendix 1 and a Table of the measures used can be seen in Appendix 2. The **Wave 3** questionnaire comprised 6 sections and 61 questions as follows:

1. Section 1: titled *About You* contains 13 questions covering socio-demographic details including details about the relationship between the caregiver and the care recipient and receipt of social welfare allowances in respect of caring.
2. Section 2: titled *Support you provide to the person* contains 3 questions each of which comprise 15 questions covering type, frequency and intensity of support given.
3. Section 3: titled *Understanding your experience of caring* contains 7 questions asking about the difficult and the positive aspects of caregiving, coping strategies used and support received from family and friends.
4. Section 4: titled *Family and social networks* contains 2 questions; one of which asks whether leisure and recreational activities are limited by caregiving and one which asks the caregiver to rate the support received from people within the household, family, friends and people in the workplace.
5. Section 5: titled *Quality of Life* contains 2 questions asking the caregivers to rate their quality of life and the quality of the life of the person for whom they care.
6. Section 6: titled *Your health* contains 16 questions about the health of the caregiver including questions about how they rate their health, health conditions they may suffer from and the extent to which any conditions impact on their daily life, social life and responsibilities. These questions cover both physical and mental health.
7. Section 7: titled *Satisfaction with services* contains 10 questions asking about satisfaction ratings for services received by the caregiver and services received by the care recipient and whether there are any services which are needed but not received.

8. Section 8: titled *Future planning* contains 8 questions asking the caregiver about any worries, concerns, hope and dreams that they have for themselves and the care recipient. The section also contains questions about future planning for the care recipient.

The final questions ask whether the caregiver would be prepared to be involved with future research.

4.6.2: Researcher's involvement

I was a field researcher in **Wave 1** and **Wave 3** of the IDS-TILDA study and was allocated a caseload within my geographic area. In **Wave 1**, I had an assigned caseload of thirty-five participants and, on completion of this caseload, I completed another ten interviews in other geographic areas. In **Wave 3**, I had a caseload of thirty-eight participants. The interviews took place over a **period of three months in both waves**.

Prior to data collection in both waves, I received three day's intensive training which included:

- Effective scheduling and interviewing
- Confirming consent
- Role playing interviews
- Administering the CAPI protocol, the Test for Severe Impairment and mental health tools,
- Uploading completed CAPI materials to the secure shared drive
- Maintenance of quality and
- Confidentiality in all protocol administrations

(McCarron *et al.* 2014)

During the **Wave 3** training, an independent advocate with intellectual disability reviewed elements of the training programme and assessed the field researchers in the administration of these elements.

As a field researcher, I was provided with an encrypted laptop computer which was pre-loaded with the CAPI questionnaire. As per the protocol I would, in the first instance, make telephone contact with each participant, their family member or support worker, reminding them of the IDS-TILDA study and confirming their continued participation. When we agreed a date and time for the interview I notified the IDS-TILDA headquarters from where the participant was sent: an information leaflet, a PIQ, a consent form

and a “calling card” with the my contact details, my photo and the time and date of the planned interview. On the day of the interview or the day before the interview, I would make telephone contact with the participant and/or their supported telephone to remind of the appointment and to re-schedule if the agreed time is no longer convenient. Supported interviews with participants in their day service or in residential settings were more likely to be re-scheduled than interviews in family homes due to changes in staff rostering and other demands on staff times.

Each interview took place at a location convenient for the participant which, most frequently, was their day service or their home. On arrival at the location, I would introduce myself to the participant and to their supporter where relevant, talk to the participant about the study and the procedure for the interview, check that the PIQ had been completed and obtained signed consent. When the participant appeared to be comfortable and at ease, the interview would begin.

All participants were encouraged to participate in the data collection process to the extent of their ability to do so. Some participants were able to fully participate in the interview and the consent process but many required partial support from a family member or support worker and some interviews were conducted through a proxy. Where it was possible, the proxy interviews were conducted in the presence of the participating person with intellectual disability. I would invite the participant to sit beside me so that they could see the screen of the laptop to generate a sense that the interview was an inclusive activity rather than something that was being done to the participant. Some of the older adults with intellectual disability engaged with what was happening on the screen whereas others were disinterested; family and staff supporters tended to engage well with that more participatory approach.

Some interviews were completed during one appointment. However, if the participant became bored or fatigued or if a family or staff member had other demands on their time an interview could take two or three visits to complete. My experience was that at **Wave 3**, staff had more demands on their time and were less available to provide the support to complete the process within one appointment. Family members tended to prefer to complete in one session and were usually extremely hospitable and engaged with IDS-TILDA. On completion of the CAPI interview, the data was uploaded and sent electronically in encrypted form to the IDS-TILDA head office.

In both **Wave 1** and **Wave 3** I visited the homes of participants of the IDS-TILDA study whose family member were participating in the Carer’s Study. If the carer had completed their questionnaire prior to my visit, I would check through it for completion. In a few instances, the carer had not yet filled in the questionnaire and completed it in

my presence. In other instances when the carer had not yet completed the form, the carer offered to complete the form and sent it back to IDS-TILDA headquarters. Follow-up telephone reminders were sometimes required.

4.7: Data

4.7.1: Cleaning and verification and analysis

At the start of this study all the **Wave 1** and **Wave 2** and some of the **Wave 3** data had been inputted into SPSS by a number of people at different times. In order to have complete confidence in the dataset and to immerse myself in the data, I returned to the hard copies and cleaned and verified the data from all 163 participants over the three waves.

4.7.2: Longitudinal study data

The data used in the longitudinal component of this study used data from **Wave 1** and **Wave 3** allowing for an exploration of intrapersonal changes over a period of six years. Using the data from **Wave 1** and **Wave 3** maximises the longitudinal perspective and excluding the data from **Wave 2** obviates any confounding effects of the data collected through a different mode of questionnaire administration.

Carer participants are allocated an ID number which links them to the family member for whom they provided care. If a different family member participates in the Carer's Study in different waves, the ID number remains the same. A carer of twenty-two older people with intellectual disability participated in both **Wave 1** and **Wave 3** of the IDS-TILDA Carer's Study. Of these, seventeen are manifestly the same respondent in both Waves. In four other instances, the participant in **Wave 3** was a sibling whereas it was a parent in **Wave 1**; in one case a different sibling completed the survey in **Waves 1** and **3**. The data included in the longitudinal study relates to the seventeen carers who are identifiably the same person who completed the questionnaire in **Waves 1** and **3**.

4.7.3: Quantitative data analysis

A descriptive statistical analysis was performed to meet objectives 3, 4 and 5 of this study and the data is presented in the form of graphs and tables. The literature identifies factors which may impact on the health and wellbeing of carers including their financial

circumstances (Lai 2012, Covinsky *et al.* 2003), the amount of support they receive and reasons for providing care (Perkins & LaMartin 2012, Llewellyn *et al.* 2010). Carers' perceptions of the negative impact of caring and the positives accruing from caring have also been identified as important factors (Yannamani, Zia & Khalil 2009, Broese van Groenou, de Boer & Iedema 2013). Therefore, these variables were the focus of the analysis.

The aim of this analysis was on elucidating the details of a cohort of carers who receive little attention from policy makers. The data will also provide an important baseline upon which further research can be conducted.

The data from two parent and two sibling participants in the longitudinal study are presented as case studies. These participants are not intended to be representative of the overall participants but the use of case studies spotlights the highly individual and varied nature of the caregiving experience.

4.7.4: Qualitative data analysis

The study included qualitative data in two forms. Data was generated through responses to questions which asked the carers to expand on the previous closed question; for example carers who indicated that they had given up or cut down on workforce participation were asked for the reason why they had done so. These responses provided insight into and captured the context of the experiences of the responding carers however in many instances the level of detail provided was limited. The text responses to these questions are largely presented in the results chapter as a series of quotes that exemplify the responses of the caregivers.

The second form of qualitative data was provided in responses to "free-standing" questions which asked the caregivers about their hopes, dreams and fears for their own future and the future of their family member for whom they provide care and from a question which invited the caregivers to make further comment at the end of the questionnaire. These questions provided a more detailed level of response and this data was analysed thematically.

Thematic analysis is a flexible qualitative analysis method which is not tied to specific epistemological approaches (Braun & Clarke 2006). Themes are built from codes that indicate patterned responses in the data and which capture elements important in relation to the overall research question (Braun & Clarke 2006).

An ID number was assigned to each participant in each wave before the qualitative data from the free-standing" were extracted and exported under question headings to Excel. This ID number was different to the ID number attached to each participant in the main database in order to further protect the carer's anonymity. The data was then

exported from Excel to Nvivo 12, a computer software package that can assist in the organisation, analysis and visualisation of qualitative data.

The analysis followed Braun & Clarke's (2006) six phases of thematic analysis:

- Familiarisation with the data
- Initial coding
- Developing the codes into themes
- Reviewing themes
- Defining and naming themes
- Writing-up the data in the form of an analytical narrative that both describes the data and presents an argument in relation to the research question.

4.8: Ethics and IDS_TILDA Carer's Study

4.8.1 Ethical approach

The IDS-TILDA study is underpinned by a fundamental commitment to the wellbeing of the study participants and the wider cohorts from which the older adults with intellectual disability and their family caregivers are drawn. An ongoing inclusive and participatory approach was taken to the development, design and implementation of the study.

The findings of this study provide important baseline data on lives of family members of older people with intellectual disability in Ireland. Considering these findings in the context of the Irish social policy response to caregiving in Ireland reflects an ethical approach which locates the "problem" of carers at a societal rather than an individual level.

4.8.2 Ethical procedures

Ethical approval for the IDS-TILDA study was granted by Trinity College Dublin, Faculty of Health Sciences Research Ethics Committee in 2009 following intensive piloting of the measures and the data collection approach. Ethical approval was also sought and granted by the 138 service providers who support the participants in the study.

Ethical protections and data security are embedded throughout the data collection and data analysis processes in IDS-TILDA. Information about the study is provided in an accessible format and informed consent is given by participants themselves or a family member or support staff on their behalf prior to the commencement of all interviews. However, consent within the study is seen as an ongoing and negotiated matter and is

underpinned by the principles of ‘process consent’. Participants are informed of their right to withdraw from the study or to terminate an interview and field researchers are required to be sensitive to indications that an individual is withdrawing consent. Participants are also advised that they are free to decline to answer any question(s) that make them feel uncomfortable.

Each participant in the IDS-TILDA study and the Carer’s Study is assigned a unique personal identification number (PIN) and all communications within the team about participants utilise this number. All electronic communications are by way of a secure private virtual network (PVN) and all computers used in the study are encrypted. Hard copy documents are stored in a locked cabinet in a secure office in the IDS-TILDA head office and a complete prohibition exists of the storage of data on hard drives or memory sticks.

4.9: Conclusion

This chapter has detailed the aims and objectives of the study and its research question. It has outlined the research paradigm underpinning the study and identified the researcher’s positionality. The chapter includes a description of the IDS-TILDA Carer’s study on which this thesis is based and its sister study, the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing. The quantitative and qualitative data analysis was described and the chapter finished with an overview of the ethical processes which underpin the study.

The following chapter, Chapter 5, presents the data findings.

Chapter 5: Data

5.1: Introduction

This chapter presents the data findings from **Waves 1, 2 and 3** of the Carer's Study IDS-TILDA. The data will be presented both as a whole and as a subset. The larger data set comprises all participants in the three waves of the study; the smaller subset comprises data from 17 caregivers who participated in both **Wave 1** and **Wave 3** of the study.

An aim of this chapter is to present a portrayal of the lives, health and wellbeing of the participants caregivers in the IDS-TILDA Carers Study. The literature identifies factors which may impact on the health and wellbeing of carers including their financial circumstances, the amount of support they receive and reasons for providing care. Carers' perceptions of the negative impact of caring and the positives accruing from caring have also be identified as important factors. Therefore, these variables have been included in the analysis presented in this chapter.

Forty-seven caregivers took part in **Wave 1** of the IDS-TILDA Carer's Study; 72 in **Wave 2** and 44 in **Wave 3**. The individual, participating caregiver of the older person with intellectual disability was not always the same person across the waves. Thus one parent may have completed the questionnaire in **Wave 1** and the other parent may have completed it in **Wave 2** or **3**; likewise a sibling may have responded in later waves whereas a parent did so in **Wave 1** or a different sibling may have completed the questionnaire in different waves.

The structure of this chapter is designed to present a broad picture in the first instance identifying the characteristics and experiences of the 163 respondent caregivers in **Waves 1, 2 and 3**. The sample in each wave comprised different caregivers, therefore the data does not support an exploration of changes occurring in and for the same caregivers over time. However, this series cross-sectional data provides an insight into the health and wellbeing of caregivers of older people with intellectual disability in Ireland at three points in time over six years.

Attention is then turned to a more granular exploration of the data from the seventeen caregivers who completed the questionnaire in both **Wave 1** and **Wave 3**. Their data offers a small but unique and important insight into the lives of caregivers of older people with intellectual disability in Ireland and the extent to which their lives changed over a period of six years. To further illuminate this data, a number of vignettes are included. The section concludes with qualitative data giving an insight into the caregivers' vision of the future for themselves and for the family member for whom they provide care and support.

5.2 Cross-sectional data

5.2.1 Demographics

5.2.1.1: Relationship to the person supported

The generational transfer of care from parent to sibling between the waves was evident from the data. Although most of the participating caregivers across all the waves were siblings of the older adult with intellectual disability, the percentage increased across the waves from 58% (n=26) in **Wave 1** to 75% (n=33) in **Wave 3**.

It is important to acknowledge that primary carers of older people with intellectual disability may be other than parents or siblings and a small number of caregivers with other relationships to the care recipient also participated in the survey. In **Wave 1** one respondent was a carer for a neighbour and others reported that the care recipient was a brother-in-law (n=1), sister-in-law (n=2) and niece (n=2). In **Wave 2** five carers reported caring for an in-law and one cared for a niece. The one “other” response in **Wave 3** named a care recipient. The percentage of parent and sibling carers in each wave is presented in Figure 4.

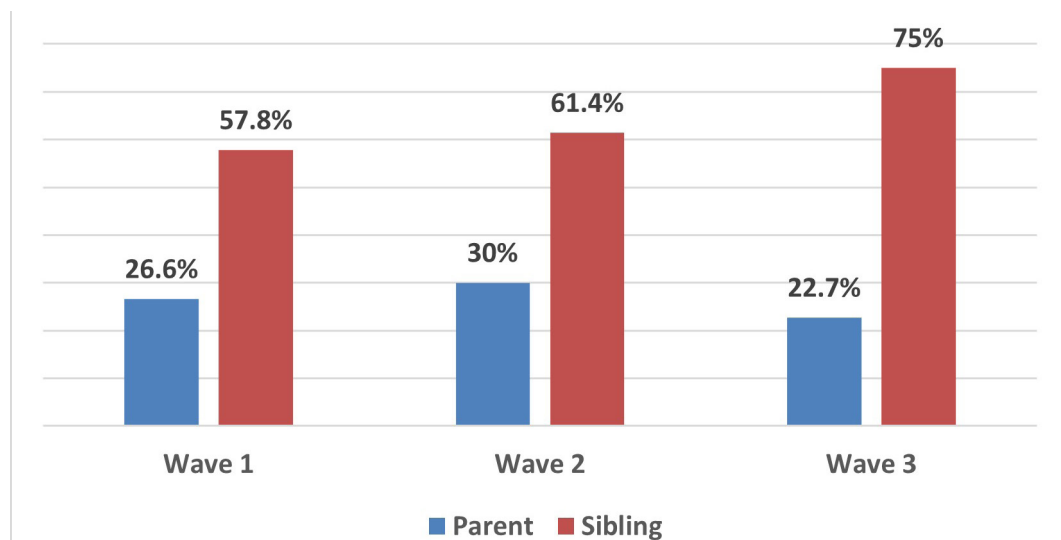


Figure 4: Caregivers' relationship to care recipient

5.2.1.2: Gender

In all three waves, the caregivers were predominantly female. Three quarters (n=33) of the **Wave 1** participants were female and the proportion rose to almost 90% in **Wave 2** (n=62) and females comprised just over 84% (n=37) of the **Wave 3** sample.

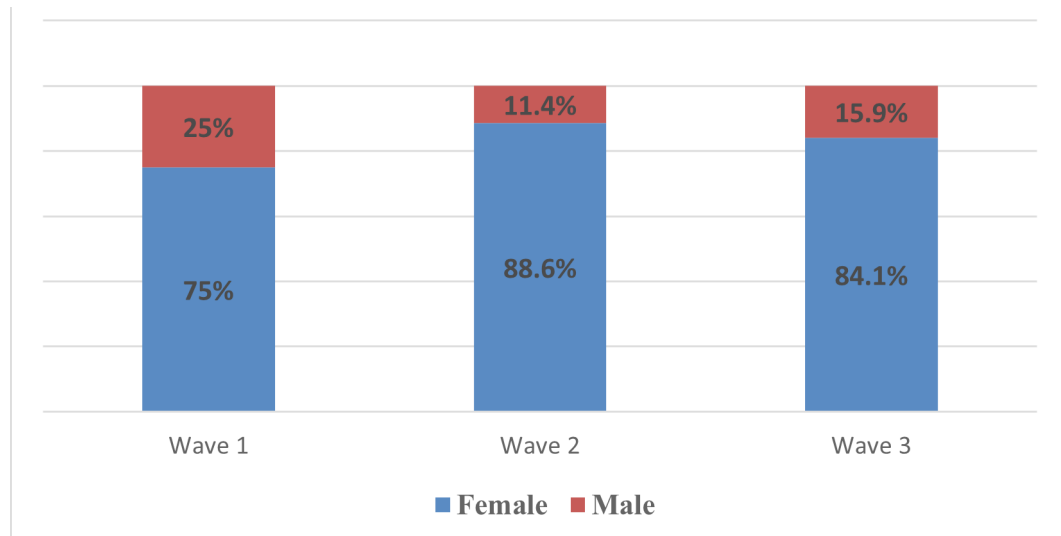


Figure 5: Gender

5.2.1.3: Age

Across all the Waves, most carers were aged between 46 and 65 years: 56.8% (n=20) in **Wave 1**, 54.2% (n=38) in **Wave 2** and 63.6% (n=27) in **Wave 3**. More than one third of carers in **Wave 1** (38.6%, n=19) were over the national retirement age, this percentage rose to 40% (n=28) in **Wave 2** and dropped to 27% (n=15) in **Wave 3**; this lower percentage in **Wave 3** is consistent with the decreased number of parent caregivers and increased number of sibling caregivers. Two carers in **Waves 1** and **3** were aged 85 years or more. Two carers were in the lowest age group of 36 – 45 years in **Wave 1**, 4 in **Wave 2** and 2 in **Wave 3**.

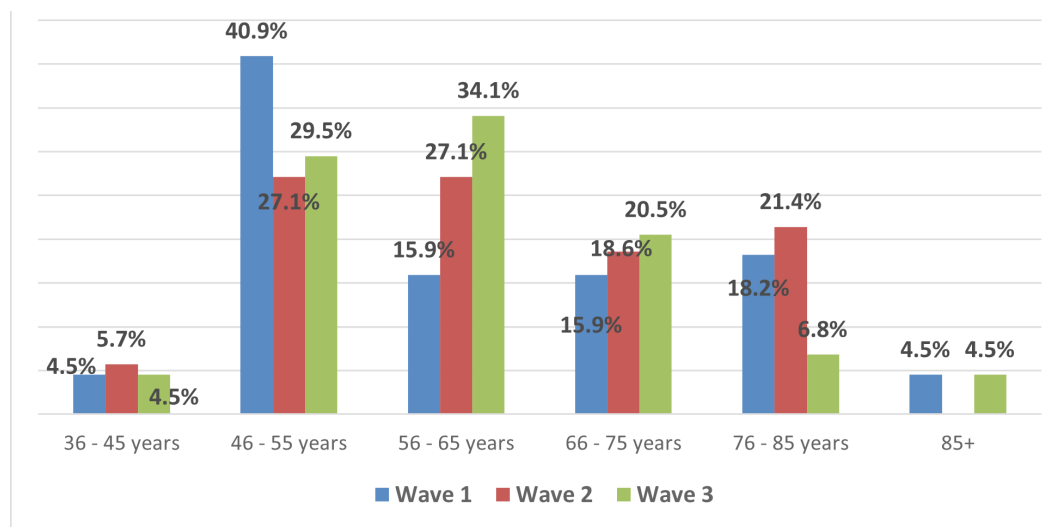


Figure 6: Participant age groups across waves

5.2.1.4: Other care responsibilities

Fewer carers in **Wave 2** and in **Wave 3** reported that they provide care for another person other than the older person with intellectual disability. Almost 30% (n=13) of carers in **Wave 1** reported having other care responsibilities, reducing to more than 28% (n=20) in **Wave 2** and reducing again to 25.6% (n=11) in the **Wave 3** sample.

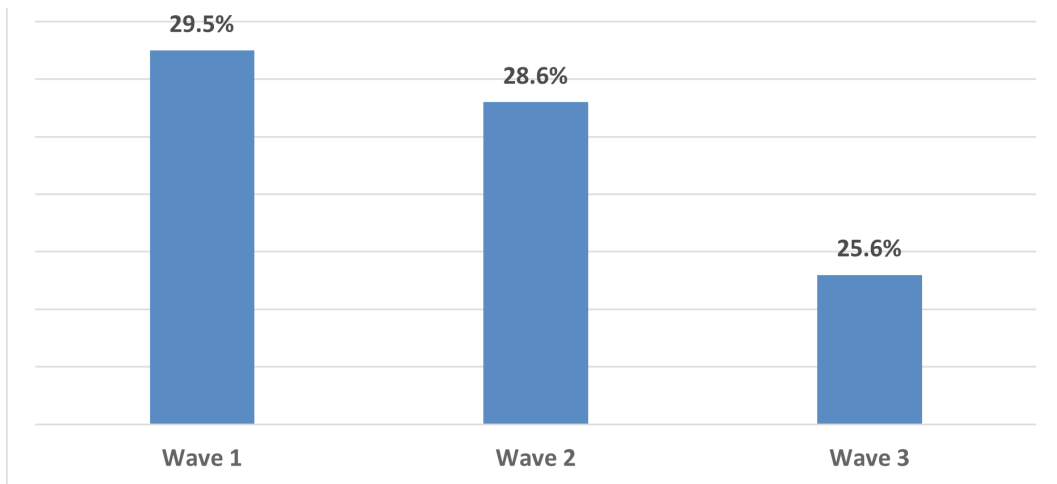


Figure 7: Other care responsibilities

One carer in **Wave 1** and three carers in **Wave 3** reported that they also cared for their children; in **Waves 2** three carers reported caring for grandchildren. However, in all three Waves carers most frequently reported also caring for parent(s), parent(s)-in-law or their spouse. Some carers reported having multiple care responsibilities.

5.2.1.5: Marital status

As the sample changed and the proportion of sibling caregivers increased, the percentage of those who were married or partnered decreased. Thus, sibling caregivers were increasingly likely to be carrying without the support of a partner.

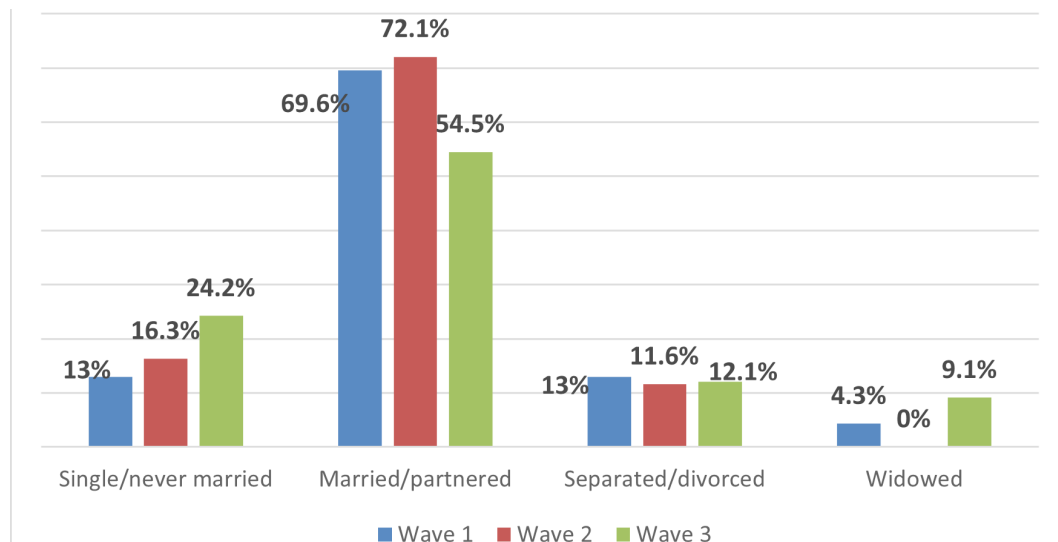


Figure 8: Marital status of sibling carers by wave

5.2.1.6: Employment status

No parent reported that they were in paid employment; in each wave the parents reported either that they were retired or were looking after home or family. Since 2014 the retirement age in Ireland is 66 years. Using 66 years as the cut-off point, the great majority of the sibling carers in each sample were of working age. In **Wave 1** this percentage was 87.5%, (n=21) in **Wave 2** it was 81.4% (n=35) and the percentage of working age carer siblings in **Wave 3** was 81.8% (n=27). However, only around one-third of sibling carers in **Wave 1** (n=14) and **Wave 3** (n=12) were actually in paid employment; the percentage in **Wave 2** was over 50% (n=34). The percentage of sibling carers reporting that they

were unemployed decreased in the different samples over the Waves and the percentage reporting that they were looking after their home and family increased.

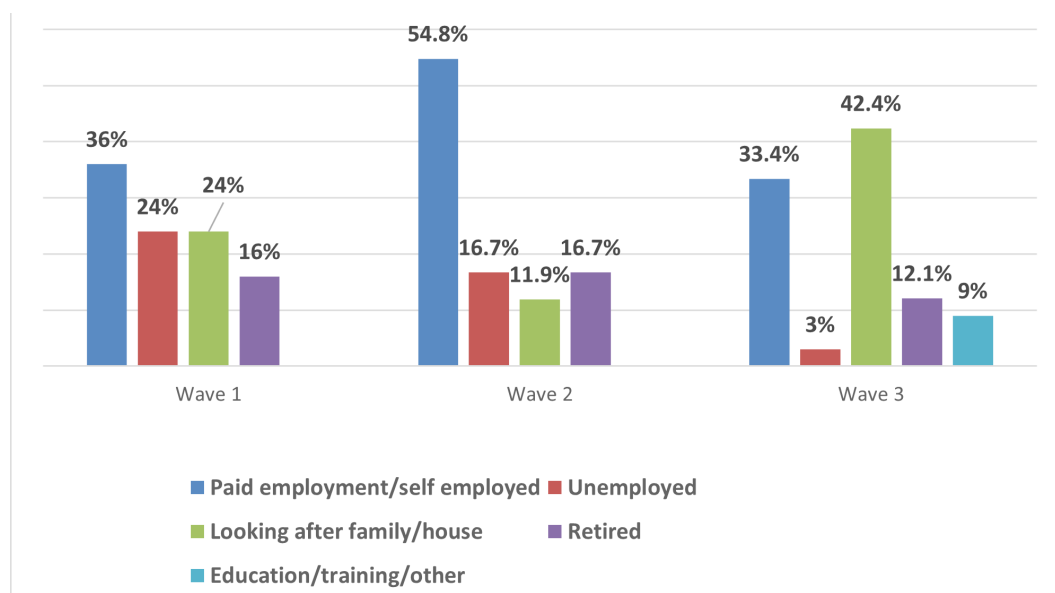


Figure 9: Sibling carers' employment status by wave

Four sibling carers in **Wave 1** (44.4% of responding carers); 13 sibling carers in **Wave 2** (34.2% of responding carers) and 10 carers in **Wave 3** (47.6% of responding carers) reported that they had given up work or cut down on their work hours because of their care responsibilities. Carers in each Wave were asked to give details about why they had given up or cut down on work some of which referred to reasons other than the care needs of the person with intellectual disability. Such reasons included the need to provide care to a parent or children and injury suffered by the carer. One carer in **Wave 2** identified that s/he works enough hours to stay eligible for Carers Allowance, however most responses referred to the need to provide care and can be typified by the following quotes:

Need to be here to put [name] on bus and to either collect him or let him in when bus drops him home (W104)

Inheriting caregiving role of sister (W260)

to be able to prepare and bring [name] to local services every day and be at home when she returns (W330)

Another **Wave 3** carer forfeited her job when s/he assumed the caring role and took a less well paid one that was more compatible with new responsibilities

Given up full time well paid job when I took on caring role. Had to go back to work for money and took a job that fitted in with caring hours and day service. (W337)

5.2.1.7: Finances

In each Wave, less than half the carers reported that they were in receipt of Carer's Allowance and only ten carers in both **Wave 2** and **Wave 3** reported that they were in receipt of the Half Carer's Allowance. Just one carer in **Wave 2** and **Wave 3** were in receipt of Carer's Benefit.

Six carers in **Wave 2** reported that they, themselves, were not in receipt of the Carer's Allowance but that other family members were. Three of these specified that their parent received the allowance and one explained that a qualifying family member was in receipt of it: "would have only got half carer's allowance due to pension so other daughter gets it" (W204)

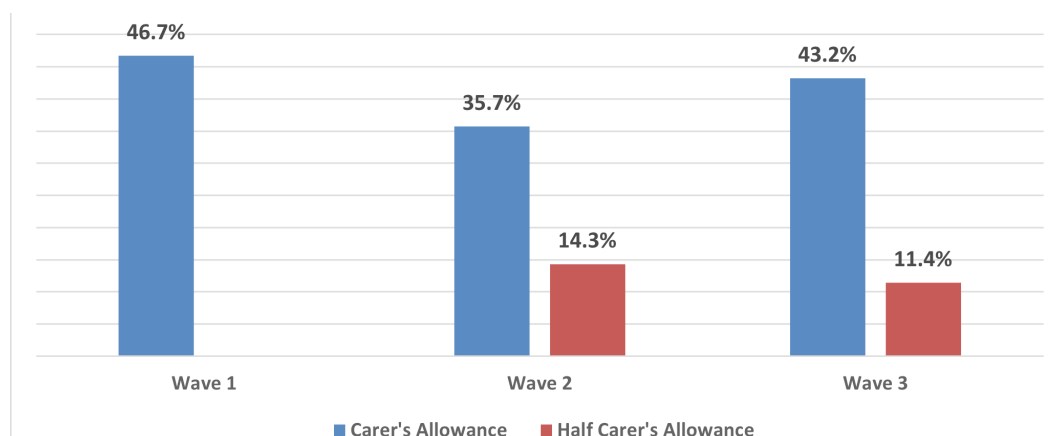


Figure 10: Carers in receipt of Carer's Allowance and Half Allowance

The Respite Grant, which has been retitled Carer's Support Grant, is an annual payment made to carers in receipt of Carer's Allowance, Carer's Benefit or the Domiciliary Care Allowance which is paid to qualifying parents of children with extra care needs. Despite that this payment should be paid automatically in June of each year only slightly more than 30% (n=22) of **Wave 2** carers reported receiving the Respite Grant and only 27% (n=12) in **Wave 3**.

The **Wave 3** questionnaire included additional questions about income. Twenty per cent of carers chose not to disclose their annual income. Almost 20% (n=8) of the 35 carers

who did respond reported an annual income of less than €15,000 and a further almost 20% reported an annual income of between €15,000 and €19,000. No carer reported an income of between €40,000 and €49,000. Three carers reported an annual income of €50,000 or more.

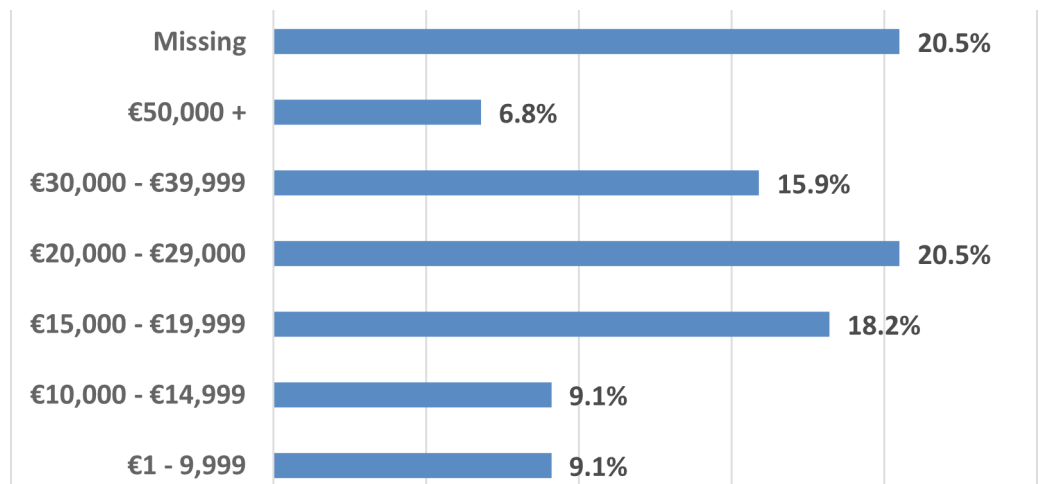


Figure 11: Annual income

All 44 **Wave 3** respondents answered the question which asked how they had managed financially in the last 12 months. Of these, six (13.6%) reported that they were living comfortably and 45.5% (n=20) that they were “doing alright”. Two carers reported that they were finding it difficult or very difficult and 36.4% (n=16) considered that they were “just about getting by”.

Half the 43 carers who answered the question about how they felt about their present income and almost 16% (n=7) felt that they were living comfortably. Twelve carers (27.3%) found it difficult to live on their income and one carer found it very difficult.

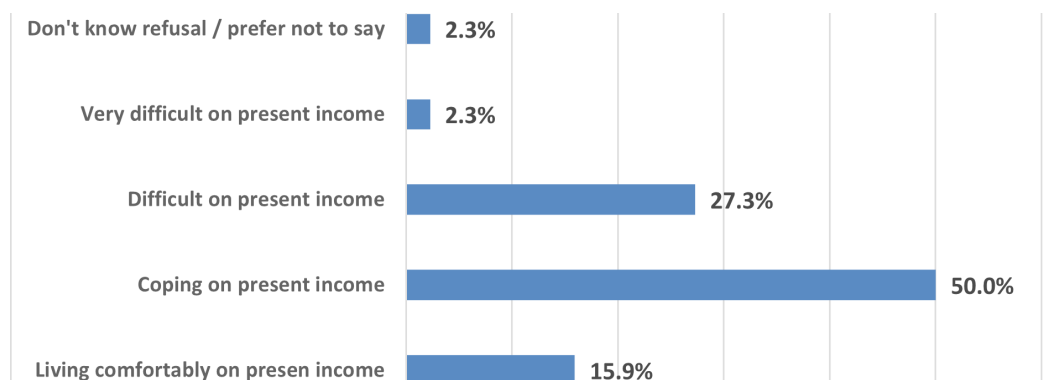


Figure 12: Feelings about household income

5.2.2: Support provision

5.2.2.1: Length of time in caring role

Wave 3 carers were also asked how long they had been in the caring role. Just over 30% (n=12) of the 39 carers who responded to the question had been caring for ten years or less and just under 30% (n=11) had been caring for between eleven and twenty years. One carer reported that s/he had been caring for more than sixty-one years and two others that they had been caring for between fifty-one and fifty-five years. Eight carers were in the caring role for five years or less. The range of responses to the question about length of time caring is presented in Figure 13 below:

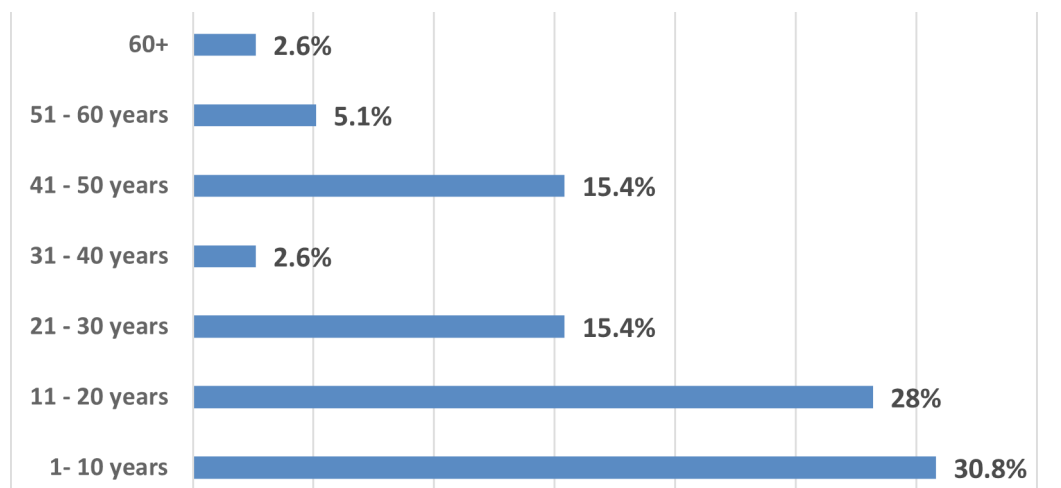


Figure 13: Number of years caring (Wave 3)

5.2.2.2: Care tasks

Carers were asked about the support they provide to the person they care for. This was framed around Activities of Daily Living (ADLs, n=8), Independent Activities of Daily Living (IADLs, n=4), a question about support for behavioural needs and one about support given with socialising and activities within the home.

The care tasks supporting activities of daily living which most frequently required support once or more than once a day are presented in Table 2 below. In all these instances a greater percentage of carers in **Wave 2** and **Wave 3** reported providing support with these care tasks, at that level of frequency.

Table 2: Percentage of carers providing support with ADLs once or at least once a day

	Wave 1	Wave 2	Wave 3
Medication	51.2% (21)	48.5% (32)	61.9% (26)
Dressing	35.3% (12)	28.4% (19)	48.7% (19)
Walking	21.6% (8)	12.1% (8)	26.3% (10)
Bathing	29.7% (11)	37.3% (25)	48.7% (19)
Oral Care	25.7% (9)	26.2% (16)	33.3% (13)
Getting in & out of bed	11.8% (4)	10.6% (7)	26.3% (10)

The IADL for which support was most frequently given was the preparation of a hot meal; 86.6% of carers in **Wave 1** provided such care, 89.2% in **Wave 2** and 85.8% in **Wave 3**. Most of these provided a meal at least once a day. As with the ADLs, a pattern of increased care provision is evident between Waves **1** and **3** which may suggest increasing dependency of the care recipients. Likewise, a great majority of carers provide support with money management, hot meal preparation, and grocery shopping. The percentage of carers providing support with IADL once or at least once a day is presented in Table 3.

Table 3: Percentage of carers providing support with IADLs once or at least once a day

	Wave 1	Wave 2	Wave 3
Hot meal preparation	63.4% (26)	73.8% (48)	73.1% (31)
Shopping	23.1% (9)	7.9% (5)	35.7% (15)
Phone calls	31.6% (12)	3.5% (2)	39% (16)
Managing money	35.9% (14)	13.1% (8)	41.5% (17)

5.2.2.3: Type of support required

Carers were asked to report the level of support which they provided, if at all, for the specific care tasks. The tasks most commonly requiring full physical assistance were hot meal preparation, money management, grocery shopping and bathing and showering. Carers in **Wave 2** and **Wave 3** more frequently reported providing partial of full support with medication, walking, bathing, oral care and getting in and out of bed than did the carers in **Wave 1**. This data is presented in Table 4.

Table 4: Percentage of carers providing partial or full physical support

	Wave 1	Wave 2	Wave 3
Medication	30.7% (12)	30.3% (20)	35% (14)
Dressing	35.1% (13)	9.2% (6)	32.5% (13)
Walking	22.2% (8)	11.1% (7)	28.2% (11)
Bathing	40.5% (15)	23.1% (15)	40% (16)
Oral Care	14.7% (6)	14.6% (9)	32.5% (13)
Getting in & out of bed	14.3% (5)	11.1% (7)	25% (10)

5.2.3: Understanding the experience of caring

5.2.3.1: Reasons for providing care

In **Wave 3** carers were asked to identify, from a list, the reasons that they provide care and could choose more than one option. The most frequently cited reason why the carers provide support was because “I am needed” (n=17). One quarter of the carers (n=11) reported that they provide support because they have always done so and 22.7% (n=10) because they are the parent of the care recipient. Just over 20% (n=9) of the carers reported that they provide support because they enjoy it and want to provide support. Almost 16% (n=7) of the carers felt obliged to provide support and 13.6% (n=6) provide support because of lack of services.

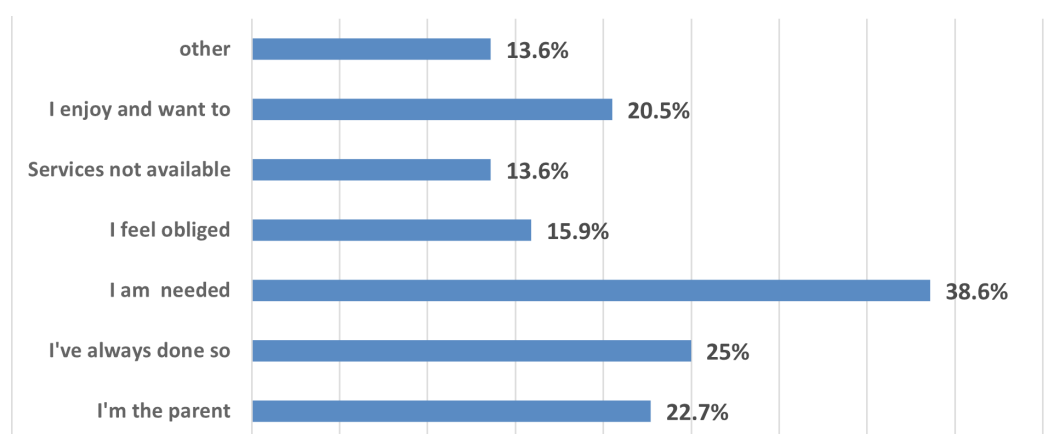


Figure 14: Reasons for providing care

Six carers reported that they provided care for reasons other than those offered and offered a text elaboration three of which focused on family relationships. One indicated that there was no alternative: “no other family members, no services available” (W327). Another carer identified that they provide support out of love for the care recipient:

because the person I support has expressed the wish to remain at home and I am trying to make this a reality for as long as I can. I also feel it is often the best place for anyone at home. Because I love and want the person to be happy (W335)

5.2.3.2: Difficulties associated with caring

Carers were asked about difficulties they experienced as caregivers and the most difficult aspects of caregiving.

5.4.2.1: In response to the first question and, across the three Waves, carers frequently endorsed the statement that caring is confining. More than half the carers in **Wave 1** and **Wave 3** endorsed this statement.

Just under half the carers in **Wave 1** and **Wave 3** endorsed the statement that they felt completely overwhelmed by their role, this percentage was 30 % in **Wave 2**. Just under half the carers in **Waves 1** and over half the carers in **Wave 3** reported that changes had to be made to family plans, this percentage was 36% in **Wave 2**. Just over 46% of carers in **Wave 1** and over 44% of carers in **Wave 3** reported that their care responsibilities had required adjustments within their family, one third of carers in **Wave 2** endorsed this statement. Fewer carers in **Wave 2** also reported that caring was a financial strain or that work adjustments had to be made. Carers in **Wave 2** more frequently reported that caring was inconvenient (30.4%) compared with those carers who participated in **Wave 1** (19.5%) and **Wave 3** (16.2%).

Endorsement of the statement that some care recipient behaviour is upsetting was 24.4% in **Wave 1** and 29% in **Wave 2**; the percentage of the **Wave 3** carers who endorsed the statement was 37.8%. Just under a quarter of carers in **Wave 1** reported that emotional adjustments had been required and the percentage rose to 30.4% in **Wave 2** and to 40% in **Wave 3**. Almost 30% of the **Wave 1** carers reported sleep disturbance, just over 30% of the **Wave 2** carers did so and this increased to almost 44% of the **Wave 3** sample of carers.

The suite of responses to the question is presented below in Table 5 below. The extent to which the individual questions were answered has resulted in some data appearing incongruous although it is, in fact accurate. Thus 41 of the 44 carers in **Wave 3** answered the question about sleep disturbance and 18 (43.9%) answered that their sleep was disturbed; whereas 38 of the 44 carers answered the question about family adjustments and 17 (44.4%) answered affirmatively.

Table 5: Impacts of caring

Impact	Wave 1	Wave 2	Wave 3
Completely Overwhelmed	48.8% (n=20)	29.9% (n=20)	48.7% (n=19)
Financial Strain	37.5% (n=15)	21.7% (n=15)	34.4% (n=11)
Work Adjustments	37.5% (n=15)	23.2% (n=16)	27.8% (10)
Changes in the care recipient is upsetting	12.2% (n=5)	22.1% (n=15)	30.6% (11)
Some care recipient behaviour upsetting	24.4% (n=10)	29.9% (n=20)	37.8% (14)
Emotional adjustments required	24.4% (n=10)	30.4% (n=21)	40% (n=14)
Changes made to family plans	48.8% (n=20)	36.2% (=25)	53.8% (21)
Family adjustments required	46.3% (n=19)	33.3% (n=23)	44.4% (17)
It's confining	51.2% (n=21)	47.8% (n=33)	51.4% (19)
A physical strain	12.5% (n=5)	29.4% (n=20)	30.8% (12)
It's inconvenient	19.5% (n=8)	30.4% (n=21)	16.2% (n=6)
Sleep is disturbed	29.3% (n=2)	30.4% (n=21)	43.9% (18)

5.4.2.2: Compared to **Wave 1**, fewer of the carers who participated in **Wave 3** carers identified lack of sleep and guilt as the most difficult aspect of the caregiving experience. However, all other difficulties were identified by more carers in **Wave 3** than in the other two Waves. Being constantly on-call was the most frequently cited difficulty and more than half the carers identified stress and emotional strain as the most difficult aspect of caregiving.

Just over one-quarter of the **Wave 3** carers did not associate any of these difficulties with their own experience. However, that percentage was lower than reported by either the **Wave 1** or **Wave 2** carers.

Table 6: Most difficult aspects of caring

Aspect	Wave 1	Wave 2	Wave 3
Lack of sleep	30.2% (13)	10.6% (7)	24.4% (10)
Isolation	20.9% (9)	7.6% (5)	24.4% (10)
Stress	37.2% (16)	18.2% (12)	56.1% (23)
Emotional strain	41.9% (18)	13.6% (9)	51.2% (21)
Being constantly on call	34.9% (15)	47% (31)	61% (25)
Frustration	27.9% (12)	12.1% (8)	34.1% (14)
Sadness for the person I care for	32.6% (14)	19.7% (13)	39% (16)
Guilt	16.3% (7)	9.1% (6)	14.6% (6)
None of these	32.6% (14)	33.8% (22)	26.8% (11)

In **Wave 1** Five respondents added a narrative to expand on their responses and these are presented below:

I can't do anything on the spur of the moment, I have to check respite etc (W144)

In my case, being abandoned by my other two siblings to take care of my sister by myself (W137)

Unable to do normal things with my own children/give them time (W103)

Big responsibility, non-acceptance by siblings that this person needs constant care and attention (W128)

Someone has to be with him at all times (W109)

Eighteen carers in **Wave 2** reported that there were other things that were the difficult consequence of caring. However, thirty-two respondents expanded on their response. Some took the opportunity to say there were no difficult issues with providing care and to reference how undemanding the care recipient is (in one instance it was specified that this was because the care recipient was only with the carer at weekends):

None he is very easy (W217)

Low maintenance guy, very good in terms of behaviour and health (W257)

Two carers reported that the carer and care recipient cared mutually for each other. Three carers suggested that acceptance of the situation was important

Don't let it get you down. Accept it. Lucky, she is great (W248)

Just accept that this is the way it is (W224)

Other carers identified the stress of always being on-call and never having time to oneself:

very stressed out. No time alone. He goes nowhere. It's not easy but then he is my brother and I love him" (W234).

Two expressed their sadness for the care recipient: “Disappointment for the loss of opportunities that having an ID limits” (W223) and two experienced guilt at not being able to give their own children as much time as they would like to. A carer expressed resentment that s/he was the family member providing care without input from siblings; others also described the isolation of caring “No connection with other carers. It’s all about being cared for. It’s like you don’t exist” (W260). Two carers were caring for a person who was changing due to dementia: “Telling you something 100 times a day” (W258). Several carers identified a generalised level of stress: “stress of whole situation” (W230) or worry including worries for the future or worry experienced when the care recipient is elsewhere: “worry about him when I am not here” (W253).

Three carers reported behavioural difficulties on the part of the care recipient as difficulties with one noting that the behavioural difficulties were “small things” that “add up” and which “can drag you down” (W251). Others gave details about the experience of confinement, not being able to make plans of their own, being tied to the needs of the care recipient and the level of organisation required if the carer wanted some time on their own. One carer noted that although s/he doesn’t “mind caring for him”, it still “would sometimes drive you mad” (W252). Another identified the very close connection the s/he had with the sibling with intellectual disability: “Grew up with him “”part of who I am” and their perception that this deep connection was being exploited: “the system takes advantage of this ‘cruel’, so cruel” (W255).

Six carers in In **Wave 3** added a text response. Some expressed the benefits which they get from caring

keeps me company sometimes. She’s very pleasant (336)

keeps connection with family and my sister...gives a sense of value to my children and appreciate family (W301)

seeing brother coming out of severe depression because of positive help (W322)

Two carers spoke of the love that they felt for their family member including the carer quoted below:

[name] is family, we have cared for her 26 years before she developed dementia so of course we would continue as we love her deeply and hope she will always understand we love her (W320)

For another carer, life as a carer was characterised as a battle

constantly having to fight to get him what he needs (W312)

5.2.3.3: Positive aspects of caring

Carers were asked to report on positive aspects related to caring by indicating how much they agreed with eight statements.

5.2.3.3.1: *Feeling useful*

Almost two-thirds of the carers in the **Wave 1** sample agreed with the statement that caring made them feel useful with 37.2% (n=16) agreeing “a lot”. A smaller percentage of the **Wave 2** sample agreed (59%, n=39) and a smaller percentage again of the **Wave 3** carers did so (52.4%, n=22). The percentage agreeing “a lot” was also lower in the responses in **Wave 2** (27.2%, n=18) and **Wave 3** (28.6%, 12).

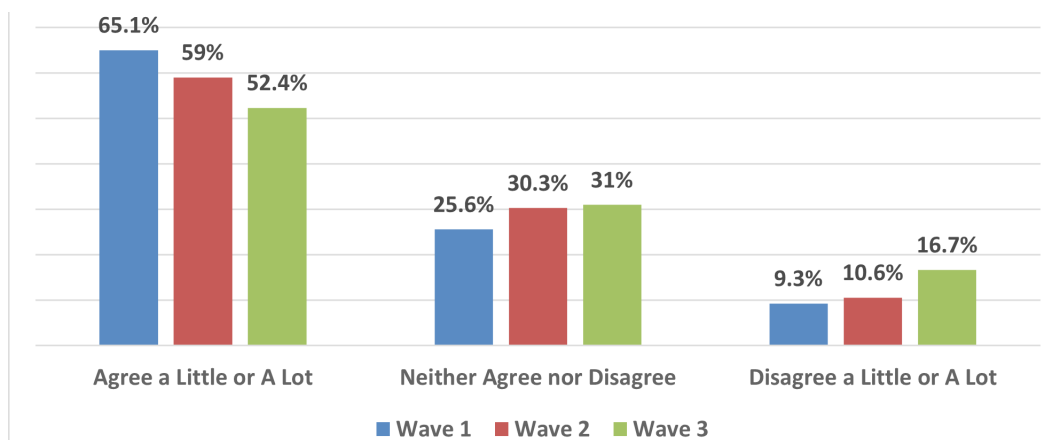


Figure 15: Providing support makes me feel useful

5.2.3.3.2: *Feeling good*

In **Wave 1**, almost 60% (n=25) of the participating carers agreed that providing care made them feel good about themselves; most of these (35.7%/15) agreed “a lot” with the statement. The carers in subsequent waves were less positive. In **Wave 2** the percentage of carers who agreed was 54% (n=34) (30.2%, n= 19 agreeing a lot) in **Wave 2** and in

Wave 3 it was 45.2% (n=19) with 23.8% (n=10) agreeing “a lot”. Whereas less than 12% (n=5) of **Wave 1** carers disagreed with the statement, 19% (n=8) in **Wave 3** did so.

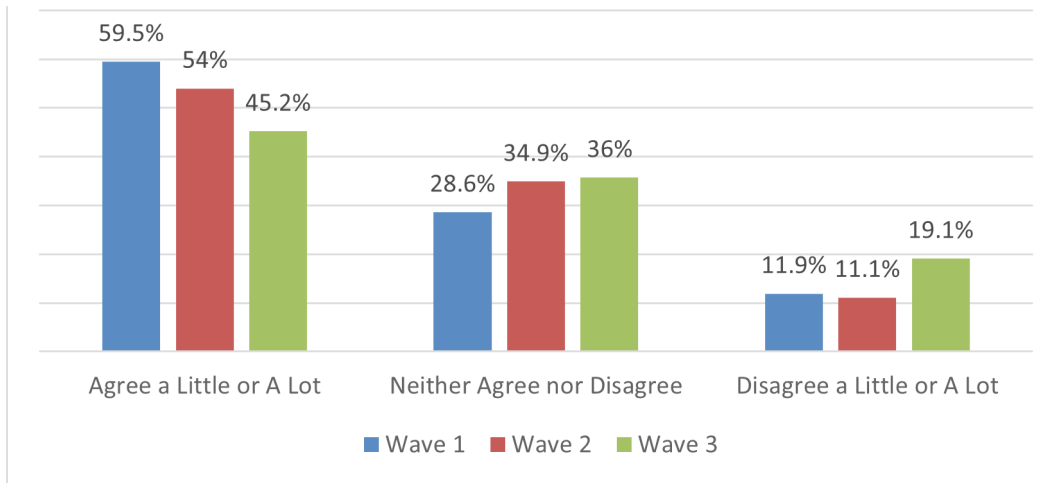


Figure 16: Providing care makes me feel good about myself

5.2.3.3.3: *Feeling needed*

Most responding carers in **Wave 1** agreed that providing care made them feel needed with just over 60% (n=16) agreeing with the statement and 32.6% (n=14) agreeing “a lot”. Just over half the participating carers agreed with the statement in **Wave 2** and 54.8% (n=23) of the **Wave 3** carers did so. The percentage agreeing “a lot” in **Wave 2** was 27.4% (n=17) and 31% (n=13) in **Wave 3**. A greater percentage of carers in **Wave 2** and **Wave 3** disagreed with the statement than in **Wave 1**.

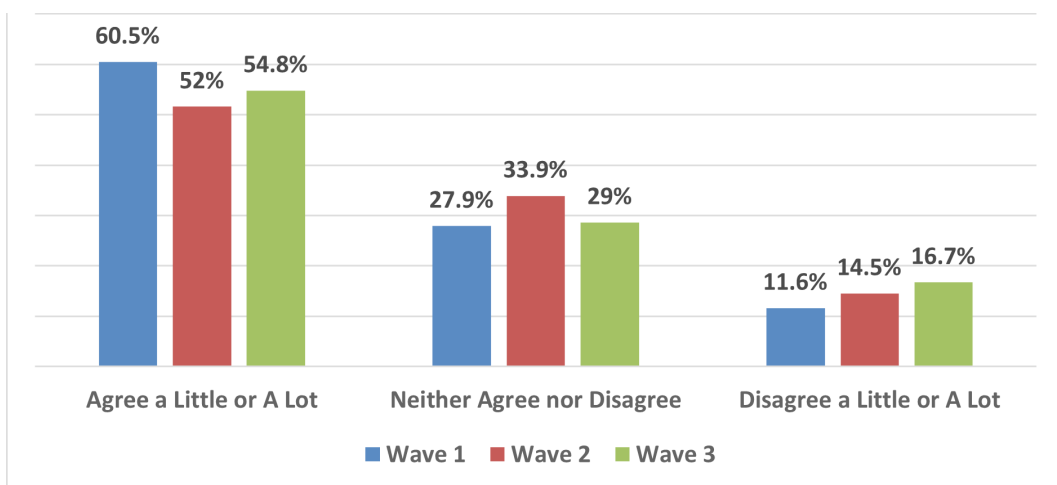


Figure 17: Providing care makes me feel needed

5.2.3.3.4: *Feeling appreciated*

As with the previous statements, the percentage of carers agreeing with the statement that providing care made them feel appreciated was highest among the **Wave 1** carers with just over 56.1% (n=23) agreeing with the statement; 32.6% (n=10) agreed “a lot” with the statement. The percentage of carers agreeing with the statement in **Wave 2** was 46.9% (n=30) and 40.6% (n=17) in the **Wave 3** sample. In **Wave 1** the percentage “agreeing a lot” was 24.4% (n=10); in **Wave 3** it was 21% (n=13).

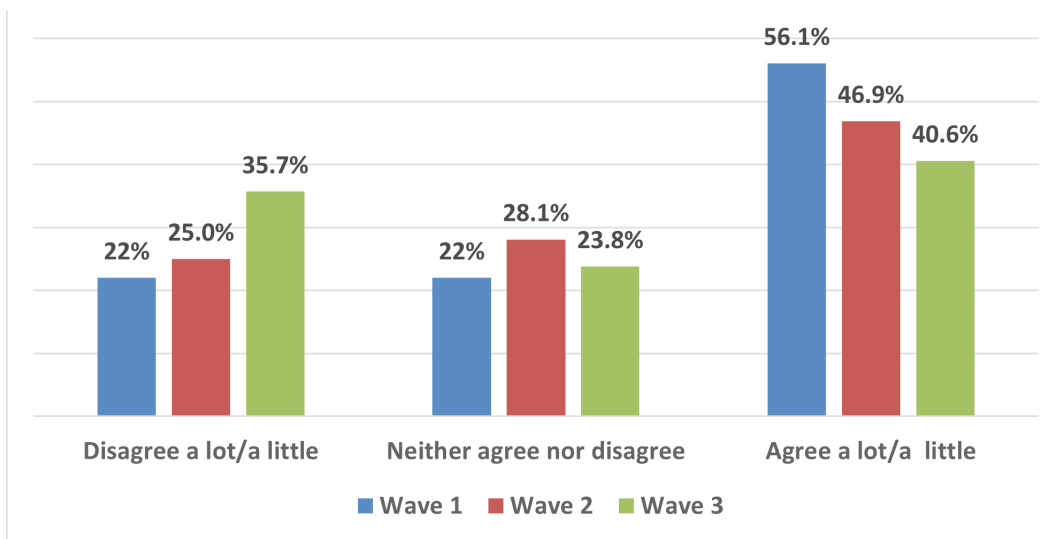


Figure 18: Providing care makes me feel appreciated

5.2.3.3.5: Feeling strong and confident

The percentage of carers agreeing with the statement that providing care made them feel strong and confident rose as highest among the **Wave 3** participants. The percentage at **Wave 1** was 22.5% (n=9), it was 25% (n=15) in **Wave 2** and 39% (n=16) among the **Wave 3** sample. Just 7.5% (n=3) agreed “a lot” with the statement at **Wave 1**; 8.2% (n=5) agreed “a lot” at **Wave 2** and most of the **Wave 3** carers who agreed, agreed “a lot” at **Wave 3**, 24.4% (n=10).

Although the percentage of **Wave 3** carers agreeing with the statement was at its highest at **Wave 3**, so also was the percentage disagreeing. More than one third of carers disagreed at **Wave 3** (n=14); slightly less disagreed at **Wave 1** (32.5%, n=13) and just over one quarter (26.2%, n=16) disagreed at **Wave 2**.

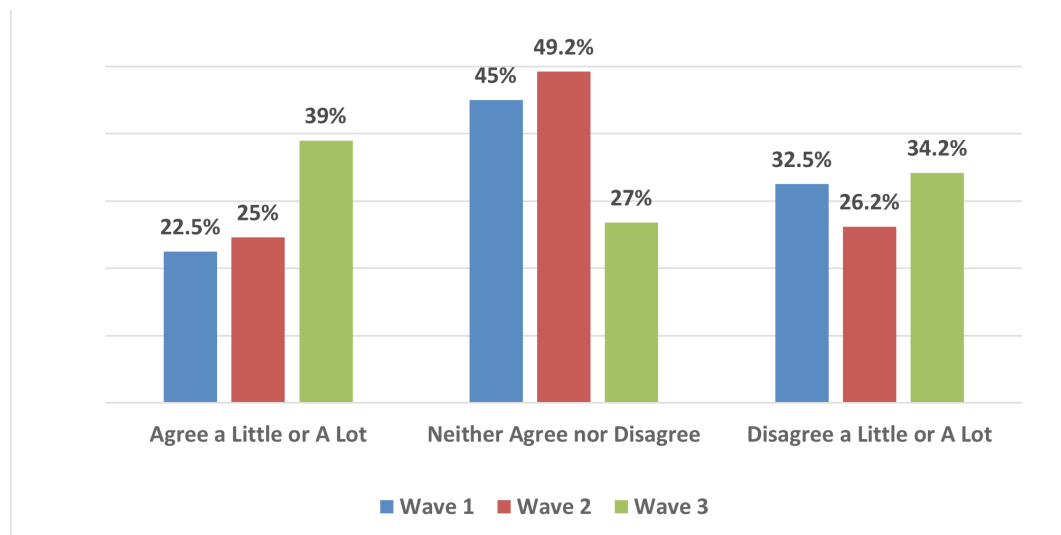


Figure 19: Providing care makes me feel strong and confident

5.2.3.3.6: Positive life attitude

The carers who participated in **Wave 1** were least likely to agree with the statement that providing care gave them a positive attitude towards life with 41.5% (n=17) agreeing (22%, n=9 agreeing a lot). **Wave 2** carers most frequently agreed with the statement

with 61.3% (n=38) agreeing (48.4% agreeing “a lot”). The percentage of carers agreeing in **Wave 3** was 57.1% (24) with 35.7% (n=15) with agreeing “a lot”.

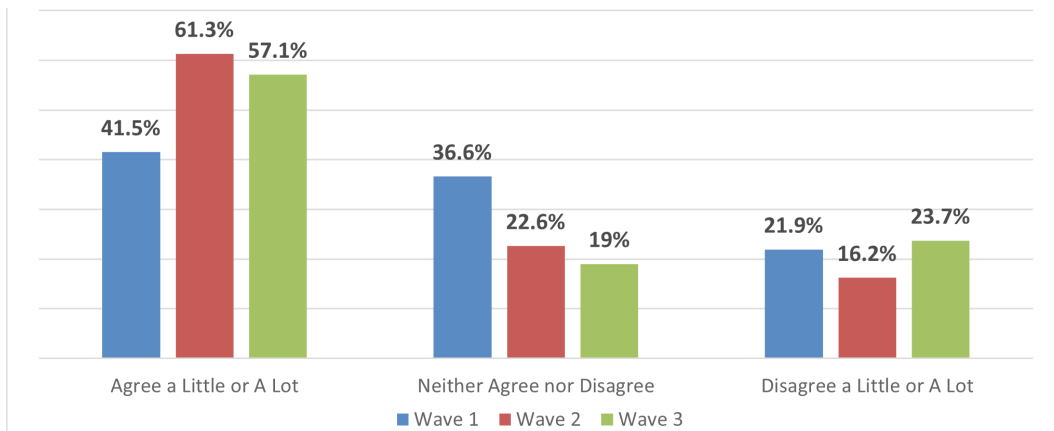


Figure 20: Providing care gives me a positive attitude towards life

5.2.3.3.7: Strengthening relationships with others

Less than half the carers in **Wave 1, 2** and **3** agreed with the statement that providing care had strengthened their relationships with others. Forty-four percent of carers agreed in both **Wave 1** (n=18) and **Wave 2** agreed with the statement (22% agreed “a lot” in **Wave 1** (n=9) and 26.2% (16) in **Wave 2**). The percentage agreeing in **Wave 3** was 39.6% (n=17) with 25.6% (n=11) agreeing “a lot”.

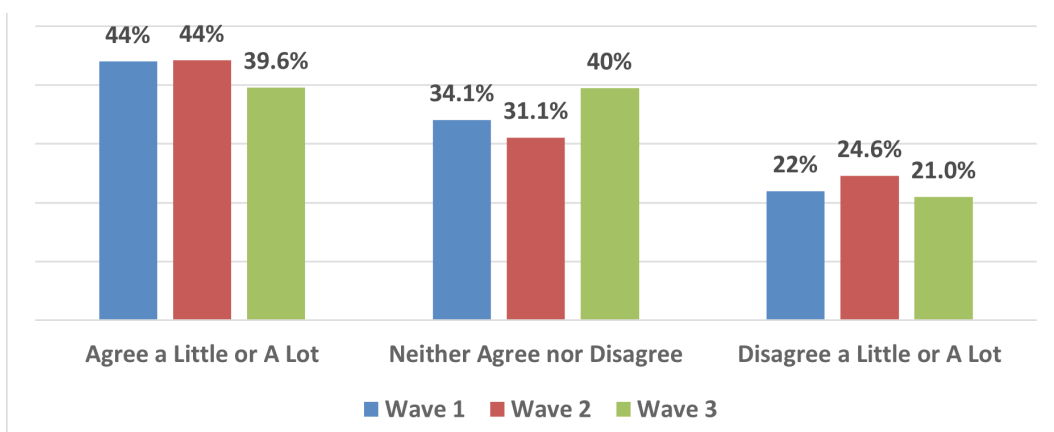


Figure 21: Providing care has strengthened my relationships with others

5.2.3.3.8: *Appreciating life more*

Almost three-quarters of the carers in **Wave 2** (n=47) agreed with the statement that providing care made them appreciate life more; and 53.1% (n=34) of these agreed “a lot”. Almost 60% of the carers who participated in **Waves 1 and 3** agreed: 57.2% (n=24) agreed in **Wave 1** and 58.5% (n=24) in **Wave 3**. The percentage agreeing “a lot” was 26.2% (n=11) in **Wave 1** and 34.1% (n=14) in **Wave 3**.

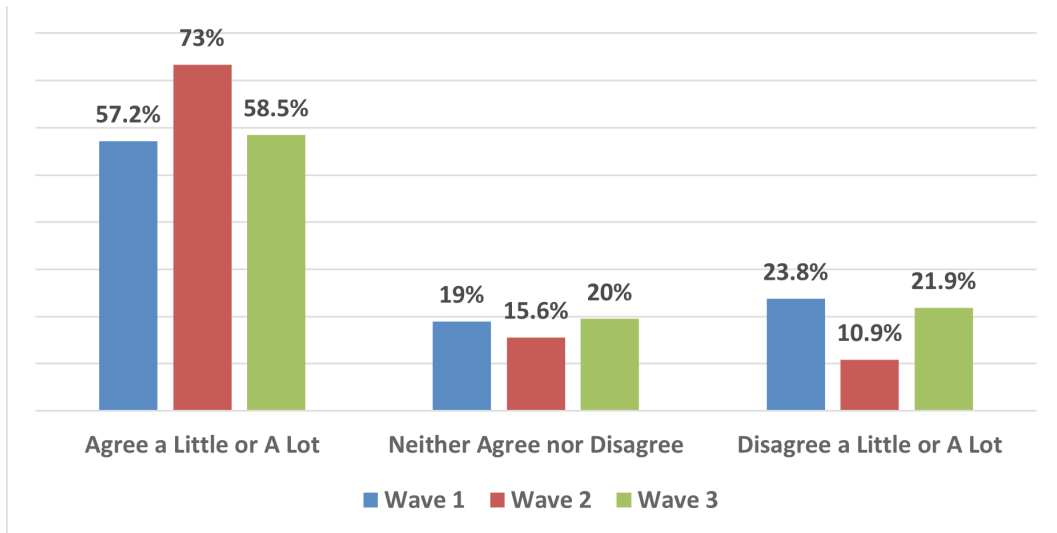


Figure 22: Providing care makes me appreciate life more

5.2.3.3.9: *Feeling important*

In **Waves 1** and **2**, carers were asked to respond to the statement that caring made them feel important. Few carers agreed with the statement in either Wave; 15% (n=9) agreed in **Wave 2** and 14.7% (6) in **Wave 1**. In both Waves, carers were most likely to neither agree nor disagree.

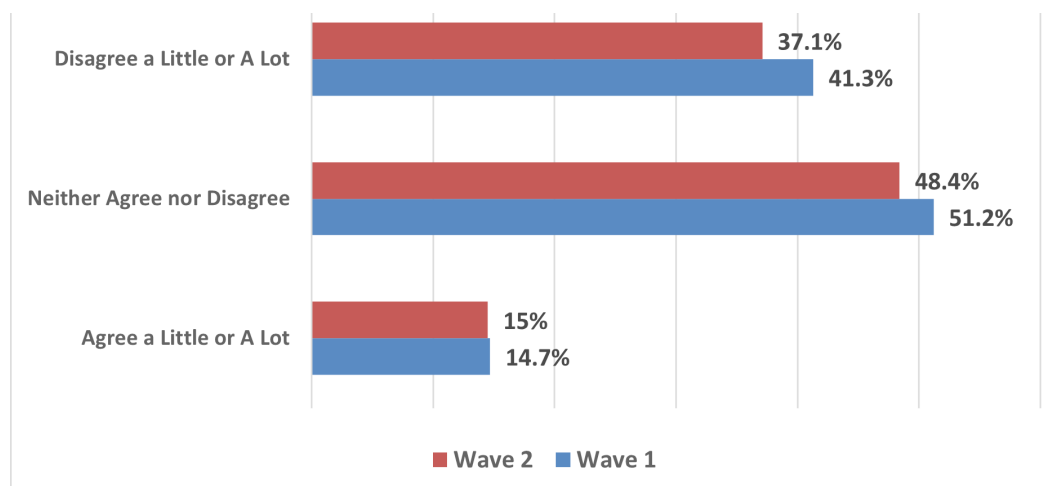


Figure 23: Providing care makes me feel important

5.2.3.3.10: *Overall positive reports*

Considering the responses to all the statements about the positive aspects of caring, carers were least likely to agree that caring made them feel strong and confident although the percentage was highest in **Wave 3**. Less than half the carers in all three Waves agreed that caring had strengthened relationships. The carers who participated in **Wave 2** and **Wave 3** less frequently agreed with the following statements that did the **Wave 1** carers: providing support has made me feel more useful; providing support has made me feel good about myself and providing support has made me feel needed.

Table 7: Positive aspects of caregiving across the three waves

	Wave 1	Wave 2	Wave 3
Feel useful	65.1% (n=28)	59.1% (n=39)	52.4% (n=12)
Feel good about myself	59.5% (n=25)	54% (n=34)	45.2% (n=19)
Feel needed	60.5% (n=26)	51.6% (n=32)	54.8% (n=23)
Feel appreciated	56.1% (n=23)	46.9% (n=30)	40.5% (n=17)
Feel strong & confident	22.5% (n=9)	24.6 (n=15)%	39% (n=16)
Appreciate life	57.2% (n=24)	73.4% (n=47)	58.5% (n=24)
Have a positive attitude	41.5% (n=17)	61.3% (n=38)	57.1% (n=24)
Strengthened relationships	44% (n=18)	44.2% (n=27)	39.6% (n=17)

5.2.3.4: Coping Strategies

Talking to friends was the coping strategy most frequently identified by the carers across the three Waves. The percentage identifying that they used this coping strategy was 48.9% in **Wave 1**, 57.6% in **Wave 2** and 66.7% in **Wave 3**. Respite was used by over 35% of the carers in **Waves 1** and **3** and by just over 40% in **Wave 2**. Exercise, as a coping strategy, was nominated by just over one third of carers in **Wave 2** and more than one half in **Wave 3**. The more passive strategy of TV watching was identified by 40% in **Wave 1** and 45.2% in **Wave 3** although the percentage was just 18% in **Wave 2**. Praying or faith was endorsed as a strategy by many carers with 44.4% endorsing it in **Wave 1**, 24.2% in **Wave 2** and 33.3% in **Wave 3**.

Very few carers identified the use of support groups or telephone support lines as a coping strategy with no carers endorsing it in **Wave 3**. Other rarely endorsed strategies were the use of alternative medicine, smoking, or drinking alcohol.

Table 8: Coping strategies across Waves 1, 2 and 3

Strategy	Wave 1	Wave 2	Wave 3
Talk to Friends	48.9% (22)	57.6% (38)	66.7% (28)
Watch TV	40% (18)	18.2% (12)	45.2% (19)
Exercise	37.8% (17)	33.3% (22)	54.8% (23)
Drink Alcohol	8.9% (4)	4.5% (3)	7.1% (3)
Smoke	2.2% (1)	3% (2)	0%
Take Medication	6.7% (3)	3% (2)	2.4% (1)
Use Respite	37.8% (17)	40.9% (27)	35.7% (15)
Attend Support Group	5.7% (3)	6.1% (4)	0%
Use Phone Line Support	2.2% (1)	7.6% (5)	2.4% (1)
Alternative Medicine	2.2% (1)	4.5% (3)	0%
Praying or Faith	44.4% (20)	24.2% (16)	33.3% (14)
None of these	8.9% (4)	13.6% (4)	9.5% (4)

In **Wave 1**, eight (17.8%) carers reported that they used strategies other than those suggested in the questionnaire and seven offered text elaborations. One comment highlighted the isolation of the carer: “No friends, no-one to talk to” (W130). Others carers identified that they: “Just get on with it” (W109); and “We just live as normal as possible” (W124). One carer wrote of support received: “Support of my own family members”(W103) and another that “I feel privileged to be able to support [name]” (W136). A carer reported that s/he attends counselling and another identified a hobby that s/he uses as a coping strategies.

In **Wave 2**, 22 (32.8%) carers reported that they use strategies other than those listed and 38 gave a text response. Five identified that the care recipient did not live with them on a full-time basis and others suggested that “coping” was not a relevant concept:

Not applicable (W214)

N/a as this is part of life (W261)

Happy to do it (W227)

He is no trouble at all (W252)

Enjoy looking after her, happy to be able to do it (W203)

he is great company. (W264)

One carer suggested that a carer can become overwhelmed even when their relationship with the care recipient is a good one: “special bond doesn’t keep you sane” (W260). It was also suggested that what was required was a positive and a ‘just get on with it’ attitude

done it so long, part of life. never give it a thought, has to be done, no big deal (W212)

never think about it. Take things day to day (W215)

work read paper, relax. Just carry on and do what I have to do (W246)

Others identified that they received the support that they require from family members and two specified their spouse. One carer stated that: “There are no support groups around” (W256) and another noted that they should explore that option. Other carers identified having outside interests including involvement in the community, photography, a book club and working with a youth club.

In **Wave 3**, carers offered the following insights into their way of coping: respite when I can get it; (W329) bingo & being with daughter (W313); help of partner (W318); hobby & craftwork (W330); involved with youth organisation (W301); play sports & dance (W344); reading (W341); talk to each other (W320); talk to family & read (W321)

5.2.4: Family and Social Networks

5.2.4.1: Regular support received

In response to the question as to whether the carer received regular support from others almost 60% (n=26) of carers in **Wave 1** reported that they received such support; 75% (n=53) of **Wave 2** carers did so and 47.3% (n=21) of the **Wave 3** sample.

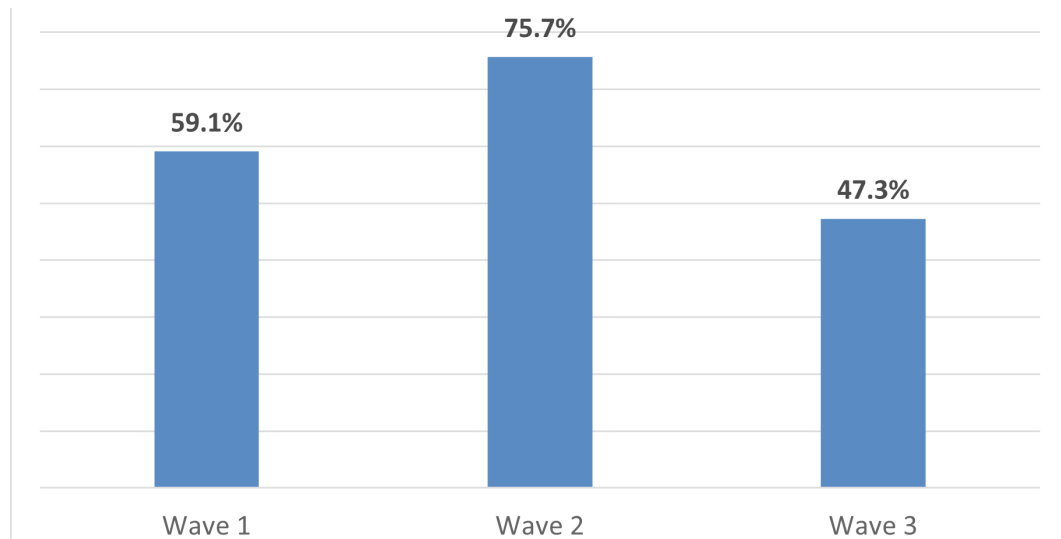


Figure 24: Regular support received from others

5.2.4.2: Support from partner or spouse

Carers were asked to rate the level of support which they received from six potential sources of support. Half the responding carers in **Wave 1** (n=21) and **Wave 2** (n=34) reported that they received a lot of support from their partner or spouse, the percentage of **Wave 3** carers was 36.8% (n=14). The percentage of carers responding that the question was not applicable to them was 40.5% (n=17) in **Wave 1** and a similar 39.5% (n=15) in **Wave 3** and 35.3% (n=24) in **Wave 2**.

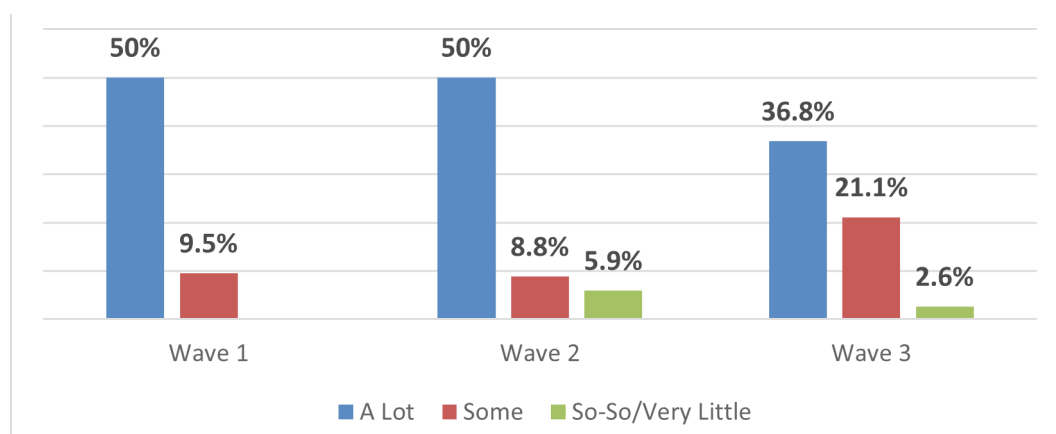


Figure 25: Rating of support given by spouse or partner by wave

5.2.4.3: Support from parents

For the great majority of carers, across the Waves, the question about support received from parents was not applicable. The rating of “a lot” of support from this source was 5% (n=2) at **Wave 1**, and 9% at **Waves 2** (n=6) and **3** (n=3). Few carers in the three waves endorsed the “little, some or so-so” rating: 3% (n=1) in **Wave 3**, 5.1% (n=2) in **Wave 1** and 7.7% in **Wave 2** (n=5).

5.2.4.4: Support from children

The question of support received from children was considered not applicable to almost one-third of carers in **Waves 1** (n=14) and **3** (n=12) and by 20% (n=13) of carers in **Wave 2**. Almost half the carers in **Wave 2** (n=32) reported receiving “a lot” of support from their children; this figure was less than one-third in **Wave 3** (n=12) and one-quarter in **Wave 1** (n=11).

The percentage of carers reporting receiving “some support” from their children was 43% (n=19) in **Wave 1**, 18% (n=12) in **Wave 2** and 13% (n=5) in **Wave 3**.

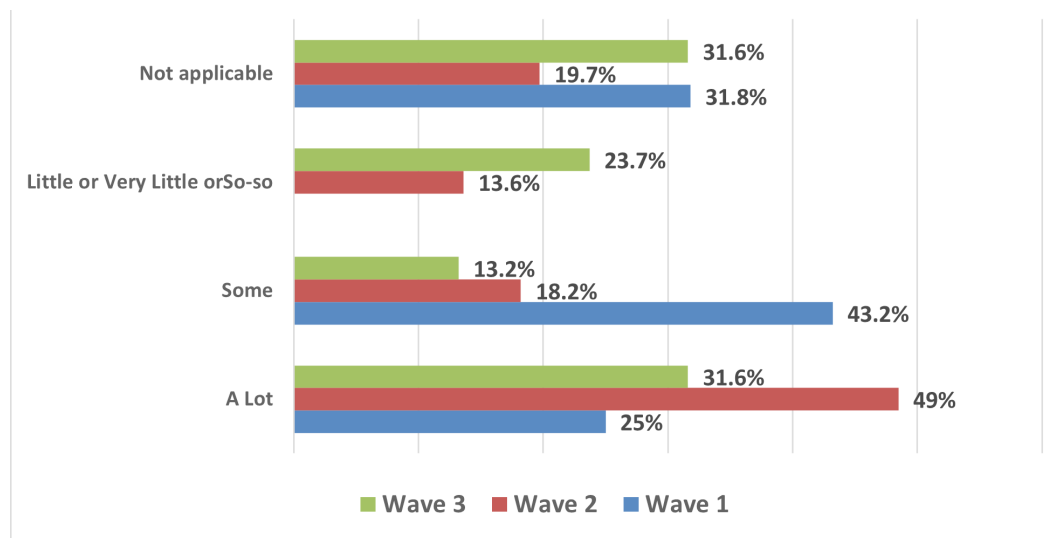


Figure 26: Rating of support from children

5.2.4.5: Support from other close relative

More than two-thirds of carers reported receiving “a lot” or “some” support from this source in **Wave 1** (n=28) whereas the percentage was just over 45% (n=28%) in **Wave 2** and just over 43% (n=17) in **Wave 3**. A smaller percentage of **Wave 3** carers reported that the question of support from other close relatives was not applicable to them 17.9% (n=7) than **Wave 2** carers 24.2% (n=15) or **Wave 1** carers 31.7% (n=13).

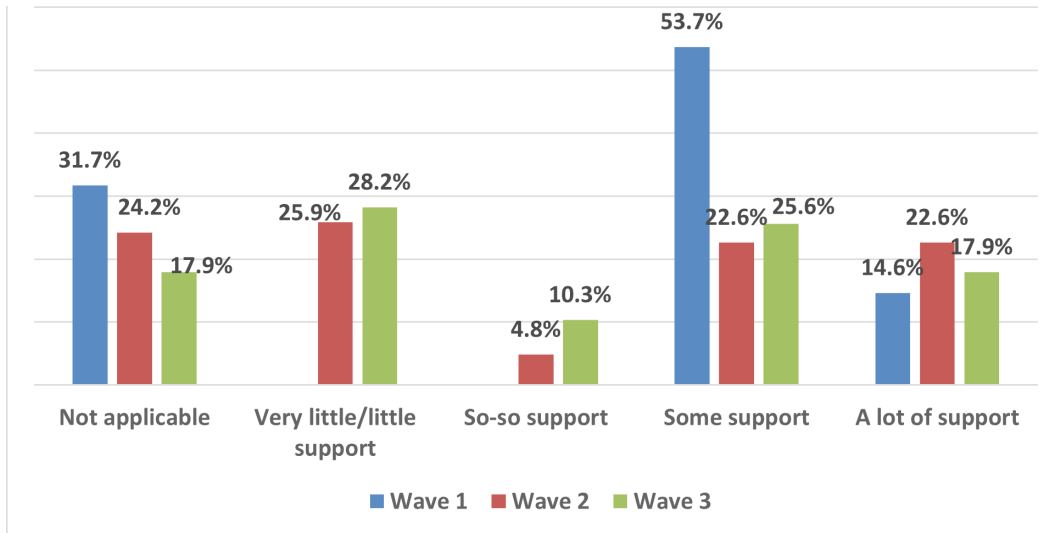


Figure 27: Rating of support from other close relatives

5.2.4.6: Support from friends

Few carers reported receiving “a lot of” support from friends; less than 5% (n=2) in **Wave 1**, 14% in **Wave 2** (n=8) and in **Wave 3** the percentage was 13.5% (n=5). More than 40% reported the question to be not applicable to them across all three Waves. In **Wave 1** almost half the carers (n=20) reported receiving “some support” from friends, this figure was 13.8% (n=8) in **Wave 2** and 19% in **Wave 3** (n=7).

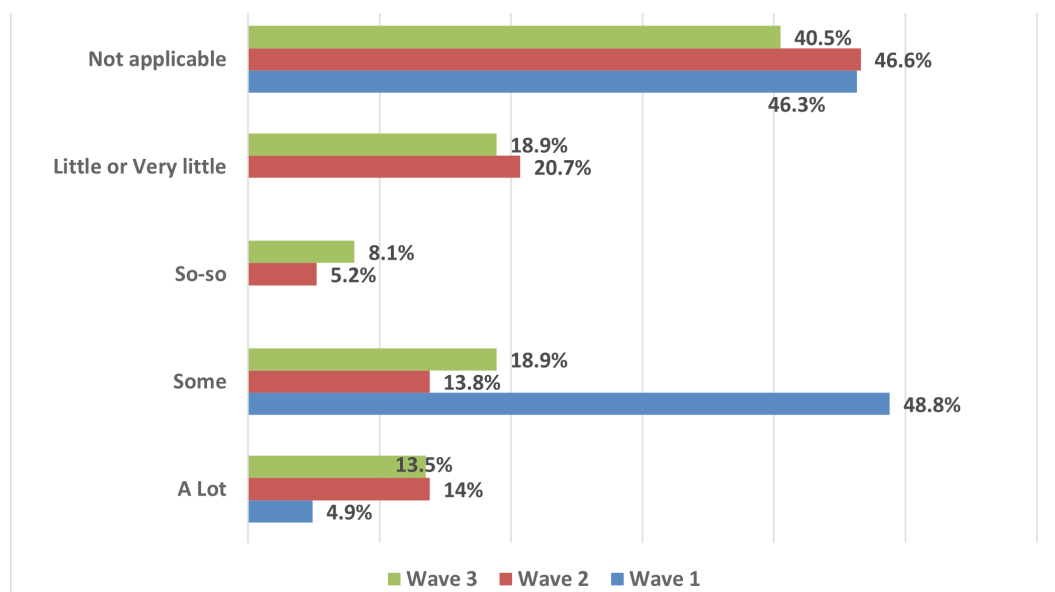


Figure 28: Rating of support provided by friends

5.2.4.7: Workplace support

The question of support in the workplace was reported to be not applicable for most of the carers across all three Waves. In **Wave 1** 80% (n=32) of responding carers reported the question about support from an employer or boss was not applicable to them. This percentage was 90% (n=56) in **Wave 2** and 78.1% (n=25) in **Wave 3**. Similarly, 80% (32) % of **Wave 1** carers reported that the question of support from colleagues was not applicable, 95% (n=59) of responding caregivers in **Wave 2** and 77% (n=23) in **Wave 3** reported likewise. The level of missing data in **Wave 3** was much higher than that in the other two Waves.

Two **Wave 1** carers (5%) reported that they received “a lot” of support from their employer or boss and no carers reported receiving such support from others in the workplace. Likewise, two carers in **Wave 2** (3.2%) reported receiving “a lot” of support from their boss or employer and two (3.2%) reported receiving “a lot” of support from others in the workplace. In **Wave 3**, the numbers reporting such support were one (3.1%) and zero respectively.

5.2.5: Carers' Health and Quality of Life

5.2.5.1: Carers quality of life

More than two-thirds of **Wave 1** (n=31) carers reported a good or very good quality of life; three quarters of **Wave 2** (n=51) carers did so whereas less than two thirds of **Wave 3** carers did so. **Wave 2** carers most frequently reported a good or very good quality of life and least frequently reported a poor quality of life (n=2). Almost 9% (n=4) of **Wave 1** carers reported a poor or very poor quality of life compared to 4.6% of **Wave 3** carers and 2.9% of **Wave 2** carers (n=1).

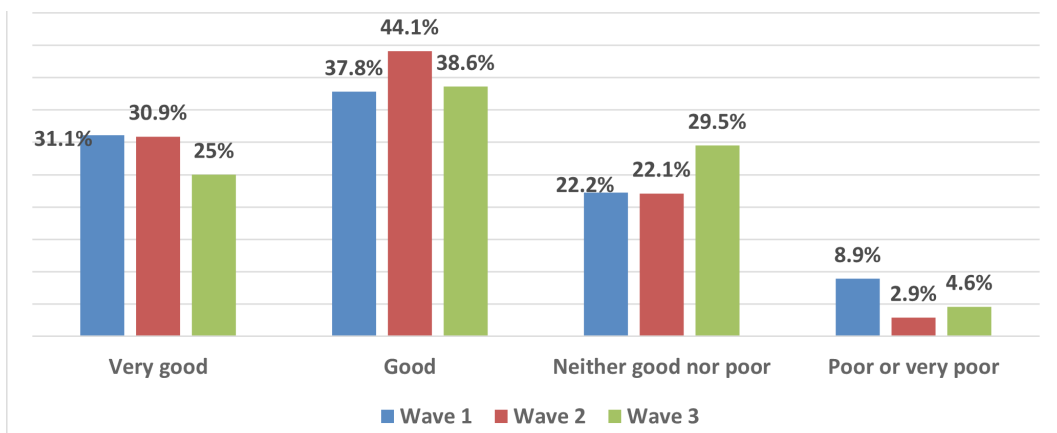


Figure 29: Carers' quality of life

5.2.5.2: Carers' general health

In **Wave 1** forty-six carers rated their general health. 80.4% (n=37) rated their health as good, very good or excellent with 17.4% (n=8) giving a fair rating and 2.2% (n=1) a poor rating. A higher proportion of the **Wave 2** carers (85.8%, n=60) rated their health as good, very good or excellent. Almost 13% (n=9) rated their health as fair and just one carer (1.4%) rated their health as poor. The carers in **Wave 3** were least positive about their health, nevertheless 75.1% (n=33) rating their health as excellent, very good or good. Less than 20% of **Wave 3** carers rated their health as fair and 2 carers (4.5%) rated their health as poor.

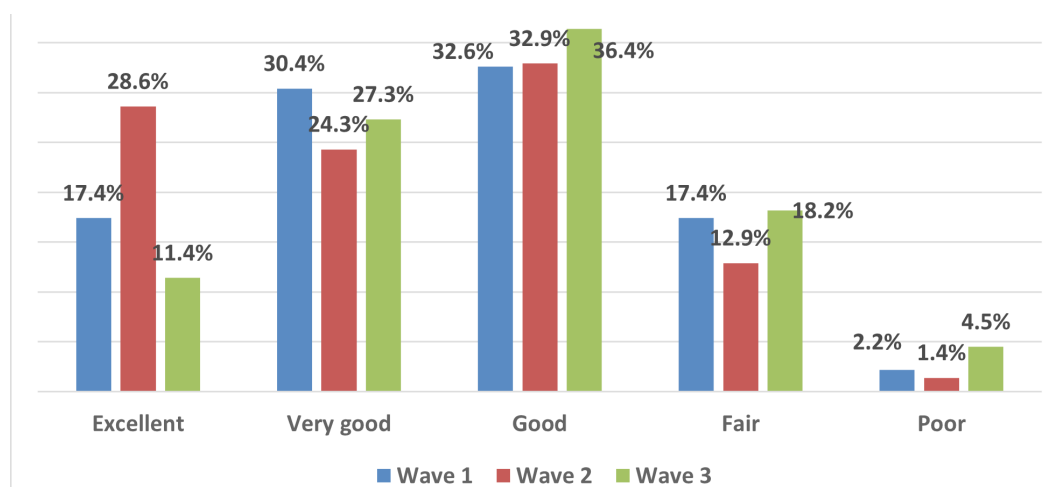


Figure 30: Carers' general health

5.2.5.3: Health over previous 4 weeks

Carers in **Waves 2** and **3** were also asked how they rated the health over the previous 4 weeks. Almost 56% (n=39) of the carers in **Wave 2** rated their health as “excellent” or “very good” and less than one-third of the carers in **Wave 3** did so. **Wave 3** carers most frequently rated their health over the previous 4 weeks as “good” and one quarter as “fair”. Three carers in **Wave 3** rated their health as “poor”; one carer did so in **Wave 2**.

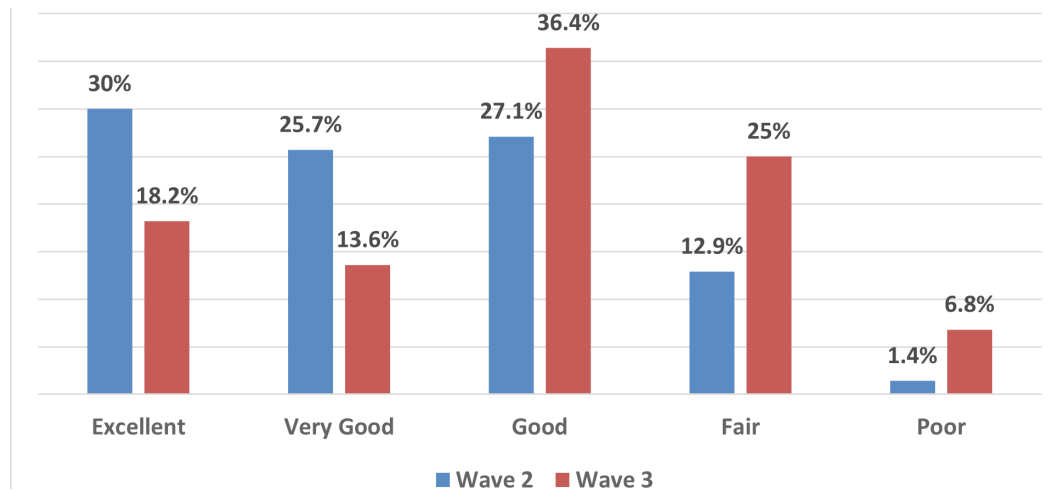


Figure 31: Health over the past 4 weeks

5.2.5.4: Limitations on daily activities

The carers who participated in **Wave 3** were least likely to report that their daily activities are limited by long-term illness, health problems or disability. Twenty-seven percent of carers in **Waves 1** (n=12) and 20% (n=14) reported such restrictions, the percentage in **Wave 3** was 18.2 (n=8)%.

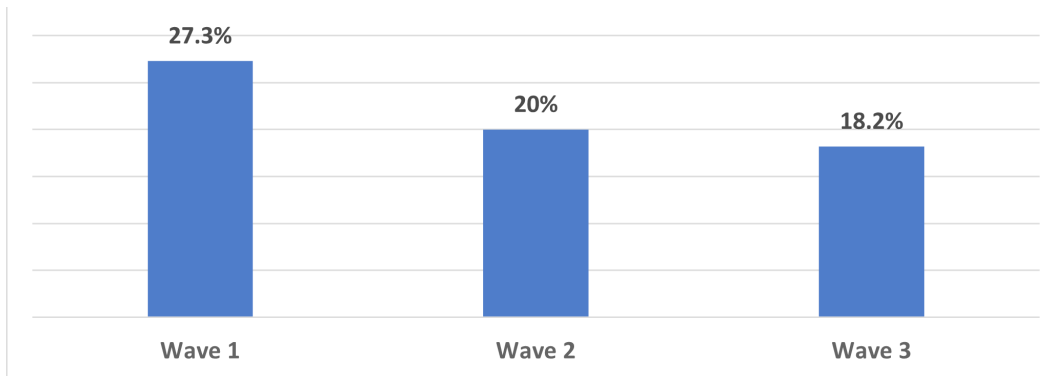


Figure 32: Daily activities limited by long-term illness, health problems or disability

5.2.5.5: Carers' health compared to others

More than half the **Wave 3** carers (52.2%) reported that their health compared to others was excellent or very good. One third of **Wave 1** carers (33.3%, n=15) and 45.7% of **Wave 2** (n=32) carers gave their comparative health an excellent or very good rating. Just over 20% of the carers (22.2%, n=10) in **Wave 1** and 15.9% of carers in **Wave 3** rated their health as fair compared to others; the percentage in **Wave 2** was just 5.7% (n=4). No carers in **Wave 1** rated their health compared to others as poor, one carer did so in **Wave 2** and two carers in **Wave 3**.

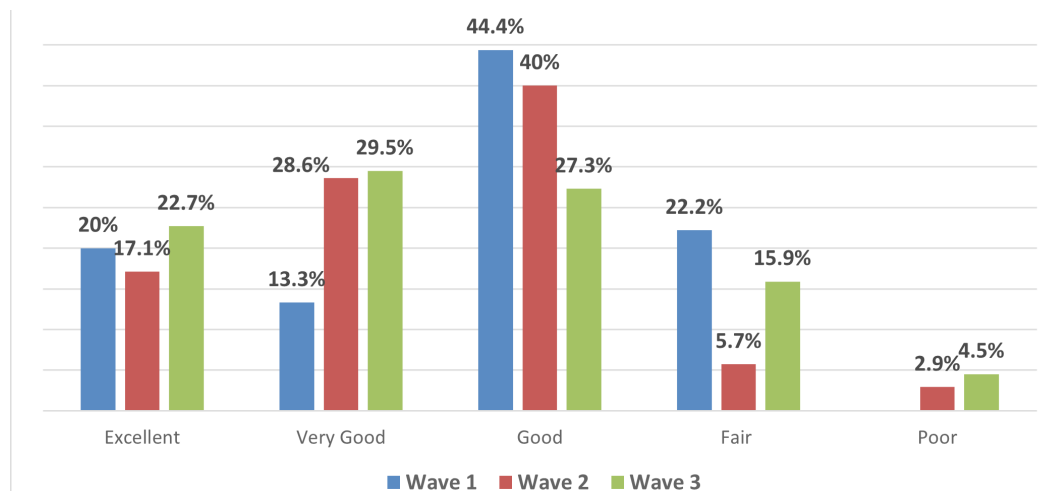


Figure 33: Carers health compared to others

5.2.5.6: Carers' satisfaction with their own health

More than three quarters of **Wave 1** carers (78.3%, n=36) were very satisfied or satisfied with their own health. A smaller percentage of **Wave 2** carers rated their satisfaction level equally high (68.5%, n=48) and the percentage in **Wave 3** was 65.9% (n=29). Two carers in **Wave 2** reported that they were dissatisfied or very dissatisfied with their health whereas 13% (n=6) did so in **Wave 1** and 20.6% (n=9) in **Wave 3**.

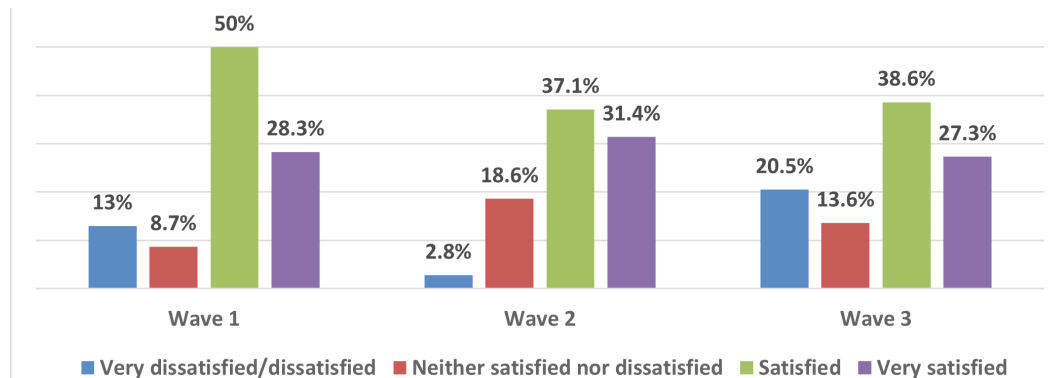


Figure 34: Carers' satisfaction with own health

5.2.5.7: Health conditions experienced by carers

Carers were asked to consider a list of conditions and indicate whether they had suffered from any in the previous twelve months. The responses are presented below in Figure 35 and show that almost one quarter of the carers in **Wave 1** reported that they had not suffered any of the conditions, compared to 1.5% in **Wave 2** and 17.1% (n=7) in **Wave 3**.

Carers in **Wave 1** most frequently experience aching joints (39.1%, n=18), back pain (37%, n=17), high blood pressure (32.6%, n=15) and stress and tension (30.4%, n=14). Carers in **Waves 2 and 3** also frequently reported aching joints - **Wave 2**: 32.4% (n=22), **Wave 3**: 43.2% (n=19) - and stress and tension (30.9%, n=25%). And although **Wave 3** carers also frequently reported back pain (43.5%, n=19) and high blood pressure (25%, n=11) the reports of these conditions were much less frequent in **Wave 2**: back pain 16.2% (n=11) and high blood pressure 16.2% (n=11).

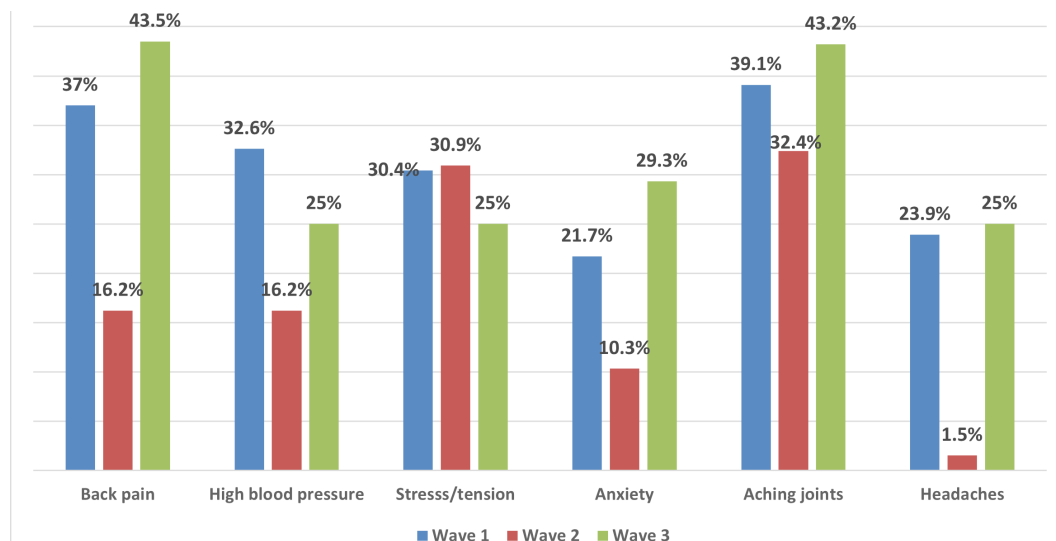


Figure 35: Most frequently reported health conditions

Extra conditions were added in the **Wave 3** questionnaire and from this list six carers (13.6%) reported that they had emotional, nervous or psychiatric problems, four (9.1%) had stomach ulcers, three had osteoporosis (6.8%), one had varicose ulcers and one reported having alcohol or substance abuse problems.

5.2.5.8: Pain in past 4 weeks

Carers in **Waves 2** and **3** were asked about pain which they had experienced in the previous four weeks. More than two thirds of carers in **Wave 2** (67.2%) reported that they had had no pain or mild pain; this figure was almost 57% (n=25) in **Wave 3**. Just over 40% (n=18) of carers in **Wave 3** reported that they had experienced moderate, severe or very severe pain in the past four weeks compared to 30% (n=21) of carers in **Wave 2**.

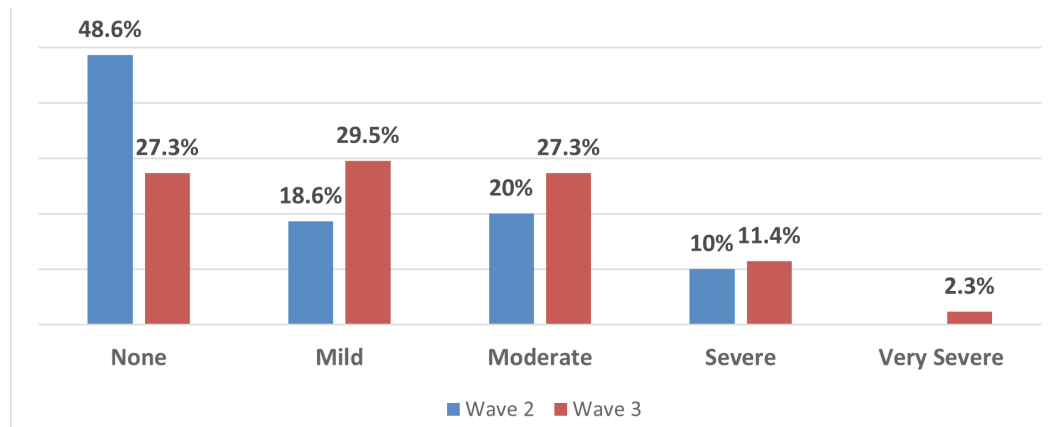


Figure 36: Experience of pain in previous 4 weeks

5.2.5.9: Health impacts of caring

A slightly higher percentage of **Wave 3** carers (n=10) than **Wave 1** (n=10) carers reported that their health had suffered due to their caring responsibilities. The level of carers reporting impacts in **Wave 2**, at 14.5% (n=10), was less than the other two Waves.

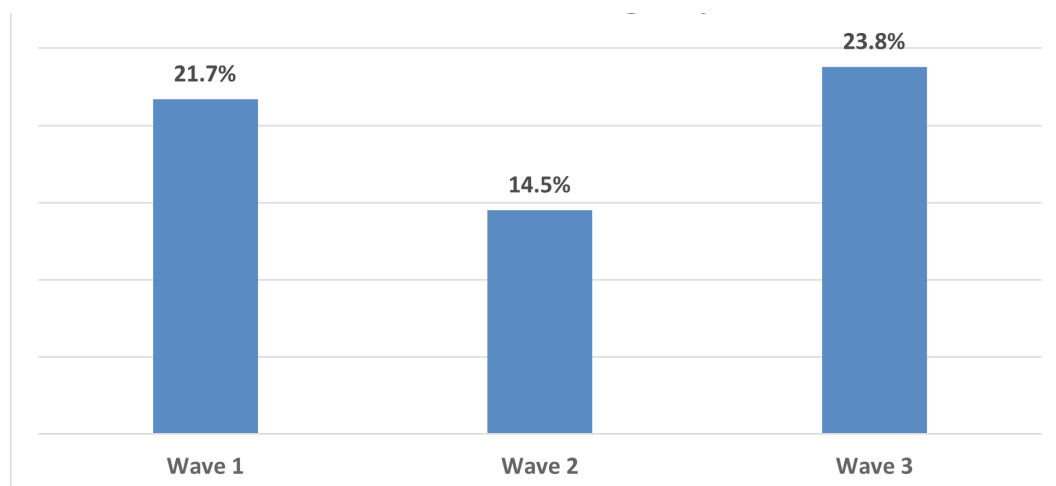


Figure 37: Health suffered due to caring responsibilities

In **Wave 1**, nine carers gave a description of the impact of caring on their health. One wrote that s/he suffered from back, hand and arm weakness as a result of lifting the care recipient and the stress induced by care-giving responsibilities was noted by five carers including one who wrote:

needs of the person I care for comes first which means things I need for myself + home are put on the long finger. I cannot plan for ourselves at a moment's notice. stress, strain pressure (W128)

Three carers cited anxiety exacerbated by a sense of isolation and lack of support for their caring. One of these carers specified that she felt unsupported by her siblings and another that s/he felt unsupported by the state:

mostly anxiety + resentment. 46 years with very little help from the government is a long time to care for someone. To me, services for carers are getting worse (W133)

In **Wave 2** ten carers expanded on their answer. As with the responses in **Wave 1**, most of the responses identified stress, and/or anxiety and/or emotional strain: "Mental and emotional health affected due to stress and strain of full responsibility. Resentment and negative feelings of being tied down" (W259). One carer associated shoulder pain

with care giving tasks; likewise another identified that lifting the care recipient into bed has taken a toll on her neck and back.

In **Wave 3** eight carers expanded on their answer and, again, most implicated the stress induced by their caring responsibilities including:

I feel that the stress of caring for my brother and mother and the worry about their future has underpinned my exhaustion and the recurrent infections (W342)

more stressed, frustrated, anxious, depressed, resentful (W336)

not having time to go to the gym or pool. Stress & depression resulted in weight gain (W313)

stress, strain, lack of sleep, worrying about [name] and the future (W320)

5.2.5.10: Leisure activities limited by caring

Almost 64% (n=28) of carers in **Wave 1** reported that their leisure or recreational activities are limited by their caring responsibilities. This percentage was 55.9%, (n=38) in **Wave 2** and 65.9% (n=29) in **Wave 3**. Carers in **Wave 2** most frequently reported that these activities were not limited at all (44.1%, n=30).

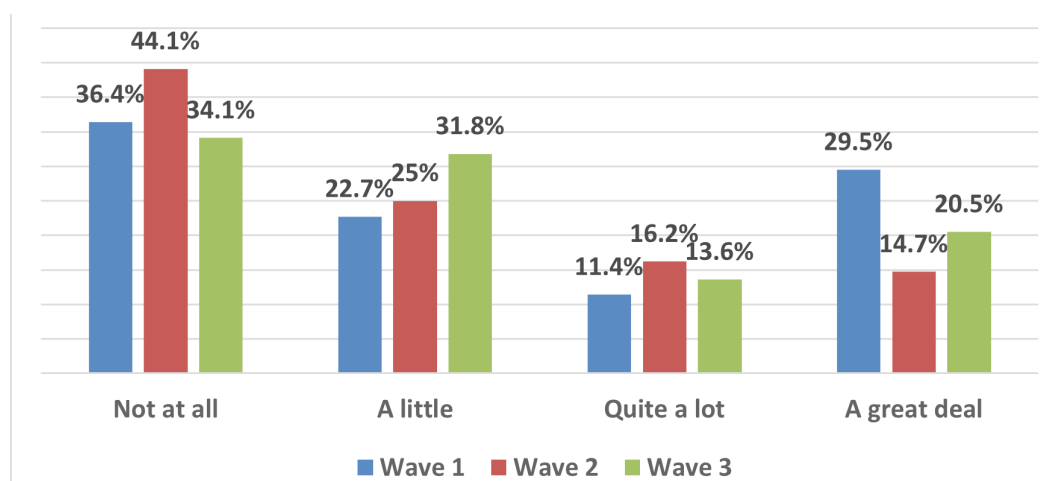


Figure 38: Impact on leisure activities

5.2.5.11: Physical health limitations

Carers in **Waves 2** and **3** were asked how much, in the previous 4 weeks, did physical health problems limit their usual physical activities such as walking or climbing stairs. Although the percentage was lower in **Wave 3** (59.6%, n=35) than in **Wave 2** (75.7%, n=26), most carers reported that they had not been so impacted in the previous 4 weeks.

5.2.5.12: Difficulties with daily work

Carers in **Wave 2** and **3** were also asked to rate the extent of difficulty they experienced in the previous four weeks doing their daily work both at home and away from home, due to their physical health. More than three quarters of **Wave 2** carers (77.1%, n=54) had no difficulty at all; this proportion was less than two-thirds (61.4%, n=27) among **Wave 3** carers.

5.2.5.13: Social activities limitations

Carers were asked whether their social activities with family and friends had been limited by their physical health or emotional problems during the past 4 weeks. More than three-quarters of **Wave 2** carers reported that their social activities had not been limited at all compared to 36.4% in **Wave 1** and 43.2% (n=19) in **Wave 3**. In **Wave 1** almost 30% of carers reported that their activities were limited “a great deal” whereas no carer reported limitations at this level in subsequent Waves. One carer in **Wave 2** reported that they could not do social activities.

5.2.5.14: Energy levels

Carers in **Waves 2** and **3** were asked to rate their energy levels over the previous 4 weeks. Whereas almost 60% of the carers in **Wave 2** (n=41) reported that they had had a lot or quite a lot of energy during that period, less than half of **Wave 3** carers (n=19) reported this level of energy. **Wave 3** carers were more likely to report having some energy (43.1%, n=15) than **Wave 2** carers (28.6%, n=20) and more likely to report having little or no energy.

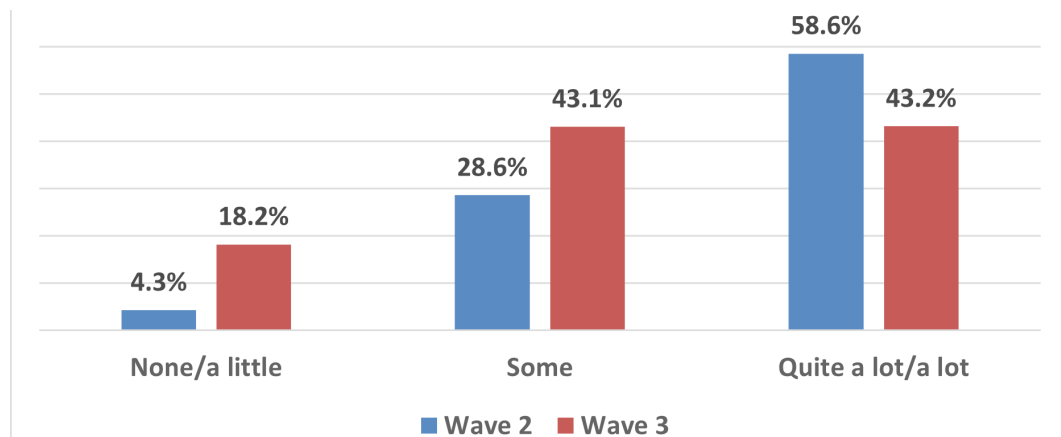


Figure 39: Energy levels in past four weeks

5.2.5.15: Bothered by emotional problems

The **Wave 3** questionnaire included a question that asked about the extent to which, if at all, the carer had been bothered by emotional problems during the past four weeks. Examples of such emotional problems included feeling anxious, depressed or irritable. Six carers (16.3%) reported that they had been extremely or quite a lot bothered by emotional problems of the previous four weeks and a further 27.9% (n=12) that they had been moderately bothered. Seventeen carers (39.5%) reported that they had not been bothered at all and 18.6% (n=8) that they had been only slightly bothered.

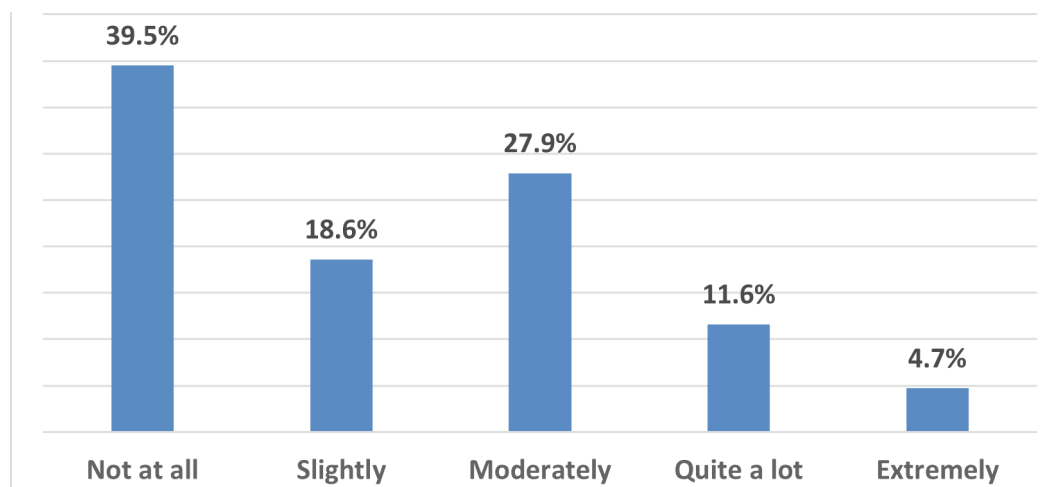


Figure 40: To what extent have you been bothered by emotional problems

Carers in **Waves 2** and **3** were asked the extent to which personal or emotional problems kept them from their usual work, school or other daily activities during the previous four weeks. One carer in each Wave reported that they had been unable to participate in their usual daily activities. Carers in each Wave reported that their daily activities had not been restricted at all although the percentage of **Wave 3** carers 38.6% (n=17) was smaller than that of **Wave 2** carers at 75.7% (n=53).

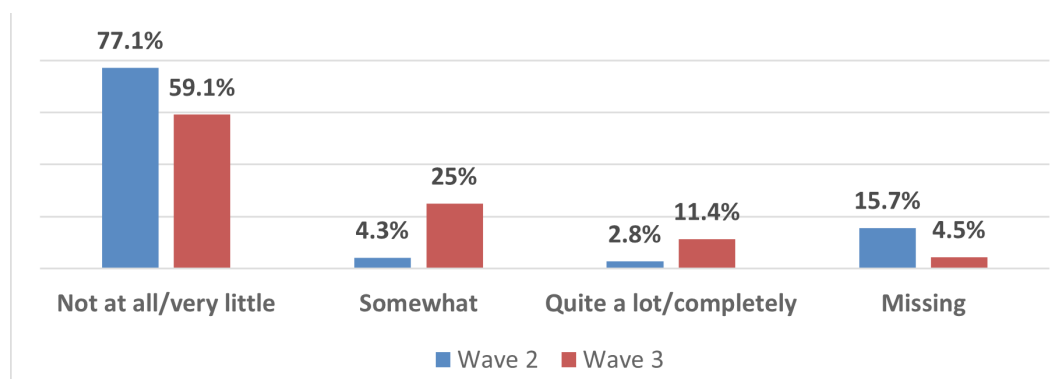


Figure 41: Personal or emotional problems restricting activities

5.2.6: Service provision

5.2.6.1: Services for carers

Carers in **Waves 2** and **3** were asked how satisfied they were with the health services that they receive such as GP services, psychological services and/or physiotherapy. In a separate question they were also asked how satisfied they were with other services they receive such as respite services, social work services and/or public health or community nurse. Whereas over 80% of carers in **Wave 2** reported that they were very satisfied or satisfied with the health services which they received, this percentage was 66% in **Wave 3**. One quarter of **Wave 3** carers responded neutrally to the question answering that they were neither satisfied nor dissatisfied.

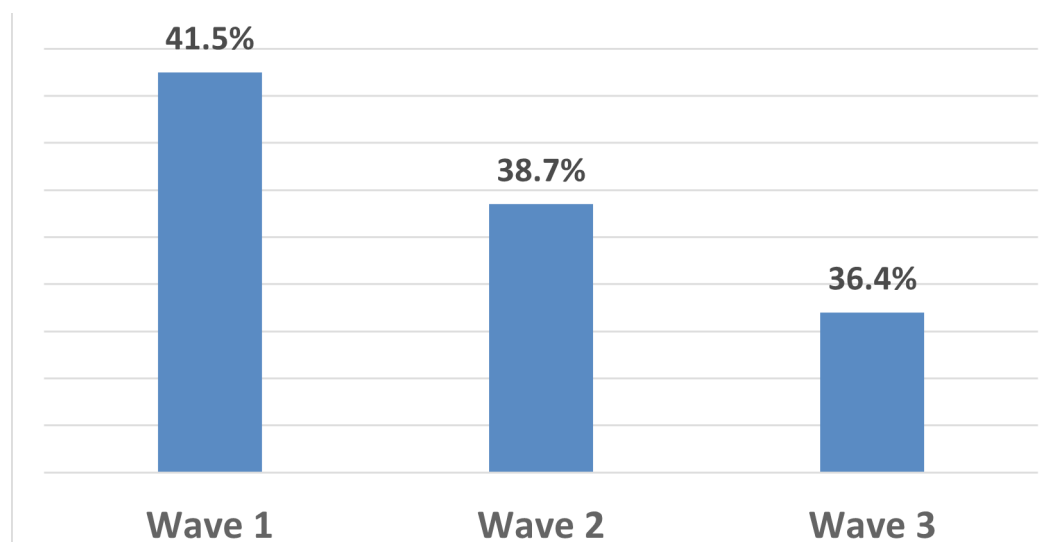
Most carers in **Wave 2** and in **Wave 3** were satisfied or very satisfied with services other than the health services. In **Wave 2**, 52.9% (n=37) of carers rated the services at this level and 47.7% (n=29) of **Wave 3** carers did so.

Table 9: Satisfaction ratings for services received by carer

Rating of Support Health Services	Wave 2	Wave 3
Very Satisfied	50% (n=34)	20.5% (n=9)
Satisfied	33.8% (n=23)	45.4% (n=20)
Neither Satisfied nor Dissatisfied	7.4% (n=5)	25% (n=11)
Dissatisfied	8.8% (n=9)	6.8% (n=3)
Rating of Support Other Services	Wave 2	Wave 3
Very Satisfied	24.3% (n=17)	18.2% (n=8)
Satisfied	28.6% (n=20)	29.5% (n=13)
Neither Satisfied nor Dissatisfied	12.9% (n=9)	29.5% (n=13)
Dissatisfied	5.7% (n=4)	13.5% (n=6)
Very Dissatisfied	7.1% (n=5)	6.8% (n=3)
Missing	21.4% (n=15)	2.3% (n=1)

5.2.6.2: Unmet service need

More than one-third of carers in **Wave 3** reported that there were services they would benefit from but were not receiving. This percentage was less than that reported by the carers in **Wave 1** (n=17) and **Wave 2** (n=27).

**Figure 42: Carers experiencing unmet service need**

Seventeen carers in **Wave 1** added further information about unmet service need. Eleven of these referred to the need for respite for reasons including the desire of carers to be able to spend more time with other family members and because the care recipient enjoys respite. The need for extra social activities was cited by two carers and help in the home by three carers. Two carers reported that they would benefit from more support

with the impact of dementia on the care recipient and another identified the need for more money. One carer wrote:

“A service in the doctors - where I would be made aware when she would call to the doctor for a complaint that is made up or heard from someone else - so medication is not used or understood” (W140)

Forty-six carers in **Wave 2** added text information, twelve of whom noted that they did not currently receive or need any services: *“is so easy, no need at the moment”* (W237). Two identified that the care recipient’s parent would not accept any services and two reported that the care recipient themselves would not accept services. Some carers were satisfied with the services that are currently received; one specified that this satisfaction related to respite, social work and public health nurse. Five carers noted that they paid privately for services including home help services and respite services. Most frequently comments referred to inadequate home help and respite services. Four carers noted that the respite service previously received had been withdrawn completely or significantly reduced; in one instance a family member had been receiving respite one weekend per month and this had been reduced to once every seven or eight months which was said to have had an unsettling effect on the person themselves. Other carers called for more flexible respite provision particularly one that would support social engagements for the carer and for the care recipient:

“All she needs is someone to take her out the odd night at the weekend. All social activities taken off due to cut backs” (W256)

sitter service, more flexible respite. would like to be able to go out on special occasions and to be able to choose the night. (W265)

One carer wanted better access to specialist services, one wanted a more helpful GP service and another wanted better mental health services for carers. One carer required a counselling service and physiotherapy for the care recipient.

Sixteen carers in **Wave 3** added text to their responses about services. Two carers reported that they did not receive any services and one simply noted *“cut backs”*. Half of the comments related to respite services with two noting that they had not had a respite

service for some time: “*no respite for a year*”; “*no respite for the last year, previously every 4-5 weeks*” (W313). Other carers were dissatisfied about the way in which respite was available

There should be more respite available for me so I'd have more time for myself; I would have a whole week for myself. The carers should be looked after also (W329)

respite service, where available, only on dates to suit [service provider] & staff - not planned to suit family needs (W301)

would like to have more respite and also to know in advance I can have it. (W336)

A number of carers wrote about the stress they experienced by what they perceived to be deficiencies in the way they are treated by services

lack of communication with health professionals / no follow up for [name] (W306)

[name] was discharged from [name of service] ow because of her dementia after 32 years, first person ever to be discharged. No care about her having to go into a nursing home as they would not provide her with full time residency (first service user ever) and were very blunt and hurtful to us in the meeting. We were summoned to tell us about her discharged (W320)

And the isolation that they feel

outside of the day service for my sister we have no services. Nobody has ever contacted me as a carer for my needs. We go under the radar and are expected to cope without emotional/ physical or financial support (W337)

Three carers identified lack of future planning or the non-availability of residential placement as problematic leaving one carer unable to envisage a future for herself

No planning for future care needs (W301)

My elderly mother with Parkinson's disease and dementia is no longer in a position to take care of my brother [name] and is seeking residential placement for him, but we have been informed that there is no funding available since 2004 for any planned entries to care (W342)

Would like to be assured that one day my sister will get supported living arrangements so that I can get my life/freedom back (W336)

In **Wave 3** sixteen carers added information to their response about unmet carer service needs. Ten of these identified respite as an unmet need, including that such respite should be regular and predictable and available at short notice if required. One carer identified Carer's Allowance as an unmet need and one needed residential care for her family member. One carer took the opportunity to highlight the impact caring can have on the long-term life chances of the individual

a service that would guide carers to plan for the future in the event that a caring role would end suddenly or after many years of caring. Support for long time carers to be able to save for a pension (W344)

5.2.6.3: Unmet care recipient need

Carers were asked whether there were services which the person they were caring for would benefit from but were not receiving. The unmet care recipient need was reported by over half the **Wave 1** participants (n=23) and just under 30% (n=13) of the **Wave 3** participants. In **Wave 2**, 42.9% (n=30) of the carers reported an unmet need.

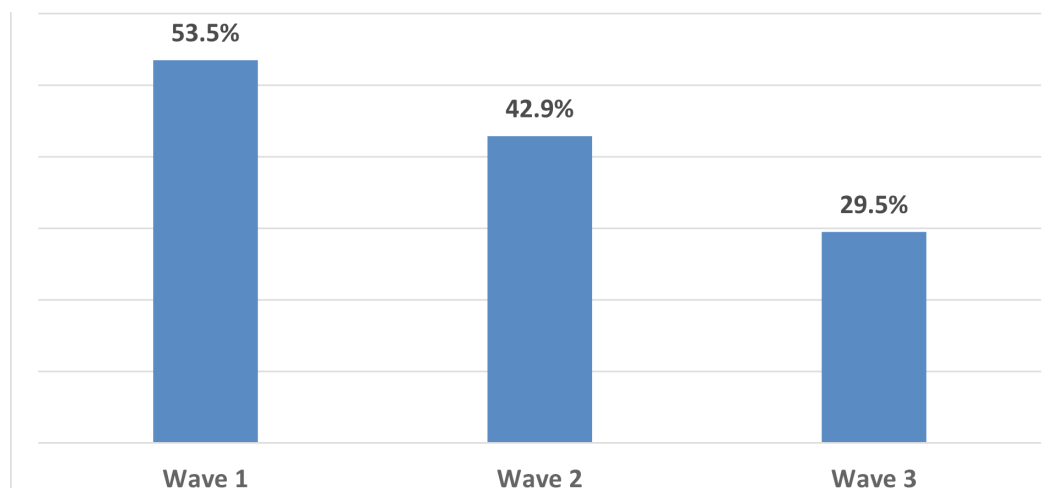


Figure 43: Services care recipients would benefit from but not receiving

In **Wave 1**, all twenty-three of the carers who identified that there were services which the care recipient would benefit from but which they were not receiving gave further information. Two referred to lack of transport, one specified transport difficulties in rural areas; two referred to the need for home help/home care packages and two for improved and more coherent health services. Carers identified lack of speech therapy, physiotherapy and general lack of professional support with the onset of dementia. Seven carers cited respite and seven identified a lack of education and training opportunities, social activities and opportunities to interact with peers. One carer specified the need for residential care.

Thirty-one carers in **Wave 2** added a further comment on the services received by the care recipient. Four praised the service which their family member received and four identified difficulties dealing with the services: “Like a battle trying to get any services. Information is not available” (W226) while another noted the futility of battling with services: “You can’t fight the services, I will need them before they need me” (W229). Ten comments referred to respite; two carers noted that they were happy with the respite service and one commented that the respite service was much improved from previously. Two carers identified that a respite service which that used to have is no longer available

and another two carer that they must pay for a respite service. Other carers identified a need for more respite opportunities particularly ones given in useful blocks of time: “Eg 3 hours a week to go to a film etc” (W201) and one wanted the service user to attend respite with his peers: “If there was a respite for people at the same level as him it would be great” (W253). One carer was particularly scathing about the standard of respite available: “Respite is not fit for purpose-it’s maintenance, do not have money to do what they would like to do, don’t have much staff” (W233). Three carers cited the lack of availability of transport for the service users. Two carers were critical of the GP service available to the care recipient and another noted that health services previously available within the service were no longer available. One carer required a home help services to assist with showering.

Ten of the seventeen **Wave 3** carers who added a text responses identified respite as an unmet need, including that such respite should be regular and predictable and available at short notice if required. One carer identified Carer’s Allowance as an unmet need and one needed residential care for her family member. Others focussed on medical and health needs including the need for specialised geriatricians, for more health professional and community services and the need for dementia training for carers of dementia sufferers.

5.3: Longitudinal data

5.3.1: Introduction

This section provides a detailed portrayal of the lives of the seventeen caregivers who completed the carers’ survey in both **Wave 1** and **Wave 3**. The data is presented in the first instance by carer group i.e. parent or sibling. Each variable is then presented alongside the individual carer’s reports of their health and wellbeing in **Wave 1** and in **Wave 3**.

The data used in this analysis is primarily from the questions which were directly comparable across the two waves. However, a number of questions used in the **Wave 3** questionnaire but not in **Wave 1** have also been included in the analysis where this inclusion can provide extra insight.

5.3.2 Case studies

All names used in these case studies are pseudonyms.

Case study 1: John

John is a widowed father in the 66-75 year age group in both **Wave 1** and **Wave 3**. He wrote: “I have always been involved in Sean’s care but more intimately so since the death of my wife.” His adult child with intellectual disability requires full physical assistance with all activities of daily living and some support with all IADLs. The level of support required increased from “monitoring” to “partial physical assistance” between **Wave 1** and **Wave 3** for medication, walking, getting in and out of bed and socialising in the home. In **Wave 1** he reported that his son had had no respite for a year; in **Wave 3** he wrote “Since Mark became oxygen dependent he has less day service and no respite. This is very unfair”.

John reported suffering from nine health conditions in **Wave 1** and twelve in **Wave 3**. The health conditions in **Wave 1** included back pain, depression, aching joints, headaches and stress and tension; by **Wave 3** other health conditions included stomach ulcers and emotional, nervous or psychiatric problems. In **Wave 3** he described that he was “rundown and therefore prone to infections. I also suffer from PTSD and the strain of looking after Mark does not help this condition”.

In **Wave 1** John reported using a number of coping strategies, in **Wave 3** he only reported “talking to friends” as a coping strategy. In both waves he classified his health compared to others his age as “fair”, was dissatisfied with his own health and felt that his health had suffered due to caring. In **Wave 1** John identified with eight of the difficulties associated with caregiving and this increased to eleven in **Wave 3**. These difficulties were said to be exacerbated by “constantly having to fight to get Sean what he needs” and could be eased by “clearly defined areas of responsibility on who provides Mark with day services and respite. The role of each support agency for Mark as he gets older”

John did not positively identify with any of the positive aspects of caregiving and strongly disagreed with most of them in **Waves 1** and **3**. In both Waves he reported unmet service need for both himself and his son and included “because services are not available” as one of the reasons that he provides care. He cited the other reasons that he provided care as “because I’m the parent”; “because I’ve always done so”; “because I’m needed” and “because I feel obliged”. He did not identify with “because I enjoy this and want to”.

John’s key concern in both waves was for his son’s future care. In **Wave 1** he wrote that he hoped that “he is not neglected after I die” and in **Wave 3** he asked “What will

happen to Mark when I'm dead?" In **Wave 3** he wrote that he had no hopes or dreams for his own future; for Mark he hoped "That he has a happy life"

Case study 2: Ann

Ann is a mother in the 66 – 75 year age group, married and, in **Wave 3**, she wrote that she had been caring for 52 years. In **Wave 1** Ann suffered from one health condition and from three in **Wave 3**. In **Wave 3** she reported that her general health was very good, that she was very satisfied with her own health which she considered was excellent compared to others her own age. She did not think that her health had suffered due to caregiving.

Ann did not associate with any of the difficulties of caregiving in **Wave 1** but reported in **Wave 3** that she was feeling "completely overwhelmed" and that the most difficult aspect of caregiving was the "physical strain. Ann stated that she provides care "because I am the parent", "because I've always done so", "because I'm needed" and "because I enjoy this and want to". She considered that she was "doing alright" on her current income.

In **Wave 1**, Ann did not report any unmet service need for herself but did so in **Wave 3** without specifying what that unmet need was. In both **Wave 1** and **Wave 3**, she indicated that her adult child had unmet service needs and specified this as speech therapy. Although Ann received regular support from friends and/or relatives in **Wave 1**, she did not report receiving this support in **Wave 3**. In both Waves she identified her faith as a coping strategy and added exercise as another coping strategy in **Wave 3**. In **Wave 3** Ann strongly agreed with all the positive aspects of caregiving; ie she considered that caring made her feel useful, good, needed, appreciated and strong and confident; also that it made her appreciate life, ensured a positive attitude and that caring had strengthened relationships. In **Wave 3** Ann wrote that they would continue to care "so as long as out health is good" and her hope and dream for herself was "That my health will keep good". Ann had a similar hope for her son's good health but identified her concern for when she could no longer care "How he will cope when we are not around as he depends on us so much"

Case study 3: Tom

Tom is a sibling caregiver; his marital status was single in both Waves. He was 60 years of age in **Wave 3** and in **Wave 3** he reported that he had been caring for 40 years. In **Wave 1** he was also caring for his father. He was finding it "very difficult" to live on his current income. Tom rated his general health and his health compared to others as "fair" in **Wave**

1 and “poor” in **Wave 3**. He was “dissatisfied” with his own health in both waves and reported that his health had suffered due to caring. Tom reported suffering from eight health conditions in **Wave 1** and 10 in **Wave 3** including back pain, diabetes, high blood pressure, depression, emotional, nervous or psychiatric problems and stomach ulcers.

In **Wave 1** Tom did not identify any unmet service need either for himself or his sibling; in **Wave 3** both he and his sibling had unmet need. While stating “I am very satisfied with his day care service he receives 5 days a week”; he identified the unmet need as respite “Respite. Very difficult to find for an adult with a disability”

In both waves Tom reported that he did not receive support from relatives or friends and coped by watching TV and through medication. In **Wave 3** he added faith/prayer to his coping strategies.

Tom identified with most of the difficulties associated with caregiving in both waves and, likewise, identified most of them as the “most difficult” aspects of caregiving. In **Wave 3** he “strongly disagreed” that providing care made him feel appreciated, strong and confident, appreciative of life or that it gave him a positive attitude or had strengthened relationships. Tom wrote that “caring 24/7 without support for a 62 year old ID person is too much”.

Tom’s dream for his sibling was continuing good health. His dream for himself was to “Become a psychotherapist & counsellor”

The only reason Tom gave for providing care was “because I love him”.

Case study 4: Mary

Mary is a sibling caregiver who was in the 46 – 55 year age group in **Wave 1** and in the 56 – 65 year age group in **Wave 3**. At **Wave 3**, she had been a carer for 18 years. She was married or otherwise living with a partner. In both waves she reported that her quality of life was very good, that her health compared to others her own age was excellent and that she was very satisfied with her own health. She did not feel that her health had suffered due to caregiving. She provides care “because I am needed”.

Mary identified with seven of the difficulties associated with caregiving in **Wave 1** and five in **Wave 3**. In both waves Mary itemised as difficulties that “sleep is disturbed”, “it is confining”, “some behaviour is upsetting”, “there have been work adjustments” and “there have been family adjustments”. She identified “there have been family adjustments” as the most difficult aspect. In **Wave 1** Mary also included “it is a financial strain” as a difficulty; she did not include this as a difficulty in **Wave 3** at which stage she reported that she was “doing alright” financially although she also itemised Carer’s Allowance

as an unmet need. Mary also reported respite as an unmet service need for both herself and her sibling.

In **Wave 1**, Mary did not report that she received regular support from friends or family but did so in **Wave 3**. In **Wave 1** she itemised her coping strategies as talking to friends, watching TV, exercise, alcohol, respite and prayer/faith. Respite no longer featured as a coping strategy in **Wave 3** and nor did alcohol or prayer/faith. Whereas Mary strongly endorsed eight positive aspects of caring in **Wave 1**, in **Wave 3** she only strongly endorsed that caring made her “feel useful” and “feel needed”

Mary’s hope and dream for herself in **Wave 1** was for “peace and happiness” and she did not identify any hopes or dreams in **Wave 3**. In **Wave 1** she identified her worry for her sibling as “That he would get anything in future that would leave him in pain. Especially as he never complains”

5.3.3: Demographics

5.3.3.1: gender, marital status and other care responsibilities

Three (17.6%) carers included in the analysis of the 17 participants were male, 14 (82.4%) were female. Two of the males were brothers of the care recipient and one was the care recipient’s father. Three (17.6%) of the females were the mother of the care recipient and 11 (64.6%) were the sister. Just under a quarter (23.5%, n=4) of the respondents were the parent of the care recipient.

In **Wave 1** two of the parents were widowed and two were married or living with a partner. By **Wave 3**, three of the parents were widowed. In **Wave 1** 84.6% (n=11) siblings were married, one (7.7%) was single and one was separated. By **Wave 3**, two of the married sibling carers had been widowed.

One of the male siblings was single and one was married and their status was constant across the waves.

No parent in **Wave 1** reported that they provided care to someone other than their adult child with an intellectual disability; one parent in **Wave 3** did so but provided no further detail. Fewer siblings in **Wave 3** (23.2%, n=3) reported other care responsibilities than did so in **Wave 1** (46.2%, n=6). Two siblings in **Wave 1** specified that they provided support to a second sibling and one provided support to a parent; in **Wave 3**, two siblings specified that they provided support to a second sibling and one provided support to her husband who is in need of constant care due to who Parkinson’s.

5.3.3.2: Age group

Evidently, all participants aged across the Waves. A parent who was over 86 years of age in **Wave 1** remained with the IDS-TILDA Carer's Study and was 93 years of age at the time of **Wave 3**; at the time of that survey another carer had aged into the 76 – 85-year age group. Whereas in **Wave 1**, eight of the sibling carers were aged between 46 – 55 years of age, only three of these carers remained in this age group by **Wave 3**. Most (n=9) sibling carers in **Wave 3** were aged between 56 and 75. This data is presented in Table 10 below.

Table 10: Age group by relationship and wave

	Wave 1 Parents	Wave 3 Parents	Wave 1 Siblings	Wave 3 Siblings
46 – 55 years			8	3
56 – 65 years			4	7
66 – 75 years	3	2	1	2
76 – 84 years		1		1
86 + years	1	1		

5.3.3.3: Length of time as a carer

Two of the parents in **Wave 3** gave information about how long they had been in the role of carer. One specified just over 52 years and one specified almost 49 years. One sibling carer responded that s/he had been caring part-time “*all my life*”. It is clear from the responses of the other twelve sibling carers that many of them also considered that they had been caring for much of their lives. The sibling responses are presented in Table 11 below.

Table 11: Number of years as a carer (Wave 3)

6 – 10 years	2 sibling carers
11 – 15 years	2 sibling carers
16 – 20 years	2 sibling carers
26 – 30 years	4 sibling carers
36 – 40 years	1 sibling carer
41 – 45 years	1 sibling carer

5.3.3.4: Occupation

In both waves, 75% of the parents were retired and 25% reported that they were a homemaker. Whereas three, (23.1%) of the sibling carers reported in **Wave 1** that they were unemployed, none did so in **Wave 3**. However, the number in employment also fell by two from six (46.2%) to four (30.8%). Three siblings classified themselves as homemakers in **Wave 1** and four (30.8%) did so in **Wave 3**. Three sibling carers (23.1%) were retired in **Wave 3** compared to one (7.7%) in **Wave 1**. In **Wave 3**, one sibling was in education or training and one chose the “other” option but did not expand on this answer.

In **Wave 1**, two (15.4%) siblings reported working 40 hours per week and one did so in **Wave 3**. Four (30.8%) sibling carers in **Wave 1** reported working between 20 and 40 hours and three did so in **Wave 3**; one carer in **Wave 3** reported working 15 hours per week. One sibling in **Wave 1** reported that they had given up work and two (15.4%) that they had cut down on work; by **Wave 3**, four (30.8%) sibling carers had given up work and one had cut down their hours of work. In **Wave 3**, one sibling detailed why s/he cut down her work hours

Sister was wandering and not keeping to safe plan. Second sister was also getting more vulnerable so full/part-time work was getting too much to deal with along with caring for sisters. My health was deteriorating. (W339)

5.3.4: Health and wellbeing

5.3.4.1: Carer’s health and quality of life

This section presents data on the carers’ general health, their level of satisfaction with their health and their rating of how their health compared to other of the same age. It also includes their reports about whether their health had suffered due to caregiving.

5.3.4.2: Quality of life

The percentage of sibling carers who classified their quality of life as good remained constant between the waves however the percentage giving a “very good” rating reduced from 38.5% (n=6) in **Wave 1** to 15.4% (n=2) in **Wave 3**. The more non-committal rating of “neither good nor poor” increased between **Waves 1** and **3** and one sibling carer in

Wave 3 reported their quality of life as “very poor.” This data is presented, by numbers, in Figure 44 below.

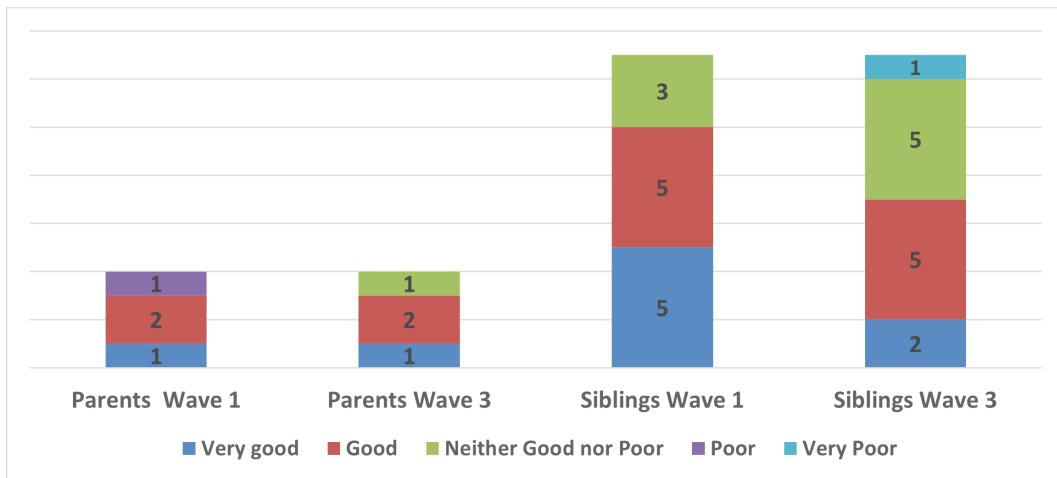


Figure 44: Carers' Quality of Life Across Waves 1 and 3

5.3.4.3: General health

The question about general health changed somewhat between **Waves 1** and **3**. **Wave 1** carers were asked to rate their general health whereas **Wave 3** carers were asked to rate their general health over the previous four weeks. However, the questions are sufficiently similar to serve as a comparison. Three-quarters of parent carers rated their general health as “excellent”, “very good” or “good” in both **Wave 1** and **Wave 3**; one parent carer rated their general health as “fair” in both Waves.

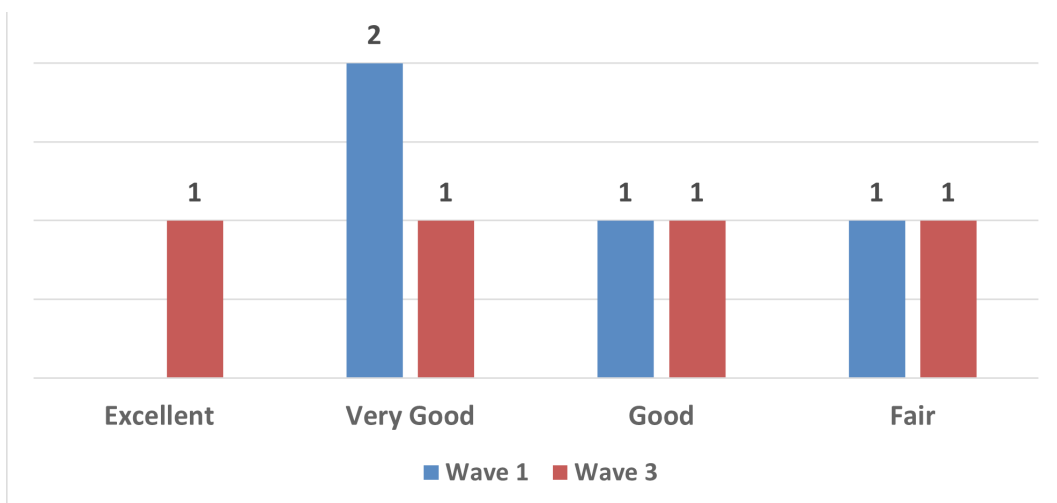


Figure 45: Parent Carers' General Health

Almost 85% (n=11) of the sibling carers in **Wave 1** classified their general health as excellent, very good or good; this percentage reduced slightly to 76.9% (n=10) in **Wave 3**. Fewer siblings in **Wave 3** rated their health as very good and a greater number rated their health as good. One sibling in **Wave 3** rated their health as poor. This data can be seen in Figure 46 below

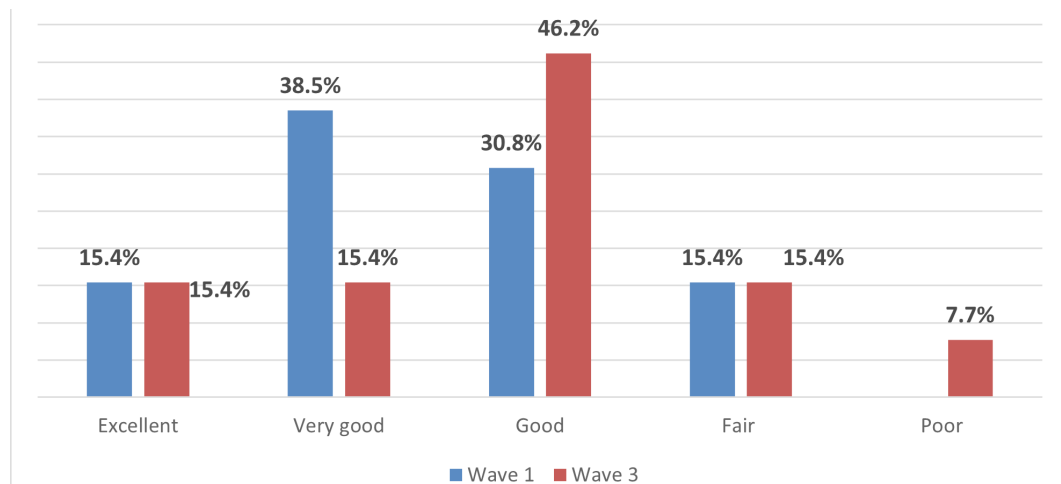


Figure 46: Sibling carers' general health

Whereas the parents' assessment of their general health remained stable between **Wave 1** and **Wave 3**, siblings more frequently reported a less favourable assessment in **Wave 3** than they did in **Wave 1**.

5.3.4.4: Satisfaction with own health

The parent carer who was dissatisfied with his own health in **Wave 1** remained dissatisfied at **Wave 3**. However, another parent’s satisfaction rating rose from “satisfied” in **Wave 1** to “Very satisfied” in **Wave 3**. Sibling carers’ satisfaction ratings dropped overall between the waves as fewer sibling carers reported that they were “satisfied” and more reported that they were “dissatisfied”. Whereas just one sibling reported being “dissatisfied” with their own health in **Wave 1**, three did so in **Wave 3** and the number reporting that they were satisfied with their own health reduced from six in **Wave 1** to two in **Wave 3**. This data is presented, by numbers, in Figure 47 below.

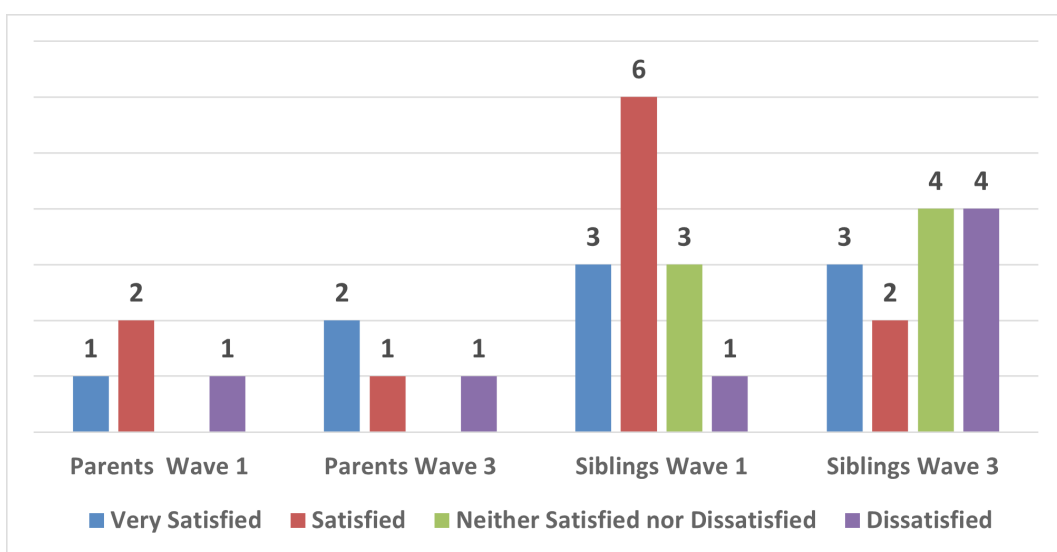


Figure 47: Satisfaction with own health: Waves 1 & 3

When asked to compare their health to other people of the same age, one parent carer considered their health to be just “fair”. This parent – a father – reported in both **Waves 1** and **3** that he believed that his health had been negatively impacted by his care responsibilities and in **Wave 1** he added: “all injuries and illnesses are aggravated” (P2). In **Wave 3**, he noted: I am run down and therefore prone to infections. I also suffer from PTSD and the strain of looking after [name] does not help this condition (P2). The other parent carers rated their comparative health as “excellent”, “very good” or “good” in both waves and none reported that their health had suffered as a result of caring. This parent data is presented, by numbers, in Figure 48.

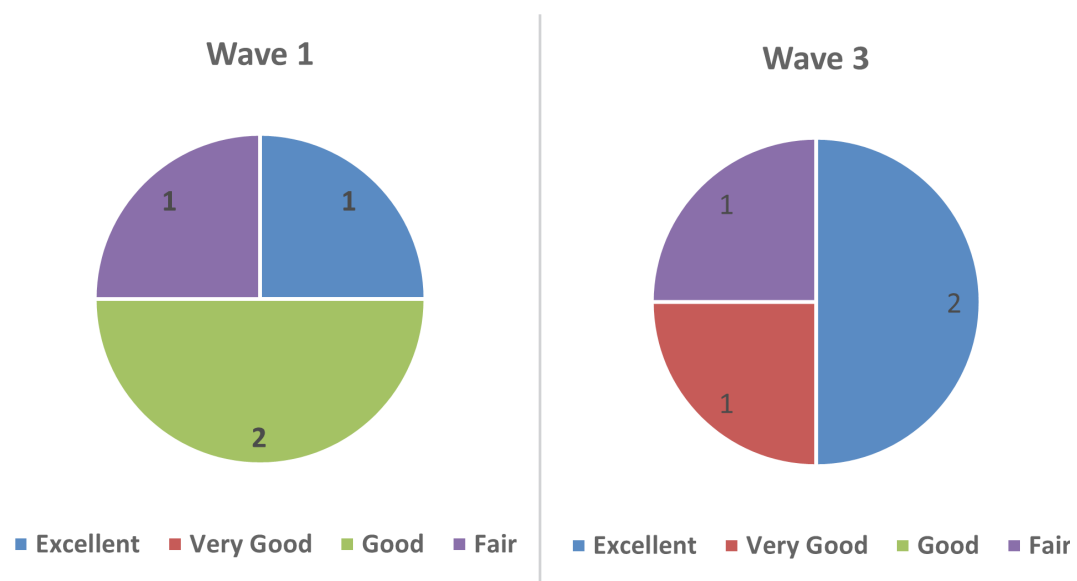


Figure 48: Parents' compared to others of same age

The percentage of sibling carers rating their comparative health as “excellent,” “very good” or “good” reduced from 83.4% in **Wave 1** to 69.3% in **Wave 3** and the percentage who rated their comparative health as just “fair” rose from 16.7% to 23.1%. The siblings’ rating of their comparative health is presented by numbers in Figure 49 below.

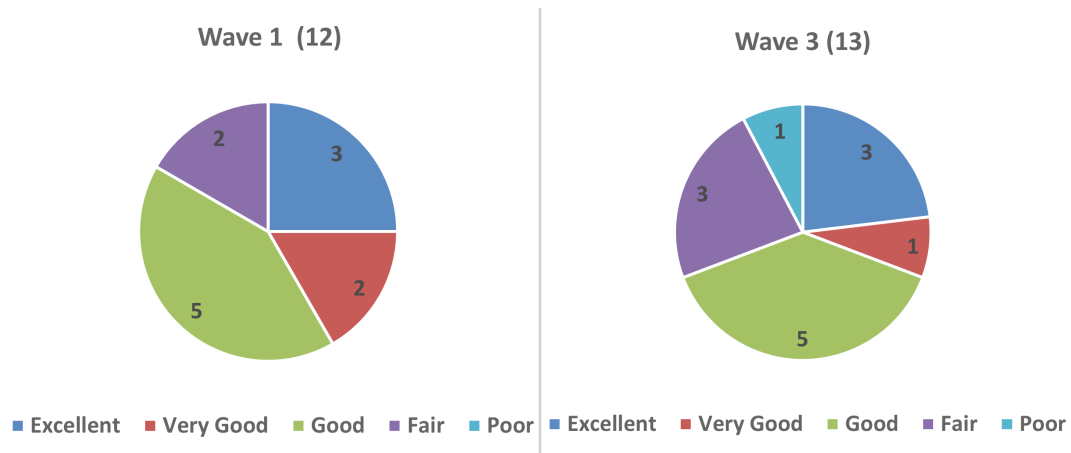


Figure 49: Siblings’ health compared to others of same age

5.3.4.5: Impact of caregiving on health

One sibling in **Wave 3** did not answer the question about whether their health had been impacted by their caregiving. Some siblings' responses differed between **Wave 1** and **Wave 3**; two siblings who reported in **Wave 1** that their health had been impacted responded differently in **Wave 3** and one who answered no in **Wave 1**, changed their response to "yes" in **Wave 3**.

Five siblings in **Wave 1** (38.5%) and four (33.3%) in **Wave 3** reported that their caring responsibilities had negatively impacted their health. Three siblings reported in this way in both waves and two of these added text responses in both waves which illuminate the ongoing strain that they were experiencing, these are presented in Table 12 below:

Table 12: Text responses to impacts

Carer	Wave 1	Wave 3
S4	HBP, general ill health due to stress and isolation	Caring 24/7 without support for a 62 year old ID person is too much
S7	In the early couple of years, having to adapt to the full responsibility was overwhelming. Physically and emotionally draining. Lack of support from remaining siblings caused huge health problems	More stressed, frustrated, anxious, depressed, resentful

Another sibling in **Wave 3** also elaborated on their answer giving an insight into the impact of their responsibilities on their mental, physical and social lives:

If I hadn't been a carer I would have had my hysterectomy sooner. I would have a better relationship with those closest to me and would not have been in a low mood (S8)

Two of siblings who despite responding "no" in **Wave 3** nevertheless added text to their response which indicate that, regardless of their answers, they have health concerns.

I worry - causing stress and anxiety (S12, W3)

Just in general - harder to sleep - so tired during the day - snappy sometimes, not eating properly. Needing to take painkillers for headaches I think may be due to stress (S10, W3)

5.3.4.6: Leisure and recreational activities

One of the parent carers reported, in both waves that their leisure or recreational activities were greatly impacted by their care responsibilities whereas the other three parents reported that their activities were not at all limited. The percentage of sibling carers whose activities were not limited fell between **Wave 1** and **Wave 3** and the percentage whose activities were a “great deal” limited rose. The sibling carer data is presented in Figure 50 below.

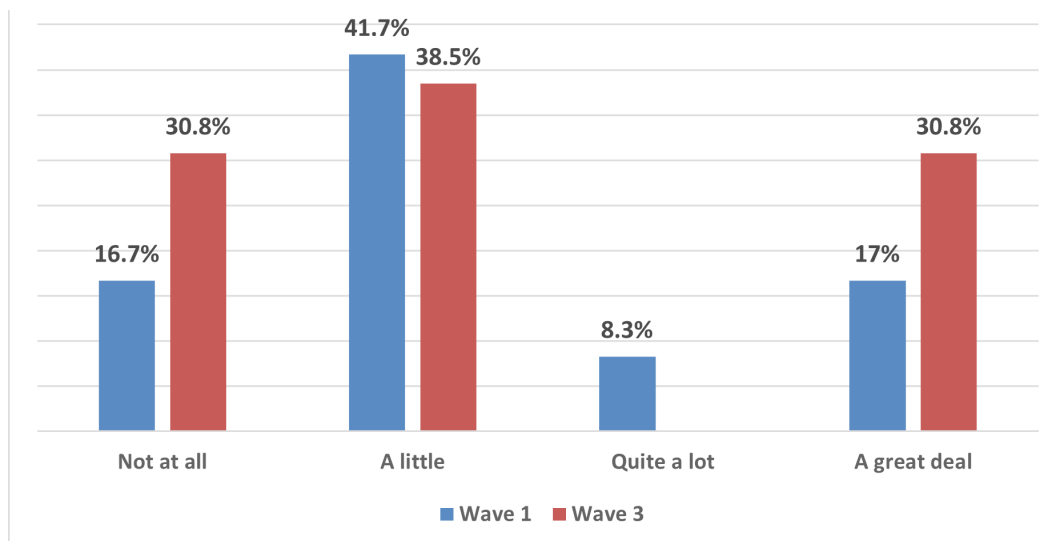


Figure 50: Leisure/recreational activities limited by caring

5.3.4.7: Individual carers’ age group, general health, satisfaction with own health and perception of whether their health had suffered due to providing care

Table 13 presents the individual carer’s data relating to age group, general health, satisfaction with health, quality of life, health compared to others and the carers’ perception of whether their health had suffered due to their care responsibilities. The table also includes data about the length of time the carers had been in the caring role.

Three of the four parent carers were “*satisfied*” or “*very satisfied*” with their own health in both **Wave 1** and **Wave 3**; 1 parent reported that they were dissatisfied in both waves. These three parents, including the oldest participant in the Carer’s Study, consistently reported that they enjoyed a good quality of life, were satisfied with their own health and rated their own health highly in comparison to other people of the same age. None of these three parents reported that their health had suffered because of their caring responsibilities. However, the parent who reported, in both waves that his health had

suffered due to caring responsibilities, reported a poor quality of life, that his health did not compare well with others of a similar age and that he was dissatisfied with his health.

Overall, most sibling carers expressed a high quality of life, satisfaction with their general health and a good level of health compared to other people of their own age. However, four sibling carers reported deterioration in all these spheres between **Wave 1** and **Wave 3**. Fewer sibling carers in **Wave 3** reported that they were satisfied and the percentage of sibling carers who reported being dissatisfied rose from 7.7% to 30.8%. Two of the sibling carers who reported in **Wave 1** that their health had suffered as a consequence of care-giving responded differently in **Wave 3**. Their reported quality of life, satisfaction with their own health and perception of their health compared to others did not change between the waves. One sibling carer changed their response in **Wave 3** to report that their health had suffered because of caring and documented a higher level of dissatisfaction with their own health and poorer comparative health in **Wave 3** compared to **Wave 1**. Three other sibling carers also reported lower ratings across these variables between **Waves 1** and **3**. Three of these four carers were in the lowest of the age groups of the sibling carers.

Between them, the two parents who answered the question about how long they had been a carer reported caring for more than 100 years. These two parents' reports of their quality of life, general health, health compared to others and satisfaction with their own health contrasted with each other as one reported very positive health and wellbeing and one reported very negative health and wellbeing. Although four of the seven siblings who had been caring for more than twenty-five years reported in **Wave 3** that their health had been impacted by providing care, three reported that their health had not been impacted. None of the siblings who had been caring between eleven and twenty-five years reported that their health had been impacted by caring and one of the two carers who have been caring for up to ten years had been impacted by caring.

Table 13: Carers' age group, general health, satisfaction with own health and perception of whether their health had suffered due to providing care

Carer Gender & Age group	Years caring	Quality of life		General health		Satisfaction with own health		Health compared to others		Health suffered due to caring	
		W1	W3	W1	W3	W1	W3	W1	W3	W1	W3
P1 F W1: 66-75 W3: 66-75	52	good	Very good	Good	Very good	Satisfied	Very Satisfied	Good	Excellent	N	N
P2 M W1: 66-75 W3: 66-75	49	Poor	neither	Fair	Fair	Dissatisfied	Dissatisfied	Fair	Fair	Y	Y
P3 F W1: 86+ W3: 86+	Missing	Very good	Good	Very good	Excellent	Very Satisfied	Very Satisfied	Excellent	Excellent	N	N
P4 F W1: 66-75 W3: 76-85	Missing	Good	Good	Very Good	Good	Satisfied	Satisfied	Good	Very Good	N	N
S1 F W1: 56-65 W3: 56-65	10	good	good	Fair	Very Good	Satisfied	Satisfied	Fair	Very Good	N	N
S2 F W1: 46-55 W3: 56-65	12	Very good	Very good	Very Good	Excellent	Very Satisfied	Very Satisfied	Excellent	Excellent	N	N
S3 M W1: 46-55 W3: 56-65	28	Very good	Neither	Very good	Fair	Very Satisfied	Neither	Good	Fair	N	N
S4 M W1: 46-55 W3: 56-65	40	Good	Very poor	Fair	Poor	Dissatisfied	Dissatisfied	Fair	Poor	Y	Y
S5 F W1: 66-75 W3: 76-85	45	Very good	Good	Excellent	Very Good	Very Satisfied	Very Satisfied	Excellent	Excellent	N	N
S6 F W1: 46-55 W3: 46-55	15	Very good	Good	Very Good	Good	Satisfied	Satisfied	Good	Good	N	N
S7 F W1: 46-55	7	Very good	Very good	Very Good	Good	Satisfied	Dissatisfied	Very Good	Good	Y	Y
S8 F W1: 46-55 W3: 46-55	26	Good	neither	Good	Good	Neither	Dissatisfied	999	Fair	Y	Y
S9 F W1: 46-55 W3: 56-65	26	Good	Very good	Excellent	Excellent	Satisfied	Very Satisfied	Excellent	Excellent	N	N
S10 F W1: 46-55 W3: 46-55	30	Good	Good	Good	Good	Satisfied	Neither	Good	Good	Y	N
S11 F W1: 56-65 W3: 56-65	"part-time all my life	Neither	Neither	Very Good	Fair	Neither	Dissatisfied	Very Good	Fair	N	Y
S12 F W1: 56-65 W3: 66-75	18	Neither	Neither	Good	Good	Neither	Neither	Good	Good	Y	N
S13 F W1: 56-65 W3: 66-75	19	Neither	Neither	Good	Good	Satisfied	Neither	Good	Good	N	N

5.3.4.8: Health and wellbeing limitations and restrictions

Several additional questions about health were added in **Wave 3**. Table 14 below presents the responses to these questions alongside the carers' **Wave 3** responses to the questions about their level of satisfaction with their health and whether their health had suffered due to caring. The parent who reported a poor quality of life and dissatisfaction with their health reported that, in the previous four weeks they suffered severe bodily pain, had been unable to do their usual physical activities and had been "*moderately*" bothered by emotional problems. One of the other parents had been "*slightly*" bothered by emotional problems and had experienced "*moderate*" levels of bodily pain but otherwise the parents present high levels of wellbeing.

Almost 80% of sibling carers reported that they had been bothered by emotional problems during the previous four weeks and almost 36% (n=5) reported experiencing "*moderate*", "*severe*" or "*very severe*" pain. All 4 sibling carers who, in **Wave 3**, reported that their health had suffered due to caring experienced a "*moderate*", "*severe*" or "*very severe*" level of pain in the previous four weeks and all had been "*moderately*" or "*quite a lot*" bothered by emotional problems.

One sibling carer reported experiencing a "*very severe*" level of pain in the previous four weeks and another reported a "*severe*" level. Both these carers reported dissatisfaction with their health and that their health had suffered due to caring and both had been bothered "*quite a lot*" by emotional problems and all were dissatisfied with their own health. One other sibling carer also reported experiencing "*moderate*" levels of pain and emotional problems but did not report that their health had suffered due to caring. This data is presented in Table 14.

Table 14: Limitations, pain, energy and emotional problems

Carer	Daily activities limited by long-term illness, health problem or disability	Physical health problems limiting usual physical activities	Bodily pain in past 4 weeks	Energy level in past 4 weeks	Bothered by emotional problems in past 4 weeks	Satisfaction with own health (Wave 3)	Health suffered due to caring (Wave 3)
P1 F	No	Not at all	Moderate	Quite a lot	Slightly	Very satisfied	No
P2 M	Yes	Could not do at all	Severe	Some	Moderately	Dissatisfied	Yes
P3 F	No	Not at all	None	missing	Not at all	Very satisfied	No
P4 F	No	Not at all	None	Quite a lot	Not at all	Satisfied	No
S1 F	No	Not at all	Mild	A lot	Slightly	Satisfied	No
S2 F	No	Not at all	None	A lot	Not at all	Very satisfied	No
S3 M	Yes	Somewhat	Moderate	Quite a lot	Moderately	Neither	No
S4 M	No	Quite a lot	Very severe	A little	Quite a lot	Dissatisfied	Yes
S5 F	No	Not at all	None	A lot	Slightly	Very satisfied	No
S6 F	No	Not at all	Mild	Quite a lot	Slightly	Satisfied	No
S7 F	No	Somewhat	Moderate	Some	Moderately	Dissatisfied	Yes
S8 F	No	Very Little	Moderate	A lot	Quite a lot	Dissatisfied	Yes
S9 F	No	Not at all	None	A lot	Not at all	Very satisfied	No
S10 F	No	Not at all	Mild	Some	Moderately	Neither	No
S11 F	Yes	Not at all	Severe	A little	Quite a lot	Dissatisfied	Yes
S12 F	Yes	Not at all	None	Some	Slightly	Good	No
S13 F	No	Very Little	Mild	Some	Slightly	Good	No

5.3.4.9: Specific health conditions

The most commonly reported health conditions reported by the parent carers are presented in Table 15 below. One parent had suffered a stroke by **Wave 3**. There was an increase of one in the number of parents reporting that they had diabetes and stress and an increase of two carers reporting anxiety. Conversely one less parent reported suffering from high blood pressure.

Table 15: Percentage of health conditions by Wave: Parents

	Parents Wave 1	Parents Wave 3
Stroke	0	1
Back Pain	1	1
Diabetes	0	1
Urinary Incontinence	1	1
Anxiety	0	2
Depression	1	1
Aching Joints	1	1
High Blood Pressure	2	1
Headaches	1	1
Stress or Tension	1	2

The health condition most frequently reported by sibling caregivers are presented in Table 16 below. There was a decrease in the number of sibling carers reporting that they suffered from back pain, depression, aching joints, headaches and stress. There was an increase in the number of sibling carers reporting that they suffered from asthma, COPD, diabetes and high blood pressure.

Table 16: Percentage of health conditions by Wave: Siblings

	Siblings Wave 1	Siblings Wave 3
Asthma	7.7% (1)	15.4% (2)
COPD	0%	7.7% (1)
Osteoarthritis	23.1% (3)	23.1% (3)
Back Pain	53.8% (7)	38.5% (5)
Diabetes	0%	15.4% (2)
Urinary Incontinence	0%	7.7% (1)
Anxiety	46.2% (6)	46.2% (6)
Depression	23.1% (3)	15.4% (2)
Aching Joints	53.8% (7)	38.5% (5)
High Blood Pressure	23.1% (3)	30.8% (4)
Headaches	46.2% (6)	38.5% (5)
Stress or Tension	38.5% (5)	30.8% (4)

The **Wave 3** survey contained a number of health conditions that were not included in the **Wave 1** survey. From this list three carers, one parent and one sibling, indicated that they had osteoporosis; two carers, one parent and one sibling, reported stomach ulcers and one sibling reported varicose ulcers. Three parents, one parent and two siblings, reported that they had emotional, nervous or psychiatric problems and one sibling reported engaging in substance or alcohol abuse.

5.3.4.10: Health conditions

Table 17 documents the number of health conditions identified by the carers in their responses to the two surveys. The responses to the extra questions included in the **Wave 3** survey are noted in brackets where applicable.

Three of the four parent carers reported no or few health conditions; the oldest participant reported fewer health conditions in **Wave 3** than in **Wave 1**. These three parents also reported high levels of quality of life, satisfaction with their general health and good health compared to others of a similar age including a parent who has suffered a stroke between the waves. One parent reported a high number of health conditions in **Wave 1** and a higher number in **Wave 3**.

Most sibling carers reported suffering from five or less conditions in both waves; a number of sibling carers reported fewer health conditions in **Wave 3**. The oldest of the sibling carers reported having none of the conditions in either wave. In general, the carers who reported few health conditions reported high levels of quality of life, satisfaction with their health and good health compared to others. However, there were a number of exceptions to this generality. One carer who reported four health conditions in both waves, gave low ratings across the variables and stated, in both waves, that their health had been negatively impacted by their care responsibilities. The other three sibling carers who reported in **Wave 3** that caring had affected their health reported a high number of health conditions in **Wave 3**. One sibling carer who reported no health conditions in **Wave 1** reported nine in **Wave 3**. This carer's reported quality of life, satisfaction with their own health and comparative health declined between **Wave 1** and **Wave 3**; this carer did not assign responsibility for their health to their care responsibilities

Seven carers reported fewer health conditions in **Wave 3** than in **Wave 1**. Three had reported a high level of satisfaction with their health and/or good health compared to others in **Wave 1** and this did not change. Two of the seven reduced their rating of their satisfaction with their own health from "*satisfied*" to "*neither satisfied nor dissatisfied*". Two carers reported a higher level of satisfaction and/or comparative health.

Most frequently across the two waves, the carers reported suffering from back pain, aching joints, headaches, high blood pressure, anxiety and stress or tension. The number in brackets in the table below refer to health conditions which were included in **Wave 3** but were not included in **Wave 1**.

The carers suffering from emotional, nervous or psychiatric problems were all carers who reported that they were otherwise heavily burdened by other health conditions and all three had reported that they felt that their health had been negatively impacted by their care responsibilities. Similarly, the sibling carer who reported that they were substance or alcohol abusing also reported that their health had suffered because of caregiving.

Table 17: Number of health conditions reported by carers

Carer (Age group years: 1 = 46–55 2 = 56–65 3 = 66–75 4 = 76–85 5 = 86+)	Number of health condition		Quality of Life		Satisfaction with own health (VS = very satisfied S = satisfied N = neither D = dissatisfied VD = very dissatisfied)		Health compared to others		Health suffered due to caring	
	W1	W3	W1	W3	W1	W3	W1	W3	W1	W3
P1 F 168 (W1: 3 W3: 3)	1	3	G	VG	S	VS	Good	Excellent	N	N
P2 M 364 (W1: 3 W3: 3)	9	12	P	N	D	D	Fair	Fair	Y	Y
P3 F 367 (W1: 5 W3: 5)	2	0	VG	G	VS	VS	Excellent	Excellent	N	N
P4 F 525 (W1: 3 W3: 4)	0	0	G	G	S	S	Good	Very Good	N	N
S1 F 163 (W1: 2 W3: 2)	4	0	G	G	S	S	Fair	Very Good	N	N
S2 F 379 (W1: 1 W3: 2)	2	0	VG	VG	VS	VS	Excellent	Excellent	N	N
S3 M 391 (W1: 1 W3: 2)	0	9	VG	N	VS	N	Good	Fair	N	N
S4 M 439 (W1: 1 W3: 2)	8	10	G	VP	D	D	Fair	Poor	Y	Y
S5 F 566 (W1: 3 W3: 4)	0	0	VG	G	VS	VS	Excellent	Excellent	N	N
S6 F 598 (W1: 1 W3: 1)	0	2	VG	G	S	S	Good	Good	N	N
S7 F 695 (W1: 1 W3: 3)	8	11	VG	VG	S	D	Very Good	Good	Y	Y
S8 F 696 (W1: 1 W3: 1)	4	3	G	N	N	D	999	Fair	Y	Y
S9 F 697 (W1: 1 W3: 2)	2	1	G	VG	S	VS	Excellent	Excellent	N	N
S10 F 709 (W1: W3:)	3	2	G	G	S	N	Good	Good	Y	N
S11 F 715 (W1: 2 W3: 3)	4	7	N	N	N	D	Very Good	Fair	N	Y
S12 F 720 (W1: 1 W3: 3)	5	0	N	N	N	N	Good	Good	Y	N
S13 F 293 (W1: 2 W3: 3)	2	2	N	N	S	N	Good	Good	N	N

5.3.4.11: IADLs and ADLs

Carers were asked about the support they provide to the person they care for. This was framed around Activities of Daily Living (ADLs, n=8), Independent Activities of Daily Living (IADLs, n=4), a question about support for behavioural needs and one about support given with socialising and activities within the home.

The number of tasks reported by carers in each wave is presented below in Table 18. The responses from two of the parent carers and two of the sibling carers were so incomplete that their data is not included, thus the data is from thirteen of the seventeen carers.

One parent and three sibling carers reported providing support, on at least a daily basis, with at least five more activities in **Wave 3** than in **Wave 1**. The parent and one of the sibling carers reported good or very good quality of life and a high level of satisfaction with their own health. One sibling's quality of life and satisfaction with their own health reduced from very positive in **Wave 1** to neutral in **Wave 3**. The fourth of these carers reported reduced quality of life and reduced satisfaction in **Wave 3**; at **Wave 3** they reported assisting, on at least a daily basis, with thirteen activities whereas they were assisting with five at **Wave 1**. This data is presented in Table 18 below.

Table 18: Number of support tasks undertaken by Wave

Carer Age group years: 1 = 46–55 2 = 56–65 3 = 66–75 4 = 76–85 5 = 86+	Quality of Life [General health]		Number of Activities of Daily Living plus behaviour support and socialising support		Number of Independent Activities of Daily Living		Health suffered due to caring	
	Wave 1	Wave 3	Wave 1	Wave 3	Wave 1	Wave 3	Wave 1	Wave 3
P1 F	Good [Good]	Very good [Very good]	5	5	4	4	N	N
P2 M	Poor [Fair]	Neither [Fair]	9	7	4	4	Y	Y
S1 F	Good [Fair]	Good [Very good]	2	2	4	4	N	N
S2 F	Very good [Very good]	Very good [Excellent]	5	7	4	4	N	N
S3 M	Very good [Very good]	Neither [Fair]	0	6	3	3	N	N
S4 M	Good [Fair]	Very poor [Poor]	5	7	4	3	Y	Y
S5 F	Very good [Excellent]	Very good [Very good]	3	2	4	4	N	N
S7 F	Very good [Very good]	Very good [Good]	2	5	3	3	Y	Y
S8 F	Good [Good]	Neither [Good]	6	9	4	4	Y	Y
S9 F	Very good [Excellent]	Very good [Excellent]	4	3	2	2	N	N
S11 F	Neither [Very good]	Neither [Fair]	2	8	4	4	N	Y
S12 F	Neither [Good]	Neither [Good]	10	9	4	4	Y	N
S13 F	Neither [Good]	Neither [Good]	7	6	4	4	N	N

5.3.5: The experience of caregiving

5.3.5.1: Impact of caregiving

Carers were asked to identify, from a list, difficulties which they experience in providing care and then to identify the most difficult things about caring.

One sibling carer did not answer any of the questions about the impact of caring in **Wave 1** and another did not answer any in **Wave 3**. Their responses have been removed from the group analysis of this data but included in the presentation of the individual data. A number of other carers did not answer some of the questions including one sibling who did not answer five questions; their responses have been included in the analysis. The data is presented primarily in the form of numbers for maximum clarity.

One parent identified with most of the difficulties associated with caring both in **Wave 1** and with all the difficulties (except work adjustments which was not applicable) in **Wave 3**. This male parent is a widow and his responses would suggest that he has been and is increasingly burdened by care responsibilities. In **Wave 3**, another parent also identified that they were “completely overwhelmed” by caring. Two parents did not identify with any of the difficulties.

The responses of the siblings to this question identifies that by **Wave 3**, the sibling carers were being increasingly impacted by their care responsibilities. In **Wave 1** the majority of carers endorsed three of the twelve listed difficulties, in **Wave 3** the majority of the sibling carers endorsed seven of the twelve difficulties. “*Feeling completely overwhelmed*” is the most extreme of the difficulties listed, at **Wave 3** almost two thirds of the sibling carers identified with this difficulty. This data is presented in Table 19 below and the percentages refer to the participants who responded to each statement

Table 19: Impacts of caring

	Parents Wave 1	Parents Wave 3	Siblings Wave 1	Siblings Wave 3
Sleep is disturbed	1 (25%)	1 (25%)	4 (36.4%)	7 (63.6%)
It is inconvenient	1 (25%)	1 (33.3%)	5 (44.5%)	2 (1.2%)
It is a physical strain	0%	1 (25%)	2 (18.2%)	5 (50%)
It is confining	1 (25%)	1 (25%)	7 (63.6%)	8 (80%)
There have been family adjustments	1 (25%)	1 (25%)	8 (72.7%)	7 (63.6%)
There have been changes in personal plans	1 (25%)	1 (25%)	8 (72.7%)	7 (70%)
There have been emotional adjustments	0%	1 (25%)	4 (36.4%)	6 (55.6%)
Some behaviour is upsetting	1 (25%)	1 (25%)	3 (27.3%)	3 (54.5%)
It is upsetting to find the person your support has changed so much from his/her former self	0%	1 (25%)	1 (9.1%)	3 (30%)
There have been work adjustments	0	0	5 (45.5%)	6 (54.5%)
It is a financial strain	1 (25%)	1 (25%)	3 (27.3%)	4 (44.4%)
Feeling completely overwhelmed	1 (25%)	2 (50%)	5 (45.5%)	7 (63.6%)

5.3.5.1.1: Most difficult impact of caring

A separate question asked the participants to identify the most difficult things about caring and were invited to tick as many options as applicable. The responses are presented in Table 20 below.

Table 20: Most difficult impacts of caring

	Parents Wave 1	Parents Wave 3	Siblings Wave 1	Siblings Wave 3
Lack of sleep	25% (1)	25% (1)	38.5% (5)	15.4% (2)
Isolation	25% (1)	25% (1)	30.8% (4)	30.8% (4)
Stress	50% (2)	50% (2)	38.5% (5)	53.8% (7)
Emotional strain	0%	25% (1)	46.2% (6)	61.5% (8)
Constantly on call	25% (1)	25% (1)	46.2% (6)	76.9% (10)
Frustration	25% (1)	25% (1)	46.2% (6)	53.8% (7)
Sadness for the person I care for	25% (1)	25% (1)	23.1% (3)	61.5% (8)
Guilt	0%	25% (1)	23.1% (3)	7.7% (1)

The father who identified major difficulties in the previous question also endorsed many of the difficulties as the most difficult impacts in **Wave 1** and all the difficulties in **Wave 3**. Another parent also identified stress as the most difficult but otherwise parents were not inclined to identify most difficult aspects of caregiving.

Whereas all the options were endorsed by a minority of the sibling carers in **Wave 1**, five of the eight options were endorsed by a majority of sibling carers in **Wave 3**. Fewer siblings in **Wave 3** reported that “guilt” and “lack of sleep” were one of the most difficult things about caring, however an increased number of carers were finding difficulty with being “being con-

stantly on call”. Clearly, it is not possible to know whether this is because the demands of the care recipient had increased between the waves or because the carers were finding it increasingly difficult to cope with being on call over an extended number of years. In both Waves, several siblings included text to identify personal restrictions as the most difficult aspect of caring

I have to put my own life on hold (W341)

No support ... no family life: has limited my time with my children (W337)

In **Wave 1**, four sibling caregivers identified “sadness for the person I care for” as one of the most difficult things about caring. The number of carers endorsing this statement increased to nine in **Wave 3**.

Table 21 presents the number and nature of the greatest difficulties which carers associated with caring alongside their assessment of their quality of life and satisfaction with their own health.

Two parents and one sibling did not endorse any of the difficulties in either wave; all three reported high satisfaction with their own health and a good quality of life. Three other carers – one parent, two siblings – endorsed difficulties in **Wave 3** but had not done so in **Wave 1**. This parent who endorsed no difficulty in **Wave 1** reported being “*completely overwhelmed*” by **Wave 3** and reported the most difficult aspect of caregiving as “*stress*”. However, this parent continued to report satisfaction with their own health and a good quality of life. Similarly, one of the siblings who endorsed four difficulties in **Wave 3** as compared to none in **Wave 1**, also continued to report positively on their quality of life and satisfaction with their own health. Conversely another sibling who reported no difficulties in **Wave 1** and ten in **Wave 3**, changed his quality of life and health satisfaction ratings to a non-committal “*neither*”.

The validated measure applied in this impact of caring question is the Caregiver Strain Index (Robinson 1983) and the scoring convention suggests that the endorsement of seven or more statements is indicative of a high level of stress. One parent met this threshold in both **Wave 1** and **Wave 3**. Seven of the siblings endorsed seven or more statements in **Wave 1**. One of these siblings did not answer the question in **Wave 3**; however seven siblings reached or surpassed the threshold for high level of strain in **Wave 3**.

Five carers in **Wave 1** and five carers in **Wave 3** identified isolation as one of the most difficult aspects of caregiving. Only one of these carers and none of these carers in **Wave 3** reported satisfaction with their own health.

The response options to the questions about difficulties are listed in Table 21 below

Table 21: response options to difficulties question

Difficulties: Sleep is disturbed; It is inconvenient; It is a physical strain; It is confining; There have been family adjustments; There have been changes in personal plans; There have been emotional adjustments; Some behaviour is upsetting; It is upsetting to find the person you support has changed so much from his/her former self; There have been work adjustments; It is a financial strain; Feeling completely overwhelmed.

Most difficult: Lack of Sleep; Isolation; Stress; Emotional strain; Being constantly on-call; Frustration; 7 Sadness for the person I care for; Guilt

Table 22: Difficulties associated with caregiving

Carer	Difficulties associated with caregiving		Most difficult aspects of caregiving	
	W1	W3	W1	W3
P1 F	None	Feeling completely overwhelmed	Stress	Stress
P2	Disturbed sleep Inconvenient Confining Family adjustments Personal plans changes Upsetting behaviour Financial strain Completely overwhelmed.	Disturbed sleep Inconvenient Physical strain Confining Family adjustments Personal plans changes Emotional adjustment Upsetting behaviour Upsetting changes in family member Financial strain Completely overwhelmed.	Disturbed sleep Isolation Stress Constantly on-call Frustration	Disturbed sleep Isolation Stress Emotional strain Constantly on-call Frustration Sadness for the person I care for Guilt
P3 F	None	None	None	None
P4 F	None	None	Sadness for the person I care for	None
S1	missing	Upsetting behaviour Upsetting changes in family member Work adjustments	Frustration	Stress Constantly on-call Frustration Sadness for the person I care for
S2 F	Disturbed sleep Inconvenient Confining Family adjustments Personal plans changes Work adjustments Financial strain	Disturbed sleep Confining Family adjustments Personal plans changes Work adjustments	None	Constantly on-call
S3	None	Disturbed sleep Physical strain Confining Family adjustments Personal plans changes Emotional adjustment Upsetting behaviour Upsetting changes in family member Financial strain Completely overwhelmed	None	Disturbed sleep Stress Emotional strain Constantly on-call Frustration Sadness for the person I care for
S4 M	Inconvenient Physical strain Confining Family adjustments Personal plans changes Emotional adjustment Upsetting behaviour Work adjustments Completely overwhelmed	Physical strain Confining Family adjustments Personal plans changes Emotional adjustment Upsetting behaviour Financial strain Completely overwhelmed	Disturbed sleep Isolation Stress Emotional strain Constantly on-call Frustration Sadness for the person I care for	Isolation Stress Emotional strain Constantly on-call Frustration Sadness for the person I care for Guilt
S5 F	None	Disturbed sleep Family adjustments Upsetting behaviour Upsetting changes in family member	None	Emotional strain Constantly on-call Sadness for the person I care for

Table 22: Difficulties associated with caregiving

Carer	Difficulties associated with caregiving		Most difficult aspects of caregiving	
	W1	W3	W1	W3
S6 F	Family adjustments Personal plans changes	Disturbed sleep Confining Completely overwhelmed	None	None
S7 F	Inconvenient Confining Family adjustments Financial strain Personal plans changes Emotional adjustment Work adjustments Financial strain Completely overwhelmed	Confining Family adjustments Personal plans changes Emotional adjustment Upsetting behaviour Work adjustments Financial strain Completely overwhelmed	Isolation Stress Emotional strain Constantly on-call Frustration	Isolation Stress Emotional strain Constantly on-call Frustration
S8 F	Inconvenient Confining Family adjustments Personal plans changes Emotional adjustment Upsetting behaviour Work adjustments Financial strain Completely overwhelmed	Missing	Isolation Emotional strain Constantly on-call Frustration	Disturbed sleep Stress Emotional strain Constantly on-call Frustration Sadness for the person I care for
S9 F	None	None	None	None
S10 F	Inconvenient Confining Family adjustments Personal plans changes Emotional adjustment Upsetting behaviour Upsetting changes in family member Work adjustments Financial strain Completely overwhelmed	Confining Family adjustments Physical strain Personal plans changes Emotional adjustments Work adjustments Completely overwhelmed	Disturbed sleep Stress Emotional strain Constantly on-call Frustration Sadness for the person I care for Guilt	Stress Emotional strain Constantly on-call Frustration Sadness for the person I care for
S11 F	Disturbed sleep Inconvenient Confining Family adjustments Personal plans changes Emotional adjustment Upsetting behaviour Work adjustments Completely overwhelmed	Disturbed sleep Physical strain Confining Family adjustments Personal plans changes Emotional adjustment Work adjustments Completely overwhelmed	Disturbed sleep Stress Emotional strain Frustration Guilt	Isolation Stress Emotional strain Constantly on-call Frustration Sadness for the person I care for
S12 F	Disturbed sleep Physical strain Confining Family adjustments Personal plans changes Financial strain Completely overwhelmed	Disturbed sleep Physical strain Personal plans changes Upsetting behaviour Upsetting changes in family member Financial strain Completely overwhelmed	Disturbed sleep Isolation Stress Emotional strain Constantly on-call Frustration Sadness for the person I care for Guilt	Isolation Emotional strain Sadness for the person I care for
S13 F	Disturbed sleep Confining Family adjustments Personal plans changes	Sleep is disturbed It is confining There have been work adjustments	Disturbed sleep Constantly on-call	Physical strain Constantly on-call

5.3.5.2: Reasons for providing care

In **Wave 3**, carers were asked to choose from a list to indicate their reasons for providing care to the older person with intellectual disability. Table 23 presents their responses. Just under half the carers included “*because I’m needed*” as one of the reasons why they provide care. Three of the four parents reported that they provide care “Because I enjoy this and want to”; the parent whose responses indicate a high burden of care did not include this option in his answer.

Two siblings also endorsed the positive option of “*Because I enjoy this and want to*”. Both were non-committal about their quality of life in **Wave 3**; one was dissatisfied with her own health and rated her health as “fair” compared to others. The other sibling reported good health compared to other and a good level of satisfaction with their own health.

One parent added that they would continue to care as long as their health remained good and a brother wrote that he provided support to the person with intellectual disability “Because I love him” (S4) . Interestingly, this sibling reported poor health, poor quality of life and that his health had been impacted by caregiving and did not report that he provided care because of lack of services. However, two other siblings who also reported that their health had been impacted by caregiving only listed lack of services as the reason why they provided support. Table 23 presents the carers’ reasons for providing care other health and wellbeing data.

Table 23: Reasons for providing care

Carer	Reasons for providing care	Quality of Life		Health compared to others		Health suffered due to caring	
		Wave 1	Wave 3	W1	W3	W1	W3
P1 F	Because I'm the parent Because I've always done so Because I'm needed Because I enjoy this and want to.	Good	Very Good	Good	Excellent	N	N
P2 M	Because I'm the parent Because I've always done so Because I'm needed Because I feel obliged Because services are not available	Poor	Neither	Fair	Fair	Y	Y
P3 F	Because I'm the parent Because I've always done so Because services are not available	Very Good	Good	Excellent	Excellent	N	N
P4 F	Because I'm the parent Because I've always done so Because I'm needed Because I feel obliged Because services are not available	Good	Good	Good	Very Good	N	N
S1 F	Because I've always done so	Good	Good	Fair	Very Good	N	N
S2 F	Because I'm needed	Very Good	Very Good	Excellent	Excellent	N	N
S3 M	Because I'm needed	Very Good	Neither	Good	Fair	N	N
S4 M	<i>"because I love him"</i>	Good	Very Poor	Fair	Poor	Y	Y
S5 F	Because I'm needed	Very Good	Good	Excellent	Excellent	N	N
S6 F	Because I'm needed	Very Good	Good	Good	Good	N	N
S7 F	Because services are not available	Very Good	Very Good	Very Good	Good	Y	Y
S8 F	Because services are not available	Good	Neither	999	Fair	Y	Y
S9 F	<i>"Because I'm his sister"</i>	Good	Very Good	Excellent	Excellent	N	N
S10 F	Because I've always done so Because I'm needed Because I feel obliged	Good	Good	Good	Good	Y	N
S11 F	Because I enjoy this and want to.	Neither	Neither	Very Good	Fair	N	Y
S12 F	Because I enjoy this and want to.	Neither	Neither	Good	Good	Y	N
S13 F	Because I feel obliged	Neither	Neither	Good	Good	N	N

5.3.5.3: Finances

5.3.5.3.1: Carer's Allowance

The same number and percentage of parents were in receipt of the Carer's Allowance in **Waves 1** and **3**; however these were not the same parents. One parent who was in receipt of the allowance in **Wave 1** no longer received it in **Wave 3** and one carer who was not in receipt in **Wave 1** reported receiving it in **Wave 3**. Three siblings who reported not receiving the Allowance in **Wave 1** were receiving it in **Wave 3** and three who were in receipt in **Wave 1** were no longer by **Wave 3**. Likewise, three of the carers in receipt of the allowance in **Wave 3** were not in receipt of it in **Wave 1**. Table 24 presents the percentage of participants in each wave who reported that they were in receipt of the Carer's Allowance

Table 24: In receipt of Carer's Allowance:

Wave 1		Wave 3	
Parent: 50% (2)	Sibling: 46.2% (6)	Parent: 50% (2)	Sibling: 46.2% (6)
Male: 0%	Female: 57.1% (8)	Male: 66.7% (3)	Female: 46.2% (6)

5.3.5.3.2: Sufficiency of income

In **Wave 3**, carers were asked how they were coping on their present income. The responses are presented in Table 25 below. Seven of the seventeen carers reported that they were “*just about getting by*” and one that he was “*finding it very difficult*”. Only one of these carers reported that they were satisfied or very satisfied with their health in **Wave 3**; four reported that they were dissatisfied, two responded “*neither*” and one carer did not answer the question. Four of the five carers who stated that providing care had impacted their health were finding it very difficult to cope on their income or just about getting by.

Table 25: Coping on present income

Carer	Quality of Life		Satisfaction with own health		Number of difficulties identified		Coping on present income Wave 3 only	Health suffered due to caring	
	W1	W3	W1	W3	W1	W3		W1	W3
P1 F	Good	Very Good	Satisfied	Very Satisfied	0	1	Doing alright	No	No
P2 M	Poor	Neither	Dissatisfied	Dissatisfied	8	11	Just about getting by	Yes	Yes
P3 F	Very good	Good	Very Satisfied	Very Satisfied	0	0	Living comfortably	No	No
P4 F	Good	Good	Satisfied	Satisfied	0	1	Doing alright	No	No
S1 F	Good	Good	Satisfied	Satisfied	Missing	3	Living comfortably	No	No
S2 F	Very Good	Very Good	Very Satisfied	Very Satisfied	7	6	Doing alright	No	No
S3 M	Very Good	Neither	Very Satisfied	Neither	0	10	Just about getting by	No	No
S4 M	Good	Very Poor	Dissatisfied	Dissatisfied	9	8	Finding it very difficult	Yes	Yes
S5 F	Very Good	Good	Very Satisfied	Very Satisfied	0	4	Just about getting by	No	No
S6 F	Very Good	Good	Satisfied	Satisfied	2	3	Doing alright	No	No
S7 F	Very Good	Very Good	Satisfied	Dissatisfied	9	8	Doing alright	Yes	Yes
S8 F	Good	Neither	Neither	Dissatisfied	9	missing	Just about getting by	Yes	Yes
S9 F	Good	Very Good	Satisfied	Very Satisfied	0	0	Doing alright	No	No
S10 F	Good	Good	Satisfied	Neither	10	7	Just about getting by	Yes	No
S11 F	Neither	Neither	Neither	Dissatisfied	9	8	Just about getting by	No	Yes
S12 F	Neither	Neither	Neither	Neither	7	7 (5 missing Responses)	Doing alright	Yes	No
S13 F	Neither	Neither	Satisfied	Neither	4	3	Just about getting by	No	No

5.3.6: Support

One sibling did not respond to the question about regular support in **Wave 3** therefore they were removed from the analysis of regular support received. The chart below presents the responses to the question as to whether others regularly supported them in caring.

One less parent in **Wave 3** reported receiving regular support than did so in **Wave 1**. A greater number of siblings reported receiving support in **Wave 3**; however, whereas more female sibling reported receiving regular support, fewer males did so. This data is presented, in numbers, in Figure 51 below.

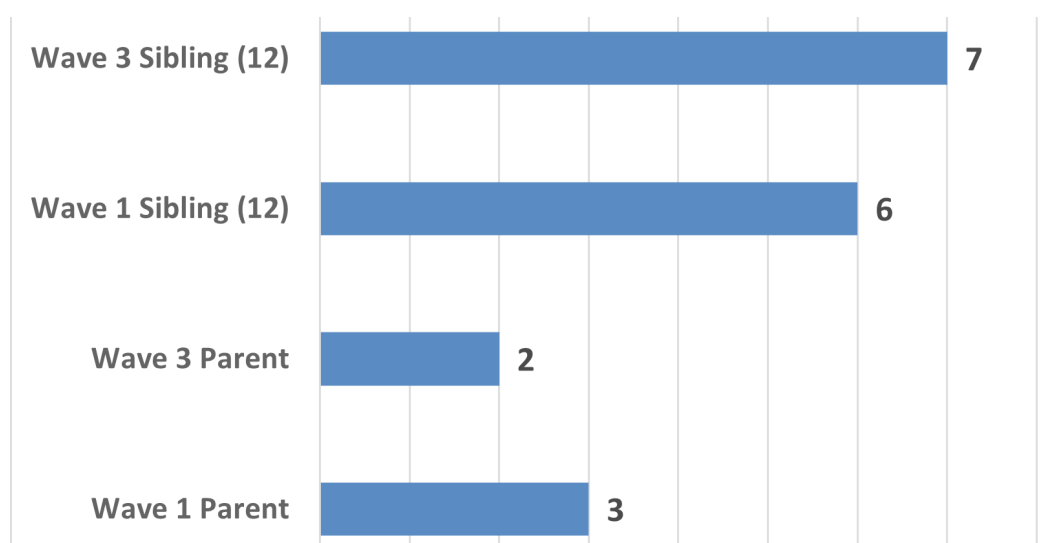


Figure 51: Regular support received

Carers were asked to identify, from a list of options, sources of support which they receive. Their responses are presented in Table 16 under the headings of “a lot” or “some” support and “not applicable”. The “not applicable” responses are included because of the frequency that this was the response chosen by the participants. Although two siblings in **Wave 1** and one sibling in **Wave 3**, reported that they received support from those within the workplace, the question was deemed “not applicable” for the great majority of the carers. Likewise, the possibility of support for the parents from their own parents was, understandably, not a relevant question but it was also deemed “not applicable” by all the sibling carers in **Wave 3** and all except one in **Wave 1**.

The three parents who answered the question reported receiving support from their children in both waves; however less than half the number of sibling carers who reported receiving support from their children in **Wave 1** did so in **Wave 3**. One parent in each wave reported receiving support from other close relatives; three quarters of the

sibling carers in **Wave 1** reported receiving support from this source and this percentage reduced to half in **Wave 3**.

The responses to this question are presented in Table 26 below. The responses by individual carer are presented alongside the responses to the questions about coping further on in this section. The numbers in brackets indicates the number of carers who responded to the question.

Table 26: Support provided by others

	Parents Wave 1		Parents Wave 3		Siblings Wave 1		Siblings Wave 3	
	A lot/some support	N/A	A lot/some support	N/A	A lot/some support	N/A	A lot/some support	N/A
From Spouse or Partner	75% (3/4)	25% (1/4)	25% (1/2)	25% (1/2)	69.3% (9/13)	30.8% (4)	58.3% (7/12)	41.7% (5/12)
From Parents	0%	75% (3/4)	0%	75% (3/4)	8.3% (1/12)	91.7% (11)	0%	90.9% (10/11)
From Children	100% (3/3)	0%	100% (3/3)	0%	58.4% (7)	41.7% (5/12)	27.3% (3/11)	36.4% (4/11)
From Other Close Relatives	25% (1/3)	66.7% (2/3)	50% (1/2)	0%	76.9% (10/13)	23.1% (3/13)	50% (6/12)	0%
From Friends	0%	100% (3/3)	66.6% (2/3)	0%	38.5% (5/13)	61.5% (8/13)	33.3% (4/12)	41.7% (5/12)
From Employer/Boss	0%	100% (3/3)	0%	100% (1/1)	16.7% (2/12)	83.3% (10/12)	0%	90% (9/10)
From Others in Workplace	0%	100% (1/3)	0%	100% (1/1)	0%	83.3% (10/12)	10% (1/10)	80% (8/10)

5.3.7: Coping

In **Wave 3**, one female sibling did not answer any of the questions relating to coping strategy; therefore this carer’s data for both **Wave 1** and **Wave 3** were excluded from the analysis given a total of sixteen respondents to this question.

The father who seems to be particularly burdened by the tasks of caring identified talking to friends and using respite as coping strategies

Table 27: Coping strategies

Strategy	Parent		Sibling	
	Wave 1	Wave 3	Wave 1	Wave 3
Talk to Friends	25% (1)	75% (3)	58.3% (7)	58.3% (7)
Watch TV	0%	25% (1)	41.7% (5)	66.7% (8)
Exercise	0%	25% (1)	58.3% (7)	66.7% (8)
Drink Alcohol	0%	0%	25% (3)	8.3% (1)
Smoke	0%	0%	0%	0%
Take Medication	0%	0%	16.7% (2)	8.3% (1)
Use Respite	25% (1)	0%	41.7% (5)	41.7% (5)
Attend Support Group	0%	0%	0%	0%
Use Phone Line Support	0%	0%	0%	0%
Alternative Medicine	0%	0%	8.3% (1)	0%
Praying or Faith	25% (1)	50% (2)	33.3% (3)	33.3% (3)

Half the carers in **Wave 1** and almost two-thirds of the carers in **Wave 3**, reported that talking to friends helped them to cope. However, males appeared less likely to talk to friends than females as in **Wave 1**, one male sibling carers reported that they would talk to friends; by **Wave 3**, none of the male siblings reported this. Another gender difference was apparent in the use of alcohol as a coping mechanism as all the carers who reported using alcohol as a coping strategy were female.

Two of the five carers – one parent and one sibling – who identified “faith or prayer” as a coping strategy also identified it in **Wave 3**; four carers who did not identify this strategy in **Wave 1** did so in **Wave 3**. Most, but not all, of the carers who used exercise reported a good quality of life.

Table 28 documents the extent to which the carers feel that they receive regular support from relatives and friends and the strategies that they use to cope with their care responsibilities. Nine carers in **Wave 1** reported that they received regular support as did nine carers in **Wave 3**, however only seven of these were the same carers. The two carers who received regular support in **Wave 1** but not **Wave 3** were both parents; their reports of their quality of life and satisfaction with their own health did not change between **Wave 1** and **Wave 3**. Likewise, there was no change in those responses in respect of

the two carers who reported in **Wave 1** that they did not receive regular support and in **Wave 3** that they did so. Four carers in **Wave 1** and one in **Wave 3** reported that they did not use any of the listed coping strategies and none were dissatisfied with their quality of life or satisfaction with their own health.

Table 28: Support received and coping strategies

Carer	Quality of Life		Satisfaction with own health		Regular support from relatives/ friends		Coping strategies		Health suffered due to caring	
	W1	W3	W1	W3	W1	W3	W1	W3	W1	W3
P1 F	Good	Very Good	Satisfied	Very Satisfied	Yes	No	Faith/prayer	Exercise Faith/prayer	N	N
P2 M	Poor	Neither	Dissatisfied	Dissatisfied	Yes	No	Use respite	Talking to friends	Y	Y
P3 F	Very good	Good	Very Satisfied	Very Satisfied	No	Yes	None	None	N	N
P4 F	Good	Good	Satisfied	Satisfied	Yes	Yes	None	Talking to friends Watching TV Faith/prayer	N	N
S1 F	Good	Good	Satisfied	Satisfied	Yes	Yes	None	Exercise Talking to friends Faith/prayer	N	N
S2 F	Very Good	Very Good	Very Satisfied	Very Satisfied	No	Yes	Talking to friends Watching TV Exercise Alcohol Faith/prayer	Talking to friends Watching TV Exercise	N	N
S3 M	Very Good	Neither	Very Satisfied	Neither	Yes	Yes	None	Watching TV Exercise Use respite Faith/prayer	N	N
S4 M	Good	Very Poor	Dissatisfied	Dissatisfied	No	No	Watching TV Take medication Alternative Medicine	Watching TV Take medication Alternative Medicine	Y	Y
S5 F	Very Good	Good	Very Satisfied	Very Satisfied	Yes	Yes	Talking to friends Exercise Alcohol Faith/prayer	Exercise Faith/prayer	N	N
S6 F	Very Good	Good	Satisfied	Satisfied	Yes	Yes	Talking to friends Use respite	Use respite	N	N
S7 F	Very Good	Very Good	Satisfied	Dissatisfied	No	No	Talking to friends Exercise Alcohol Use respite	Talking to friends Exercise Alcohol Faith/prayer	Y	Y
S8 F	Good	Neither	Neither	Dissatisfied	No	No	Talking to friends Exercise Alcohol Use respite	missing	Y	Y
S9 F	Good	Very Good	Satisfied	Very Satisfied	Yes	Yes	Watching TV Exercise Use respite	Watching TV Exercise	N	N
S10 F	Good	Good	Satisfied	Neither	No	No	Exercise Take medication	Talking to friends Watching TV; Exercise	Y	N
S11 F	Neither	Neither	Neither	Dissatisfied	Yes	Yes	Talking to friends Watching TV	Talking to friends Watching TV Use respite	N	Y
S12 F	Neither	Neither	Neither	Neither	No	No	Talking to friends Watching TV Exercise Faith/prayer	Talking to friends Watching TV	Y	N
S13 F	Neither	Neither	Satisfied	Neither	No	No	Talking to friends Exercise Use respite Faith/prayer	Talking to friends Watching TV Exercise Use respite	N	N

5.3.8: Unmet service needs

Services deficit

Compared to **Wave 1**, there was a decrease of one parent reporting that there were services that the person they care for would benefit from but are not receiving and an increase of one parent reporting that there were services that they would benefit from but are not receiving.

In **Wave 3**, most sibling carers reported that there were services that they would benefit from but were not receiving. The number of sibling carers in **Wave 3** reporting that there were services that the care recipient would benefit from but are not receiving remained the same as in **Wave 1**.

Table 29: Beneficial services not received

	Wave 1 Parent	Wave 3 Parent	Wave 1 Sibling	Wave 3 Sibling
Services the carer would benefit from but not receiving	1	2	6	8
Services the care recipient would benefit from but not receiving	3	2	6	6

Table 30 documents the carers' quality of life, their satisfaction with their own health and the number of health conditions from which they suffer alongside unmet service needs reported in **Wave 1** and **Wave 3**. The number of carers who reported that they had unmet service needs rose from seven in **Wave 1** to ten in **Wave 3**; nine carers reported that the person they support had unmet service needs in **Wave 1** compared to eight in **Wave 3**.

Five carers had an unmet service for themselves in **Wave 1** and **Wave 3**; only one of these carers reported a good quality of life and satisfaction with their own general health. All five carers, in both waves, specified respite as an ongoing unmet need. Two carers also noted that they felt unsupported:

The carer needs to be looked after acknowledged and supported. (S8)

I never ever see a HSE nurse calling to see if I am ok (S12)

All seven carers who had an unmet service need in **Wave 1** also reported that the person for whom they cared had a service need; eight of the ten carers who had a service need in **Wave 3** reported that the person for whom they cared had a service need.

In both waves, most of the specified unmet need referred to respite and other day and social activities.

Table 30: Unmet service needs

Carer	Number health condition (Wave 3 only conditions in brackets)		Quality of Life		Satisfaction with own health		Unmet Service Need Carer		Unmet Service Need: care recipient	
	W1	W3	W1	W3	W1	W3	W1	W3	W1	W3
P1 F	1	3	Good	Very Good	Satisfied	Very Satisfied	No	Yes	Yes	Yes
P2 M	9	10 (2)	Poor	Neither	Dissatisfied	Dissatisfied	Yes	Yes	Yes	Yes
P3 F	3	0	Very good	Good	Very Satisfied	Very Satisfied	No	No	No	No
P4 F	0	0	Good	Good	Satisfied	Satisfied	No	No	Yes	No
S1 F	4	0	Good	Good	Satisfied	Satisfied	No	No	No	No
S2 F	2	0	Very Good	Very Good	Very Satisfied	Very Satisfied	Yes	Yes	Yes	No
S3 M	0	9	Very Good	Neither	Very Satisfied	Neither	No	Yes	No	No
S4 M	8	9 (1)	Good	Very Poor	Dissatisfied	Dissatisfied	No	Yes	No	Yes
S5 F	0	0	Very Good	Good	Very Satisfied	Very Satisfied	No	No	No	Yes
S6 F	0	2	Very Good	Good	Satisfied	Satisfied	No	No	No	No
S7 F	8	9 (1)	Very Good	Very Good	Satisfied	Dissatisfied	Yes	No	Yes	No
S8 F	4	3 (2)	Good	Neither	Neither	Dissatisfied	Yes	Yes	Yes	Yes
S9 F	2	1	Good	Very Good	Satisfied	Very Satisfied	No	Yes	No	Yes
S10 F	3	2	Good	Good	Satisfied	Neither	Yes	No	Yes	No
S11 F	5	5 (2)	Neither	Neither	Neither	Dissatisfied	Yes	Yes	Yes	Yes
S12 F	5	1	Neither	Neither	Neither	Neither	Yes	Yes	Yes	M
S13 F	5	2	Neither	Neither	Satisfied	Neither	No	Yes	No	Yes

5.3.9: Positives

Positive aspects of caring

One parent did not answer any of the questions about the positive aspects of caring in **Wave 3**; for the purpose of comparing the responses across the Waves, this carer's responses to this section in **Wave 1** has been removed. Therefore, the number of parents included in the analysis of this data is three. The father who seemed to be particularly burdened by care disagreed with every option in **Wave 1** and with all the options in **Wave 3** with the exception of "has strengthened relationships" when his response changed from "disagree a lot" to "agree a little". One parent's responses were consistent across the waves and the other parent's perception of the positive aspects of caregiving diminished between **Wave 1** and **Wave 3**.

More siblings agreed a little or a lot with five of the eight positive statements in **Wave 3** than did so in **Wave 1**. However, fewer siblings reported feeling appreciated

and the percentage reporting that caring has strengthened relationships reduced from seven carers to just three.

Table 31: Positive aspects of caregiving: Waves 1 and 3
(Agree a lot and agree a little)

	Parents Wave 1	Parents Wave 3	Siblings Wave 1	Siblings Wave 3
Feel Useful	66.7% (2)	33.3% (1)	46.2% (6)	61.6% (8)
Feel Good About Myself	66.7% (2)	33.3% (1)	46.2% (6)	53.9% (7)
Feel Needed	67.7% (2)	33.3% (1)	46.2% (6)	61.6% (8)
Feel Appreciated	67.7% (2)	33.3% (1)	53.9% (7)	38.5% (5)
Feel Strong & Confident	0% (0)	33.3% (1)	23.1% (3)	46.2% (6)
Appreciate life	33.3% (1)	33.3% (1)	61.6% (8)	61.6% (8)
Have Positive Attitude	0%	33.3% (1)	46.2% (6)	53.9% (7)
Has Strengthened Relationships	33.3% (1)	66.6% (2)	53.9% (7)	23.1% (3)

Interestingly, when considering both the “agree” and “disagree” options, it is apparent that in **Wave 3** the participants responded more definitively than they did in **Wave 1** with a decrease in the percentage of the “neither agree nor disagree response”. As a result more carers, females in particular, disagreed or strongly disagreed with most of the propositions (in particular that they feel appreciated) and more carers, females in particular, agreed or strongly agreed with most of the propositions (in particular that caring makes them feel strong and confident and that providing support has enabled them to develop a more positive attitude towards life).

Table 32: Positive aspects of caregiving: Waves 1 and 3 by gender

	Wave 1: Agree: a lot/a little		Wave 3: Agree: a lot/ a little		Wave 1: Disagree: a lot/ a little		Wave 3: Disagree: a lot/ a little	
	Male	Female	Male	Female	Male	Female	Male	Female
Feel Useful	33.3% (1)	53.9% (7)	0%	69.3% (9)	33.3% (1)	7.7% (1)	33.3% (1)	15.4% (2)
Feel Good About Myself	0%	61.6% (8)	0%	61.6% (8)	33.3% (1)	7.7% (1)	33.3% (1)	23.1% (3)
Feel Needed	33.3% (1)	53.9% (7)	33.3% (1)	69.3% (9)	33.3% (1)	7.7% (1)	33.3% (1)	23.1% (3)
Feel Appreciated	33.3% (1)	61.6% (8)	0%	46.2% (6)	33.3% (1)	23.1% (3)	66.7% (2)	42.2% (6)
Feel Strong & Confident	0%	23.1% (3)	0%	53.9% (7)	33.3% (1)	15.4% (2)	66.7% (2)	38.5% (5)
Appreciate life	66.7% (2)	53.9% (7)	33.3% (1)	61.6% (8)	33.3% (1)	23.1% (3)	66.7% (2)	30.8% (4)
Have Positive Attitude	33.3% (1)	38.5% (5)	0%	61.6% (8)	33.3% (1)	15.4% (2)	66.7% (2)	38.4% (5)
Has Strengthened Relationships	66.7% (2)	46.2% (6)	33.3% (1)	30.8% (4)	33.3% (1)	15.4% (2)	33.3% (1)	23.1% (3)

A number of siblings in **Wave 3** added a text comment to their response including:

I love caring for my sister despite negative impact on my own quality of life. (S12)

Keeps me company sometimes, she's very pleasant (S7)

Carers were asked to identify, from a list, the positives which they felt accrued to them from providing care. The responses of the carers are presented below alongside the difficulties they had endorsed and their ratings of their quality of life and satisfaction with their own health. The responses are presented according to their “strongly agree” and “strongly disagree” responses. Three carers in **Wave 1** endorsed all the positive options and all three reported a good quality of life and satisfaction with their own health and this was also the case for the four carers who endorsed all the options in **Wave 3**. Although such a high level of endorsement of the positive mainly aligned with a small number or no reported difficult aspects of caregiving, this was not exclusively the case. For example, one sibling carer endorsed all the positive options in **Wave 1** and had reported experiencing seven of the difficulties associated with caregiving. However, in **Wave 3** this carer only strongly agreed with two of the options and strongly disagreed with five others; this pattern was replicated by another sibling carer. Conversely, two carers who had endorsed only one or no options in **Wave 1**, “strongly agreed” with all eight in **Wave 3**; their quality of life and satisfaction with their health responses remained constant between the waves. One parent carer “strongly disagreed” with all the positive options in **Wave 1** and a sibling carer did so in **Wave 3**. This sibling carer had neither “strongly agreed” nor “strongly disagreed” with any of the options in **Wave 1**; they reported being “very satisfied” with their own health in both waves.

In **Wave 1**, two carers “strongly disagreed” with the proposition that “*providing support makes me feel strong and confident*” and this number rose to nine in **Wave 3**; likewise just one carer in **Wave 1** “strongly disagreed” with the statement that providing support made them feel appreciated and by **Wave 3** this had risen to nine carers. Carers in **Wave 3** were less likely to report that “*providing support has enabled me to develop a more positive attitude toward life*” with the number doing so halving from eight to four.

Table 33: Positive aspects, quality of life and difficulties reported

Carer	Quality of Life		Difficulties Number reported		Positive aspects				Health suffered due to caring	
	W1	W3	W1	W3	W1 Agree A lot (agree a little)	W3 Agree a lot (agree a little)	W1 Disagree A lot (disagree a little)	W3 Disagree A lot (disagree a little)	W1	W3
P1 F	Good	Very Good	0	1	Feel useful Feel good Feel needed Feel appreciated Appreciate life Strengthen relationships	Feel useful Feel good Feel needed Feel appreciated Strong and confident Appreciate life Positive attitude Strengthen relationships	None	None	N	N
P2 M	Poor	Neither	8	11	None	Strengthen relationships	Feel useful Feel good Feel needed Feel appreciated Strong and confident Appreciate life Positive attitude Strengthen relationships	Feel useful Feel good Feel needed Feel appreciated Strong and confident Appreciate life Positive attitude	Y	Y
P3 F	Very good	Good	0	0	(Feel useful Feel good Feel needed Feel appreciated)	None	None	Feel useful Feel good Feel needed Feel appreciated Strong and confident Appreciate life Positive attitude Strengthen relationships	No	No
P4 F	Good	Good	0	1	missing	Feel useful Feel good Feel needed; Feel appreciated Strong and confident Appreciate life Positive attitude Strengthen relationships	Appreciate life	None	No	No
S1 F	Good	Good	missing	3	Feel useful Feel good Feel needed Feel appreciated Appreciate life Positive attitude Strengthen relationships	Feel useful Feel good Feel needed Feel appreciated Strong and confident Appreciate life; Positive attitude; Strengthen relationships	None	None	No	No

Table 33: Positive aspects, quality of life and difficulties reported

Carer	Quality of Life		Difficulties Number reported		Positive aspects				Health suffered due to caring	
	W1	W3	W1	W3	W1 Agree A lot (agree a little)	W3 Agree a lot (agree a little)	W1 Disagree A lot (disagree a little)	W3 DisagreeA lot (disagree a little)	W1	W3
S2 F	Very Good	Very Good	7	6	Feel good Feel appreciated Strong and confident Appreciate life Positive attitude Strengthen relationships	Feel useful Feel good Feel needed Feel appreciated Strong and confident	None	Appreciate life Strengthen relationships	N	N
S3 M	Very Good	Neither	0	10	Feel needed Feel appreciated Appreciate life Strengthen relationships	Strong and confident	None	None	No	No
S4 M	Good	Very Poor	9	8	Positive attitude (Feel useful Strong and confident Appreciate life Strengthen relationships)	0	Feel appreciated	Feel appreciated Strong and confident Appreciate life Positive attitude Strengthen relationships	Yes	Yes
S5 F	Very Good	Good	0	4	Feel useful Feel good Feel needed; Feel appreciated Strong and confident; Appreciate life; Positive attitude; Strengthen relationships	Feel useful; Feel needed Feel appreciated Strong and confident; Appreciate life; Positive attitude; Strengthen relationships	None	Feel good	No	No
S6 F	Very Good	Good	2	3	Feel needed Appreciate life Strengthen relationships (Feel useful Feel good Strong and confident)	Appreciate life Feel useful Feel good Feel needed (Strong and confident)	Feel appreciated	Feel appreciated Positive attitude	N	N
S7 F	Very Good	Very Good	9	8	Feel good (Feel useful Feel needed Feel appreciated Appreciate life;)	(feel needed)	None	Feel appreciated Strong and confident; Appreciate life Positive attitude Strengthen relationships	Y	Y

Table 33: Positive aspects, quality of life and difficulties reported

Carer	Quality of Life		Difficulties Number reported		Positive aspects				Health suffered due to caring	
	W1	W3	W1	W3	W1 Agree A lot (agree a little)	W3 Agree a lot (agree a little)	W1 Disagree A lot (disagree a little)	W3 Disagree A lot (disagree a little)	W1	W3
S8 F	Good	Neither	9	Missing	None	(Appreciate life Positive attitude)	None	(Feel needed Feel appreciated Strong and confident Strengthen relationships)	Y	Y
S9 F	Good	Very Good	0	0	Feel useful Feel good; Feel needed Feel appreciated appreciate life Positive attitude	Feel useful Feel good Feel needed Feel appreciated Strong and confident;	None	None	No	No
S10 F	Good	Good	10	7	(Feel useful Feel good)	(Appreciate life Positive attitude)	Feel good Feel needed Feel appreciated Strong and confident Appreciate life Positive attitude; Strengthen relationships	(Feel appreciated)	Y	N
S11 F	Neither	Neither	9	8	Strong and confident	Feel useful Feel good Feel needed Appreciate life Positive attitude Strengthen relationships	Feel useful Feel appreciated Appreciate life. Positive attitude Strengthen relationships Appreciate life; Positive attitude Strengthen relationships	(Feel appreciated Strong and confident)	N	Y
S12 F	Neither	Neither	7	7 (5 missing responses)	None	(1Feel useful Feel good; Feel needed)	None	Appreciate life (Strong and confident;)	Y	N
S13 F	Neither	Neither	4	3	Positive attitude (Feel appreciated Appreciate life Strengthen relationships)	(Appreciate life Positive attitude)	None	Feel useful Feel good Feel needed; Feel appreciated Strong and confident)	N	N

5.3.10: Future Planning

Two parent carers reported in **Wave 1** that they had engaged in future planning. The oldest of the parent carers did not report that they had done so. The parent carer who identified poor health, poor quality of life and that his health had been impacted by caregiving was the only parent who reported, in both Waves, that they had engaged in future planning. In **Wave 1**, this parent gave the name of a service provider as further information. Evidently, the plan had not been advanced in the intervening years between **Wave 1** and **Wave 3**. In **Wave 3**, three of the parent carers reported that they had thought about where they saw their family member in five years.

Seven sibling carers reported in **Wave 1** that they had engaged in future planning. One wrote that she had had looked at independent living communities and was involved in “Continuous meetings with her centre as a group” (S7). Two other responses suggest that discussing future planning with professionals was not a fruitful exercise. One sibling reported engaging in discussions with her sister’s service provider but that “funding and red tape seem to be always in the way” (S8); the other wrote that she had discussed the future with health care workers and social workers but that “challenging behaviour presents huge difficulties” (S11). The data does not suggest that satisfaction with own health or quality of life is associated with having a plan for the future.

This data can be seen in Table 34 below

Table 34: Future planning

Carer Gender & Age group	Years caring	Quality of life		Satisfaction with own health		Future plans (discussed with a professional) M = missing data		Health suffered due to caring	
		W1	W3	W1	W3	W1	W3	W1	W3
P1 F W3: 66-75	52	good	Very good	Satisfied	Very Satisfied	Yes (M)	Yes (M)	N	N
P2 M W3: 66-75	49	Poor	neither	Dissatisfied	Dissatisfied	Yes (Yes)	Yes (No)	Y	Y
P3 F W3: 86+	Missing	Very good	Good	Very Satisfied	Very Satisfied	No	No (No)	N	N
P4 F W3: 76-85	Missing	Good	Good	Satisfied	Satisfied	No	Yes (No)	N	N
S1 F W3: 56-65	10	good	good	Satisfied	Satisfied	No	No	N	N
S2 F W3: 56-65	12	Very good	Very good	Very Satisfied	Very Satisfied	No	Yes (Yes)	N	N
S3 M W3: 56-65	28	Very good	Neither	Very Satisfied	Neither	No	No	N	N
S4 M W3: 56-65	40	Good	Very poor	Dissatisfied	Dissatisfied	Yes (Yes)	Yes (Yes)	Y	Y
S5 F W3: 76-85	45	Very good	Good	Very Satisfied	Very Satisfied	Yes (No)	Yes (Yes)	N	N
S6 F W3: 46-55	15	Very good	Good	Satisfied	Satisfied	No	No	N	N
S7 F W1: 46-55	7	Very good	Very good	Satisfied	Dissatisfied	Yes (Yes)	M (M)	Y	Y
S8 F W3: 46-55	26	Good	neither	Neither	Dissatisfied	Yes (Yes)		Y	Y
S9 F W3: 56-65	26	Good	Very good	Satisfied	Very Satisfied	No	No	N	N
S10 F W3: 46-55	30	Good	Good	Satisfied	Neither	No	No	Y	N
S11 F W3: 56-65	"part-time all my life"	Neither	Neither	Neither	Dissatisfied	Yes (Yes)	Yes (No)	N	Y
S12 F W3: 66-75	18	Neither	Neither	Neither	Neither	Yes (Yes)	Yes (M)	Y	N
S13 F W3: 66-75	19	Neither	Neither	Satisfied	Neither	Yes (Yes)	Yes (No)	N	N

5.3.11: Conclusions from longitudinal data

The analysis of the individual responses to the two surveys completed six years apart demonstrates the particular nature of the experience of care-giving and the extent to which the experience is specific to each circumstance. It clearly illustrates the dynamic nature of caregiving with both positive and negative effects changing over time. Notwithstanding that, as a group, the carers who participated in both **Wave 1** and **Wave 3** of the IDS-TILDA Carer's Study reported a good quality of life, good general health and most carers in both waves compared their own health favourably with the health of others of the same age although the degree of positivity decreased between the two waves. Many of the carers, at each point in time, were enjoying good health and a good quality of life. However, it is also evident that a small number of carers are living a difficult and increasingly difficult life and are severely burdened by their care responsibilities. A close examination of their data illuminates the difficulties they are experiencing.

Three of the four parent carers consistently reported few health conditions, good quality of life and high levels of satisfaction with their own health. In **Wave 1** none of these three parents identified with any of difficulties associated with providing support although one reported physical strain as the most difficult aspect of caregiving. In **Wave 3** this carer also identified physical strain as an issue in **Wave 3** but, at this point in time, she also reported being “completely overwhelmed”, moderately bothered by bodily pain and slightly bothered by emotional pain in the previous four weeks. It is noteworthy that this parent carer reported in **Wave 3** that she was without services that would be of benefit from. She did not specify what that/those services were but she wrote, in response to another question that she worries “*about everything*” in relation to her son's future. In **Wave 3**, this parent no longer reported that she was receiving regular support from relatives or friends, however, she was deriving a high number of positives from her caregiving. The data provided by this parent suggests that despite her positivity towards giving care, she had an increasing need for help in sustaining her capacity to care.

The data from another parent indicated in **Wave 1** that he was under significant physical and emotional strain and that his difficulties were more entrenched by **Wave 3**. This father's physical and emotional health were reported as extremely poor and he considered that his health had been impacted by his care responsibilities. This carer identified with almost all the difficulties associated with caregiving and with only one of the positives in one of the waves. In both waves he reported that the person for whom he cares required support with all the activities of daily living, except toileting, all the independent activities of daily living and support with behaviour and in-home activities. This parent was the only parent who did not include “*because I enjoy this and want to*” as

a reason why they provide care. In both waves he reported that his and his son's unmet service need was for respite.

By **Wave 3**, fewer siblings classified their general health as excellent or very good, fewer rated their comparative health as "*excellent*", "*very good*" or "*good*" and in **Wave 3** less than half the sibling carers reported being satisfied with their own health. As a group, the sibling carers reported a reduction in quality of life, many were limited and increasingly limited in their leisure/recreational activities and fewer sibling carers reported feeling appreciated. However, the responses of five of the sibling carers consistently indicated a poor quality of life and low satisfaction with their own health and four reported that they were not in receipt of any regular support from relatives or friends.

The small numbers in this sub-set of the IDS-TILDA Carers Study preclude the establishing of correlations however, a number of features stand out in the analysis. Within the available data there is a clear link between sufficiency of income and satisfaction with health although it is not possible to identify whether ill-health restricts the carers from paid employment or whether lack of finances prevents the carers from engaging in positive health behaviours. However, it is notable that 80% of the carers who stated that caregiving had impacted their health also reported that they were "*just about getting by*" on their income or were "*finding it very difficult to cope*" on their income. Likewise, six of the seven carers who reported being "*moderately*" or "*quite a lot*" bothered by emotional problems in the previous four weeks were "*just about getting by*" or "*finding it very difficult*" to cope on their current income. This finding suggests an association between income insufficiency and health and well-being.

In **Wave 3** the carers were twice asked about their emotional health. Included in the list of conditions about which they were asked "*Have you had any of these in the last 12 months?*" was "*Any emotional, nervous or psychiatric problems*" and two sibling carers and one parent carer responded that this applied to them. However, a separate question asked them whether they had experienced emotional problems in the previous four weeks and almost 80% (11) sibling carers responded in the affirmative to this question; more than half of these (6) experienced these difficulties "*moderately*" or "*quite a lot*". Unsurprisingly, none of these six carers reported satisfaction with their own health. Five of the six sibling carers who experienced emotional difficulties to this extent also reported experiencing moderate, severe or very severe levels of bodily pain. As with the parent carer who reported that his health had suffered due to caregiving all four sibling carers who, in **Wave 3**, reported that their health had suffered through caregiving experienced a moderate to severe level of pain and all reported being bothered by emotional difficulties.

More sibling carers in **Wave 3** reported that there were services which they would benefit from but which they were not receiving. There was a clear overlap in service need between the carer and the care recipient such that if one had a service need then it was likely that the other also had a service need and this is unsurprising as most reported unmet service need related to respite and social activities. The data suggests a relationship between unmet service need and health; five sibling carers in **Wave 3** reported an unmet service need for both themselves and their sibling and only one of these reported a good quality of life and high satisfaction with their own health. Two siblings, who reported that their health had been impacted by caregiving, only gave lack of services as the reason that they provide care. It is not possible to assert that lack of services had a detrimental impact on the carers but it seems incontrovertible that these carers are in need of services to support and, possibly, improve their wellbeing.

The extent to which the siblings were experiencing high levels of strain is stark. At both **Wave 1** and **Wave 3**, more than half the participating sibling carers and one of the parent carers reached this threshold. Carers increasingly reported being impacted by their care responsibilities. By **Wave 3** almost two-thirds of the responding sibling carers and half the parent carers reported feeling completely overwhelmed. The data suggests that a deterioration in the health or other circumstance of the care recipient may be changing the care experience for the carers. A large increase is notable in the number of sibling carers who endorsed “*sadness for the person I care for*” as one of the most difficult aspects of caregiving. Of the nine carers who endorsed this difficulty in **Wave 3**, five also endorsed “*it is upsetting to find the person you support has changed so much from his/her former self*” and six also endorsed “*some behaviour is upsetting*”. Similarly, whereas just one carer endorsed the statement: “*it is upsetting to find the person you support has changed so much from their former self*” in **Wave 1**, five carers did so in **Wave 3**.

5.4 Qualitative responses

5.4.1: Introduction

This section presents data given by caregivers which provides insights into their expectations and anticipations of the future for themselves and for the person for whom they provide care and support. The section looks first at the issue of future planning presenting both the figures on the extent to which carers have considered the issue of future planning and also at the barriers and facilitators which the carers identify to such future planning.

The section then presents data given by caregivers which provides insights into their expectations and anticipations of the future for themselves and for the person for whom they provide care and support. This data was provided by the caregivers in response to a number of open-ended questions. In **Waves 1, 2 and 3** these questions included

- Is there anything you worry about for the future of the person you support?
- What are your hopes and dreams for the future of the person you support?
- What are your hopes and dreams for the future for yourself?

In **Waves 1 and 2** caregivers were also asked about their worries for the person for whom they provide support.

The data from these open-ended questions is presented under the themes of: worries for the future; living arrangements; hopes and dreams; the community; formal supports and restricted lives.

5.4.2: Future Planning

In **Waves 1 and 2**, carers were asked whether they had considered long-term planning for the person for whom they care; in **Wave 3** carers were asked where they saw their family member in five years. A smaller percentage of **Wave 1** carers (53.5%, n=23) reported that they had considered long term planning for the care recipient than in **Wave 2** (62.9%, n=44). In **Wave 3** over 61% in of carers reported that they had thought about the 5-year future.

Only twenty-five of the forty-seven carers who participated in **Wave 1** answered the question about whether they had discussed future plans with a professional; of these (76%, n=19) reported that they had done so. Sixty-five of the seventy carers in **Wave 2** answered the question and of these 41.4% (n=29) had discussed future plans with a

professional. Forty-two of the forty-four participants in **Wave 3** answered the question and 27.3% (n=12) had had that discussion with a professional.

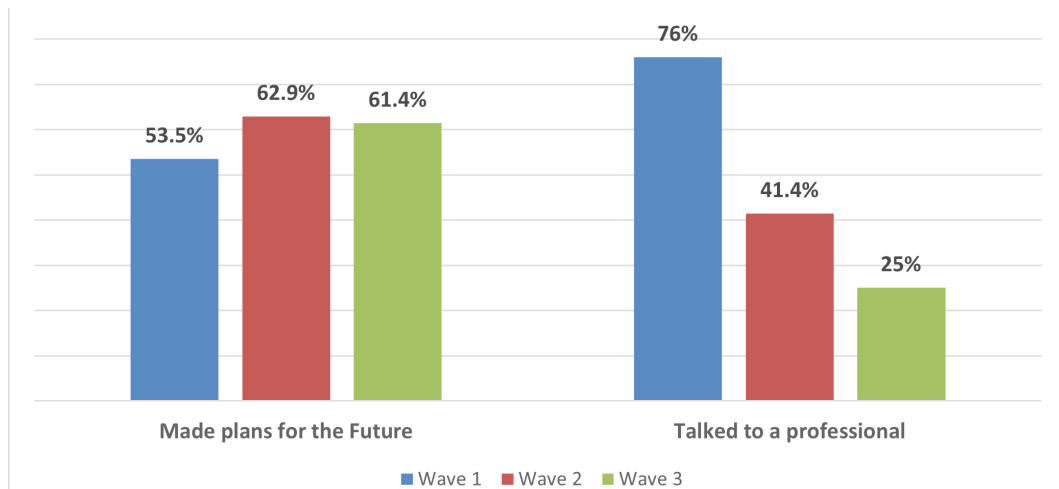


Figure 52: Future plans and discussions with professionals

Seventeen carers responded to the request to give details of discussions with professionals or groups about future planning for the care recipient. Two carers reported that the care recipient was currently living in the community and they envisaged that this situation would continue. Two carers gave the name of a service providers but did not offer any further information. Other carers identified that they have had or are in discussion with a service provider, in some instances this amounted to a “one-off” discussion whereas for others it is more ongoing. Two carers expressed frustration about their attempts to engage services in future planning. One carer identified that future planning was discussed in family conferences and another specified that s/he had made provision for the family member in the event of the carer’s death

In my will, our solicitor has instructions for her care should I die before her and she should be financially sound (W121)

In **Wave 2**, more than 60% of carers of the 70 carers who answered the questions had considered long-term planning for the care recipient whereas only 41% had spoken with a professional on the matter. Forty-one carers added to their responses about long-term planning. One care recipient had already made the transition to a full-time residential setting and three others are in the process of transitioning to living in the community. A number identified that they had had some discussions with service providers and two carers were confident that the services would take over when this became necessary and

another had received assurances from a Public Health Nurse: “PH Nurse said she will help organise it when necessary” (W266). Most, however, were not confident that support would be there when it will be needed and several expressed frustration:

Have spoken to [service] but the staff turnover every 6 months or so. ... No point in long term planning because services aren't there (W233)

... has been on the waiting list for residential for many years; ‘applying, applying, applying’ all our lives. always someone skipping the queue. Have to exaggerate what’ going on in order to get a place esp residential care, don’t want to go down this route. (W256)

Tried to engage with service but not much luck. Sick of surveys where would you like to put.... but nothing happens eg few days a week to see how manage - never came back with results, attend for a day, no feedback (W249)

Twenty-one of the carers identified that family would continue to provide for the care recipient into the future; some plans seem to be aspirational whereas others were more definite. The following quotes are representative of the information given:

hoping things will be ok. Daughters will be there if he needs them (W239)

Brother said ‘not to worry there is enough of us (siblings) here to look after him (W208)

Own children will look after him they wont put him in a home (W258)

Sister will take care of her when the time comes (W241)

Family are nearby. I don’t know if she will be able to keep him here as he is happy and familiar but I know she will do her best (W253)

In **Wave 3** carers were asked if they had thought about where their family member with intellectual disability would be in five years. More than 60% had thought about this, however only 25% identified that they had spoken with a professional about the

future. Sixteen carers responded to the request to give details of future plans. Three plans appear to be advanced although two of these are at the verbal stage

We meet with [service provider] regularly to keep all parties updated and plan to suit. (W311)

Verbal plan with day care services to house my brother in the event of my death (W322)

No written plan, but have ongoing talks with staff at local services (W330)

One carer wrote that the plan was in her will but did not elaborate on the detail of the plan and others said that they did not have “plans as yet”(W322). The plans of one carer have become redundant as the care recipient has been moved into a setting that the carer feels is inappropriate.

5.4.3: Worries for the future

Several themes cut across the data from the responses to the questions about worries that the carers had for their own future and for the future of their family member. Predominant among these themes is an anxiety about the future care of the adult with intellectual disability.

A small number of carers in **Wave 2** commented positively on their future lives or the future lives of the care recipient. These comments tended to suggest that the care recipient had lower levels of dependency

As of yet do not need many services (W241)

... is very independent, attends [service name] day service, works a few hours in the morning. Brother is a farmer living next door and sister carer lives 3 miles away (W222)

Likewise a small number of parents described that they had received reassurance from other family members about future care

I worry about when I am gone but I have a good family so they promised me that it will be ok (W269)

However even where a parent has received assurances from family members the prospect of passing care on to the next generation can be a source of concern

If I am not around who will resume care. Even though family say it won't be a problem as they will care for her-but I don't like the idea of leaving them with that responsibility (W263)

Siblings expressed apprehensions about the seemingly inevitable prospect that they will take over responsibility for the care of the family member with intellectual disability. A comment by one sibling highlights the emotional pressure that they experienced when anticipating the future

What will happen when Dad passes away. ... Would love to be hands-off but can I live with the guilt? (W236)

Parents who were currently caring as a couple noted their worry about the time when one of them will be left with the caring role when the other passes away

If anything happens to either of them, other left with caregiver role (W231)

In many instances, the concerns of the caregiver centred on the uncertainty of future care arrangements with many responses framed as questions such as the following

Where she would go if I wasn't able to care for her? (W137)

What will happen to [name] when I'm dead? (W312)

what will happen to him when we are too old to care for him (W243)

Some carers had contemplated the future alternative arrangements for their family member and perceived them very negatively

worry she will live longer than me and as we do not have brothers or sisters to take over her care, I dread to think where she might end up; (W121)

The lack of a belief in positive future care alternatives in which the care recipient would thrive and be safe and be happy appears to be the reason that many carers, both parents and siblings, wished that their family member dies before they themselves do so. Indeed, the only dream identified by one carer was that the care recipient would die before the carer

That both sisters die before me - so I will not need to worry (W140)

I worry she will live longer than me (W121)

that he is happy and that he goes before me (W317)

5.4.4: Living arrangements

Aligned to the issue of future care, the issue of future living arrangements cut across responses to the questions. One carer documented clear plans in this regard

[service name] have assessed the building and in the process of drawing up a legal document. Boys will remain in the house with nursing staff (W220)

Similarly, a small number of carers identified that they were optimistic that their family member would have a good future in an environment that suited them

... will possibly move in with her brother as he has built an extension for her (W202)

But he is used to [service name] and hope he would get into a community house. Sisters and brother-in-law would be very supportive (W221)

However, most carers had a much vaguer image of the future

may have to be put in a home, I would worry about the type of care she would get (W128)

what place would care for the person? (W118)

Some hoped that their family member would continue to live at home but did not indicate that there were firm plans in place

Hope she will be cared for at home (W328)

I worry for him in that living in his own home means everything to him and to live somewhere else would be a constant stress for him (W115)

Hopefully he will remain with family, can't imagine him going anywhere (W335)

The preferred type of accommodation was specified by some carers who variously wrote that they would like to see their family member in independent living accommodation, social housing, in a community group home and living with friends. One specified what they wanted and what they did not want

well cared for (in her home as far as possible) If not, in house resembling home as much as possible (not large unit) (W301)

However, many carers had particular concerns about the availability and the appropriateness of available residential care for older people with intellectual disability and the standard of care that would be given to their family member in that setting. One carer noted that her anxiety was heightened by media coverage of specific residential care settings.

5.4.5: Hopes and dreams

Most commonly carers identified their hopes and dreams, for themselves and the person that they care for, in terms of health and happiness.

Carers variously hoped, for themselves, for health, longevity, contentment, companionship and peace of mind. Others expressed a hope to move house, to learn a musical instrument, to finish a 100k cycle race, for improved finances and one carer identified her hope to start a family. In each wave a number of carers specified that their own health

was crucial to their hope to continue to care for their family member with intellectual disability.

just to get a little better health to be here for him (W132)

To be healthy enough to continue to care for her (W222)

As long as I stay healthy, that's the main thing. I'll keep looking after him to the best of my ability (W329)

Frequently carers identified a desire to travel, either for travel's sake or to spend time with other members of their families particularly children and grandchildren who live abroad.

To be able to travel to my older children who are overseas (W137)

Some carers were clear that they did not want to pass the responsibility for care onto another generation

I really would not want my children to do the caring I have done for the past 20 years, so I would like to think that something would be in place for the future. This can be a worry (W128)

Carers hopes for health and happiness for their family member reflect those they wished for themselves – and sometimes more.

That he would remain healthy and happy and that some day soon one of his scratch cards will show up a winner! (W270)

Our hope for [name] is that he continues to be healthy and happy for the rest of his life (W315)

That he is happy and that he can live his life to the best of his ability (W22)

However, of the responses also referred to concerns for the future health of their family member and, in some instances, the implications which deteriorating health would

have for future care and the uncertainty and stress created by the perceived dearth of appropriate care for people with intellectual disability as they age

What will happen he or I get sick. He wouldn't be very patient, would be hard to manage; (W257)

What will happen when he gets 'bad in the head'? (W258)

If and when her health deteriorates, will there be a suitable nursing home for her (W105)

That he would get anything in future that would leave him in pain. Especially as he never complains (W113)

hoping hospital care is available if needed (W114)

5.4.6: The community

The community featured in the hopes of some carers when considering the future for their family member. Some expressed a hope for more community involvement and others that the person with intellectual disability would maintain their presence in their own community

That he continues to live his life and be well in our village with an environment similar as it is today (W136)

to remain living at home and in the community where she has been for the past 49 years (W306)

enjoy continued support within the local community (W330)

Would like her to be settled in the community in her own town (W256)

A number of carers expressed hopes that their family member would achieve more independence, get enjoyment and fulfilment from their lives as exemplified by the following statement from a carer in **Wave 3**

That the person would continue to learn new things, be in more programmes, be stimulated, have more choices and be happy and healthy (W344)

5.4.7: Formal supports

The role of formal supports for the caregivers was another theme which permeated the responses to the questions. A very small number of carers expressed confidence that services will be there if required. Carers wrote of their hopes for more support for their family member particularly in relation to respite and social activities and their hopes that existing levels of support would not be subject to cutbacks. Some expressed the hope that day services would continue whereas others noted that the day service was becoming less appropriate for the older person with intellectual disability. A carer in **Wave 2** argued against what they considered to be a one-size-fits-all approach to service provision

Hope services realise every one is individual case with needs that differ (W254)

However, the key theme of the comments relating to formal support was the caregivers' sense of disillusionment with supports available to carers and their sense that they were coping without any formal support

Myself, my children and my sister have managed quite well with the caring role. The obstacles and stresses have come from outside of our home. Lack of recognition of this role as a real and important/essential role has downgraded it. Only for the personalities of the people involved could this have continued. Apart from 2 years once off payment of the respite grant, the government has not ever acknowledged the contribution paid by carers. In general, a carer is often the QUIET one and finds it difficult to shout for their needs and I feel as long as this is the case no one cares for the carer. (W337)

A carer itemised the extent of support s/he receive after almost five decades of providing care

I get help known as 'Home help' for one hour every morning and evening paid for by the state. Apart from that I live and care for my daughter full time. She is unable to speak, walk, use her hands since birth and is now 47 (W102)

The lack of acknowledgment by the state and the pain that this causes was echoed in comment by a caregiver clearly angered by the fact that the Carer's Allowance is located within the Social Welfare system

I am so angry that carers get an allowance from social welfare. We are not social welfare scroungers. We are workers, saving the country millions, instead of what you hear - a burden on the state (W144)

The Carer's Allowance was also mentioned by another carer who reported that being in receipt of the Carer's Allowance may lead to a limiting of formal services and wrote that s/he was told by a service provider

you are getting carers allowance-just get on with it (W203)

The responses of other carers focussed on the perceived lack of services for people with intellectual disability as they age

just severe disappointment with how [name] was discharged from [service name] after 32 years when all prior service users were treated very differently. We are sad, angry, and totally at a loss of a charity being so uncaring (W337)

Important to highlight that people with disabilities are living longer and services need to be looked at for their care between 50-65 other than hospital beds. (W301)

Services were perceived to be reactive rather than proactive. Carers who are identifying changing and increased support needs for their family members may feel that they are negotiating this unknown territory alone

I feel there is little co-ordination in agency approach to [care recipient's name] condition & ageing. I have also contacted Down's Syndrome Ireland and to date have received no information or response to queries about the ageing process and what we can do or what to look out for (W104)

5.4.8: Restricted lives

The dream of one carer was to be able to take a break once a year, another wanted to do things of her own choosing now that her children were reared but, she wrote, she “still can’t go” (W249). A carer in **Wave 2** simply wanted to be able to go for a walk “care-free” (W201). Several carers wrote of their sense that their lives were passing them by

To have a lot of freedom to choose when and where we can go before we are too old (W133)

The feeling of having no freedom to travel or do things I always wanted to do as I am tied to caring for my sister (W137)

I will be too old to have a life of my own. As I care for my sister and brother for 25 years and mother. My life has passed me by (W144)

A carer in **Wave 2** spoke of the regrets that they felt about their own life including things that they never got the opportunity to do, sadness that herself and her partner were not able to do things together because of their care responsibilities and the fact that their other children believed that they always took second place to their sibling with intellectual disability. This carer was adamant that she would not pass the care responsibilities on to her children. The sense of confinement was apparent in other responses, one noted that they needed time to themselves and that they were “ready to let [person] go”. The carer quoted below saw little potential for change in their circumstances

when it came to 20 year mark of providing care I looked around and asked myself, is this my life for the next 20 years?’ (W321)

Some carers reported that they wanted to continue to care but not at the current level of intensity

that I would have more free time in order to have a life alongside being a carer (W344)

Freedom eventually from full time responsibility. Would always want to be involved though (W259)

One participant specified that she did not want to relinquish caring for her sibling but that she needed support. Her comment also reflects a previous comment highlighting

the difficulty of combining care to a family member with intellectual disability with care for other children in the family

I am happy to take care of my sister. Just overwhelmed at having the full responsibility on my own. Worry that the recession and cut backs will further deteriorate the support my sister receives. Am lucky that my children are grown up, otherwise I couldn't do it (W137)

However, more frequently carers noted their dream that their care responsibility would end and that they could live a life of their choosing

to live my life free from being a carer (W138)

That I can live MY life free of worry, stress and sadness (W337)

To be able to get back to a proper routine, to find time to put me first and my wants and needs. (W313)

to get support and get my freedom back. (W336)

Almost 18% of carers in **Wave 1** and 10% of carers in **Wave 2** stated that they had no hopes or dreams for themselves, fewer carers did so in **Wave 3**. Most carers did not expand on this answer but others specified that they felt that any such hope or dreams were fruitless

Don't have any. Can't see life changing (W142)

How can I dream of anything except caring for my brother and sister while they need me and I can do it? (W144)

A carer in **Wave 2** spoke of feeling guilty for hoping for a "life that is my own" and said that

The caring role is so all consuming it is hard to think outside of it. (W337)

However, other carers did not share the sense of entrapment; it was noted that some did not see themselves as carers and one participant noted that

all is ok, we just get on with it (W246)

Chapter 6: Discussion and Conclusion

6.1: Introduction to chapter

This study has a number of important and unique characteristics. The study situates robust data about the health and well being of family caregivers of older people with an intellectual disability in Ireland within the Irish social policy context and alongside a synthesis of the wider theoretical and philosophical literature of care.

The data identifies that many carers of older people with intellectual disability in Ireland are enjoying good health and wellbeing and are caring, by choice, for a family member with whom they have a deep and affective relationship. However, others are experiencing less positive health and wellbeing and are feeling isolated and unsupported by the formal services leaving them vulnerable to further negative impacts on their emotional and physical health. The data from Waves 1, 2 and 3 of the study evidences a changing demographic caring for older family members with intellectual disability whose health and wellbeing will be subject to some different pressures to those experienced by the parent carers. The implications of this changing demographic will be discussed further in this chapter.

The longitudinal data provides valuable evidence of the within-person and between-person differences in the experience and trajectory of health and well-being of a small sub-set of the caregiver study participants and such longitudinal studies of caregivers are uncommon (Henwood *et al.* 2017; Capistrant 2016, Liu *et al.* 2015). This longitudinal data also addresses the dearth of repeated assessments (Capistrant 2016) and demonstrates the highly individual and subjective nature of the care experience. The longitudinal data throws a revealing spotlight on how the lives of carers are impacted and compromised when they have no options other than to continue to care despite that their mental and physical health is failing and their personal resources are depleted. Carers who were struggling to cope with their care responsibilities in **Wave 1** were increasingly impacted by **Wave 3** and no adequate response from the formal health and social care services was apparent.

The fundamental duty of a State is to protect its citizens; part of that duty should be to state should equalises and share the social risks that are beyond the control of an individual. The Irish National Carer's Strategy sets out the State's response to families and individuals who provide the bedrock of social care in Ireland. The critical policy analysis undertaken in this study identified that the Strategy is of limited relevance to

family carers of older people with intellectual disability in Ireland and fails to account for their lived experiences.

Irish carers have no entitlement to an assessment of their needs and no pathway through which they can identify and prioritise the services and supports which can protect and promote their well-being. Providing care for older people with intellectual disability may have become invisible, a normality which is not interrogated by either the family themselves or health professionals or service providers. The problem and the solution to the “problem” of carer lies in the socio-political system (Purkis & Cici 2014); however the Irish national carer’s Strategy fails to provide an adequate solution. Lunskey *et al.*’s (2014) assertion that parent and sibling carers of adults with intellectual disability are rarely visible in carer policy holds true in the case of Irish policy and these carers are at risk of being part of the “growing ‘hidden’ population that is at risk of being forgotten about both in the literature, in policy, and in terms of receiving support. (Forester-Jones 2019, p. 14).

The key the social policy challenge is to meet caregivers of older people with intellectual disability where they are as individuals in their own life circumstances and work with them to ensure that they and their family member are given the support, respect and dignity that they earn as citizen-carers. Such support would include respecting individual choices about the extent of informal care. A paradigm shift is required to turn away from the current ‘burden of care’ approach (Leslie *et al.* 2020) towards a personalised supportive system that values caregivers and addresses their individual needs to the extent that needs exist at any point in time.

This chapter will continue with a discussion of the key findings of the study, mapping the landscape and indicating the direction of future research. The arguments presented in this chapter are made under the thematic headings of: generational transfer; employment; income; support and social connections; health and wellbeing; respite; living their own lives; positives and future planning. The chapter will conclude with a number of recommendations for future research, policy and practice.

6.2: Generational transfer

An important finding from the cross-sectional data is the extent to which the care of the older adult with intellectual disability in Ireland is transferring from parent to sibling. The trend towards sibling caregiver is apparent over the three waves rising from 58% in **Wave 1** to 75% in **Wave 3**. Interestingly, the rate of generational transfer apparent in the IDS-TILDA data is numerically larger than that reported in the NIDD statistics (2013 to 2017) for primary residential settings. This may suggest siblings are assuming primary carer responsibilities although not necessarily (at this stage) co-residing with the sibling with intellectual disability. An alternative explanation is that the living circumstances of the individual with intellectual disability can change without the services – who provide the data to the NIDD - being informed or aware.

This evidence of generational transfer of care indicates an urgency for further research to understand the dynamics and the extent to which siblings are assuming primary care of their adult brother or sister who is ageing with intellectual disability particularly with regard to the factors that support successful intergeneration transfer (Egan & Noonan Walsh 2001). Such research would both elucidate the experience of these siblings at this key transition point and serve to inform the development of appropriate supports and resources. Across the waves, increasing percentages of carers reported the need to make family and emotional adjustments and this may flag issues arising as the primary carer responsibilities transfer to siblings. Anticipated care may be very different to actual care; at the time of transition sibling carers not only assume new responsibilities but also have to manage the adjustments that will be required to other aspects of their lives (Glaesser 2018, Coyle *et al.* 2014). Previous research has identified the tendency of sibling caregivers to put the needs of their family member before their own (Holl & Morano 2014, Hodapp *et al.* 2010). Regardless of a pre-existing supportive relationship with their brother or sister, the reality of primary caregiving may differ from the reality that was anticipated (Glaesser 2018, Burke *et al.* 2016). Few studies have focussed on co-residing sibling caregivers of people with intellectual disability (Glaesser 2018), however, previous research has indicated that siblings may experience different and difficult challenges in accessing the care services (Redquest *et al.* 2020, Holl & Morano 2014) and that the needs of siblings who were not included in transition planning may be more acute (Burke *et al.* 2016). Siblings lack the lifetime of experience of the parents in navigating the service system and services, typically, are not proactive in offering support to siblings as they take over the role of primary caregiver (Burke *et al.* 2016). Services may be unaccustomed to working with siblings (Glaesser 2018) and there has been little research into the extent to which services support sibling caregivers (Holl & Morano 2014).

The data from Waves 1, 2 and 3 provides important evidence about the sibling carers not least that they were less likely than the parents to be caring with the support of a spouse or a partner. Without support, lone carers will be physically and psychologically vulnerable to negative impacts. Across the waves, increasing percentages of carers reported the need to make family and emotional adjustments and this may flag issues arising as the primary carer responsibilities transfer to siblings.

An urgent need clearly exists to identify and engage with siblings to protect their wellbeing as they provide care for an increasingly ageing sibling. Policy makers and services need to pay attention to the needs of these sibling carers or the whole edifice of family care of older people with intellectual disability may collapse. This would be tragic for the sibling carers and those for whom they care but would also have severe consequences for the health and social care system.

6.3: Employment

Siblings are providing care in a world-apart from that in which their parents provided care. Parents, largely, belonged to a generation wherein the Breadwinner model prevailed with mothers taking care of the home and family and fathers working in paid employment, paying taxes and receiving the social insurance benefits of pensions and social assistance, when required. In this era family care both enabled and envisioned women to provide care in the home (Leitner 2003). The neoliberal social policy shift towards an Adult Worker model and its focus on individual autonomy and independence through employment provides a very different social policy environment for working age caregivers and one in which care is conceptualised as “a temporary stage in an otherwise employment centred life course” (Pfau-Effinger 2005, p. 322) and therefore does not accommodate those for whom caregiving spans a lifetime. Consistent with the apparent generational transfer, the percentage of caregivers aged 66 and older decreased between the waves. Just under 70% of **Wave 3** carers were aged under 66 years, the current age of retirement in Ireland. However, across the three waves a decreasing percentage of the sibling carers reported being in paid employment and almost half (47.6%) the responding sibling carers in **Wave 3** reported that they had cut down or given up work due to their care responsibilities. The issue of reconciling care responsibility and paid employment is an important one which has become prominent on European and Irish policy agendas. The Irish policy response in respect of childcare and elder care has been to facilitate the

marketisation of care through private sector formal care providers (Murphy & Turner 2017). Although a number of carers in this study made reference to paying privately for some care support services, most carers of adults with intellectual disability do not purchase services in the open market in the way in which child care can be purchased from a market offering the flexible service around which parents can reliably organising their work life. Carers in each of the three waves of this study reported that they had cut down or given up work because of their responsibilities towards their family member with intellectual disability. The high number of working age carers who are not in paid employment may be indicate that the current employment protection measures are unsuitable to this cohort of carers and that the policy drive towards individualisation and the commodification of care is blind to the complexities of many care relationships and to the choice that some caregivers make to prioritise care (Lewis & Guilleri 2005). The National Carers' Strategy (2012) acknowledged the importance of paid work for those carers who wish to participate in the labour force and foresaw a system wherein carers are supported in this by flexible and responsive respite services, and through part-time and flexi-time working, job-sharing and tele-working. The text responses from some of the carers suggests that they have not found caregiving and employment to be compatible and current provisions may not provide adequate flexibility to compensate for the unpredictable nature of some caregiving and the lack of flexibility of services provided to their family member. Further research to understand the barriers to combining care of older people with intellectual disability and labour force participation is clearly required.

6.4: Income

The literature and the National Carer's Strategy (2012) identify many advantages to carers when they maintain links with the labour market not least of which is income. Financial instability has been implicated in negative psychological outcomes for caregivers (Savage & Bailey 2004) and caregiver depression and distress have been shown to be associated with a caregiver's level of income adequacy (Covinsky *et al.* 2003). Working age caregivers have an increased risk of poverty compared to non-caregivers (Colombo *et al.* 2011) and caregivers who are not in the labour market are under greater financial strain than non-caregivers (Eurofound 2015). The longitudinal data identified the association between the participants' perception of their health and wellbeing and their perception of income sufficiency. The **Wave 3** data from the cross-sectional study provides stark detail on the financial circumstances of many of the carers. This is consistent with

reports from other studies which have identified that carers of people with intellectual disability are particularly vulnerable to financial difficulties compared to other caregiver groups (Tosika *et al.* 2017). Only 16% of the caregivers reported that they were living comfortably on their income; 50% were coping and almost 30% were finding it difficult or very difficult. **Wave 3** data was collected between October 2016 and February 2017; the Central Statistics Office reports that the average annual earning in Ireland in 2017 was €37,637. However, 56.9% of **Wave 3** carers reported an income of less than €30,000 and a further 15.9% reported an income of between €30 and €40,000. Thus, the income of most of the carers was under the average annual income. Carers in receipt of Carer's Allowance, aged less than 66 years of age, will have an annual income from that source of €11,388, an income that is €26,249 less than the average annual income in Ireland in 2017. Irish households that include an adult, or adults, with a disability are amongst those with the highest poverty levels (Watson & Nolan 2011, Russell *et al.* 2010, Emerson 2007) and people with a disability in Ireland are three times more likely to live in consistent poverty than people without a disability (Inclusion Ireland 2020). The caregivers in the longitudinal study who identified that they were struggling on their income also identified poor health and wellbeing. Poverty affects health; individuals at the lower end of the social ladder are at, at least, twice the risk of serious illness and premature death than individuals towards the top of the social ladder (Wilkinson & Marmot 2003). Financially disadvantaged carers lack the resources to buy in care and fewer options or to engage in activities of their choice outside the home.

Clearly financial support through the existing Carer's Allowance is inadequate to protect families from this level of poverty. Supporting family care is highly cost-effective compared to residential care provision (Kelly *et al.* 2019, Romeo & Molosankwe 2010). No studies have explicitly explored the impact of Carer's Allowances on the health and wellbeing of carers. However, the well-established correlations between poverty and health and between disability and poverty indicates the potential importance of this income stream to caregivers. Informal carers are of inordinate economic value to Irish health and social care services, the decision whether to recompense their work is a political choice. At present, in return for the work of informal carers, the state provides a financial acknowledgement at a level that is 30% of the average annual income and in a form of a welfare allowance rather than a legitimate wage with the potential stigmatising of the caregivers as welfare recipients (Murphy & Turner 2017). Welfare entitlements are fragile; they are subject to cuts in times of austerity and to changes as political ideologies transform welfare policies (Kröger 2009).

6.5: Support and social connections

Previous Irish studies reported that over one-third of the family carers of people with intellectual disability in their studies were single, separated, divorced or widowed (Lafferty *et al.* 2016b, Barron *et al.* 2006); in another study, inclusive of a range of caregivers, just 27.8% of the sample were single, separated, divorced or widowed (O’ Sullivan 2008). However, in **Wave 3** of the present study more than 45% of the carers reported these relationship status and siblings were more likely than parents to be caring without the support of a partner. More than a quarter of the **Wave 3** siblings had never married and others had lost their intimate partner through death or separation or divorce. Associations have been identified between the positive health and wellbeing of ageing caregivers and having a partner and the close support of family and friends (Baumbusch *et al.* 2017; Llewellyn *et al.* 2010). The extent to which the caregivers participating in the three waves reported that they received regular support from others decreased across the Waves. Whereas in **Wave 1** almost 60% of carers reported that they did regularly receive such support, less than 50% of those participating in **Wave 3** reported receiving this support. Unsurprisingly given the increase in the number of caregivers who do not have a partner or spouse, the percentage reporting receiving support from that source decreased and possibly this may account for the reduction in reported support received from children. However, fewer carers reported receiving a lot of support from close relatives (**Wave 1**: 17.9%; **Wave 3**: 14.6%) or from friends (**Wave 1**: 13.5%; **Wave 3**: 4.9%). This trend worryingly suggests that caregivers are increasingly caring without support and may be aligned to the rising percentage of carers identifying “being constantly on-call” (**Wave 1**: 34.9%; **Wave 3**: 61%) and isolation as the most difficult aspect of caring (**Wave 1**: 20.9%; **Wave 3**: 24.4%).

Interestingly in light of the very low percentage of carers who reported receiving regular support from friends, the most frequently identified coping strategy used by carers was “talking to friends” suggesting that the carers conceptualised support as instrumental support. However, not all carers identified friends in relation to coping and isolated caregivers such the one who wrote: “No friends, no-one to talk to” are likely to be particularly at risk of experiencing negative health and well-being outcomes. Very few carers in this study accessed support groups. In some instances, this may be because “There are no support groups around” or possibly it is because they are unaware of the existence of local support or national support groups or are unable, logistically, to access existing groups. Internet support groups have been found to provide positive virtual communities for caregivers offering solidarity and support and facilitating the exchange of information (Perkins & LaMartin 2012). Inclusion Ireland, among other voluntary

groups, has a forum for carers of people with intellectual disability and Family Carers Ireland offer carer support, advice and practical help to carers in general, however these do not appear to be availed of by some carers for whom they may be of great benefit.

6.6: Health and wellbeing

Overall, the caregivers in this study perceived themselves to be healthy and the majority of caregivers in all three waves reported high levels of satisfaction with their own health. Likewise, in all three waves the majority of carers reported that they enjoyed a good quality of life, that their leisure or recreational activities were not limited by their caring responsibilities, that their physical health did not limit their usual physical activities or their daily work, and that their social activities with family and friends had not been limited by their physical health or emotional problems during the past four weeks. However, it is notable and should be a matter of concern that on all except one measure, the caregivers who participated in **Wave 3** perceived their general health and their satisfaction with their health less positively than did the caregivers in the previous waves. The sample in each wave differed and the cross-sectional data therefore does not supported evidence of changes within the sample. However, the carers who participated in **Wave 3** more frequently reported experiencing moderate, severe or very severe pain and were also more likely to report that their daily activities are limited by long-term illness, health problems or disability. In **Wave 3** almost 42% of caregivers identified that they had been “extremely”, “moderately” or “quite a lot” bothered by emotional problems included feeling anxious, depressed or irritable during the past four weeks. Although only a minority of carers considered that their caring responsibilities had negatively impacted their health, once again **Wave 3** carers more frequently (23.8%) did so than carers in **Wave 1** or **Wave 2**. Thus although the majority of caregivers enjoy robust health and quality of life, the data indicates a significant and increasing minority do not

The extant evidence about the health and wellbeing impact of caregiving is inconclusive and sometimes contradictory (Schultz 2020). Most carers in this study did not attribute poor health to their care giving responsibilities, a finding that is consistent with other studies of carers of people with intellectual disabilities (Totsika 2017). Reported or objectively measured poor health indicators are not necessarily an impact of caregiving and the relationship between health impacts and caregiving is not a linear one but rather one mediated by a myriad of intrapersonal and external resources (Henwood *et al.* 2017) and caregivers may be reluctant to attribute their ill-health to their care for a

family member. Henwood *et al.* (2017) suggests that it is important to understand which aspects of caregiving are associated with adverse effects. However, the health and well-being of caregivers may be relatively independent of the caregiving role (Schultz 2020) and negative outcomes may not be a consequence of caregiving per se but a consequence of performing the role relentlessly with an inadequate income and without regular, reliable breaks akin to those that are mandatory for those that work in paid employment. Caring is a complex, multi-dimensional, highly individualised activity; Brown & Brown (2014) reject what they call the “modal message” that caregiving is harmful and argue for a recognition that investing in caregivers benefits not just the caregivers and the people they support but also society as a whole. So it may be of less importance to be able attribute ill health or poor quality of life to caregiving responsibilities than to identify the difficulties experienced by carers and ensure their needs are met regardless of the root cause of these and without caregivers having to identify with the notion of their family member being a burden. Rather they should be given the support that they need because of their social and economic value to society (Brown & Brown 2014, Feinberg *et al.* 2011) and because of their status as citizen-carers.

In **Wave 1** and **Wave 3**, almost half the carers reported feeling completely overwhelmed. This suggests that these carers are reaching, if they have not already reached, the threshold of their available resources which should be a matter of concern to both the health services and policy makers. A feeling of confinement was identified by half the carers in **Wave 1** and **Wave 3**. The intensity of the feeling of confinement was articulated poignantly by some carers in their qualitative responses and some expressed a belief that their responsibilities as carers dominated their lives and prevented them from living a life of their own choosing and envisioned little chance of the situation changing. This perceived lack of freedom may have significant implications for the caregivers as autonomy is a well-established associate of well-being (Maguire, Hanly & Maguire 2019)

6.7: Respite

Interestingly, the percentage of carers reporting that their family member had unmet service needs was lower among the carer participants in **Wave 3** than in earlier waves. Nevertheless, the experiences of some of the carers has left them feeling overlooked and unsupported by the services or the statutory authorities. Carers considered that services were reactive rather than proactive and lacking in the flexibility that would support them to have the time, energy and backup to confidently enjoy other aspects of their

lives while continuing to provide a level of care. Inadequate support makes caregivers care beyond their capacity, drives carers to crisis, makes parents unwilling to pass burden on and siblings reluctant to take on the role. A consistent theme within the qualitative data was the need for respite that was regular, predictable and available at short notice if required. Carers described significant reduction in the availability of respite and its complete withdrawal; respite services that are available were characterised as inflexible and timed to suit the services rather than the needs or the wishes of the caregiver or the care recipient. Between the years of 2008 and 2018 cuts of almost €160 million were made to Irish disability services. These austerity cuts to funding for disability and social care services made in the aftermath of the economic downturn in 2008 are still reverberating as individuals with intellectual disabilities and the families who support them experience the consequences of the underfunding and inconsistency of respite, residential provision and community support services (Family Carers Ireland 2020, Malli 2018, Inclusion Ireland 2013).

The carers' perceptions of a contraction in respite services is evidenced by Kelly *et al.*'s (2019) analysis of the provision of overnight respite breaks for people with intellectual disability and their families in 2007 and 2017. Many essential supports are discretionary and not based on entitlement compounding the geographical inequities (Family Carers Ireland 2020). Provision is decreasing at the same time that the need for family care is increasing and, as with all home care support services, respite is not based on entitlement or need. The Equality Authority (2005) characterised the current Irish approach to respite as a minimalist one that fails to address the importance of regular, daily or weekly basis to ensure a reasonable quality of life for the carer and pre-empt deterioration in their well-being and capacity to care. (p. 83). In 2018 Family Carers Ireland suggested that carers should have a statutory entitlement to a minimum of twenty days respite equivalent to the statutory leave entitlement of workers in the paid labour market (Family Carers Ireland 2018a), however there is no national policy on the provision of respite despite its importance as a support to families (Gadd 2019). A right to respite may be highly aspirational, however Merriman and Canavan (2007) argue that both the EU's Madrid Declaration and the UN Declaration of the Rights of Persons with Disabilities (2006), both of which underpin the National Disability Strategy (2004), contain implicit references to such a right. Regardless of any moral obligation for the state to protect the wellbeing of caregivers, reducing supports which might scaffold the sustainability of informal care is very dubious economics.

In 2007 Merriman and Canavan stated that the definition of respite depends on who is asked and thirteen years on, this remains the case. The Irish Carer's Strategy strongly endorses the importance of respite for carers and identified respite as a priority area. How-

ever respite has not been conceptualised in a way that would render the term useful and implementable for carers of adults with disability. O’ Shea and colleagues (2017) sought to establish what “respite” means to key stakeholders in dementia in order to build an evidence base on concepts that are well developed and understood by all. A similar exercise in the context of intellectual disability is a clear priority to underpin the development of services that are fit for the purposes envisioned in the Irish carer’s Strategy.

6.8: Living their own lives

The literature is replete with evidence that the health and wellbeing of some caregivers are negatively impacted when the physical or psychological strains exceeds their capacities and/or because the role confines them and prevents them from living a life of their choosing or attending to other roles which they have, or which they may choose to have, such as parent or career professional or friend. The tagline of National Carer’s Strategy (2012) is “Recognised, Supported, Empowered”; in reality the choices available to carers are bounded by limited acceptable options thus undermining the agency of the caregivers. When caregivers struggle to access flexible respite, it is hard for them to envisage anything on a greater scale. The National Carer’s Strategy (2012) identifies empowerment as a guiding principle asserting confidently that “Carers will feel empowered to make decisions about how they choose to live their lives as individuals in their own lives” (p. 9). However, when carers are not even in a position to choose to go for a “*care-free*” walk, the goal of empowerment is still somewhat distant. Consistent with the findings in other studies many of the carers are content with the arrangement of the person living in the family home (Barron 2006, McConkey, Sowney, Milligan & Barr 2004) however that does not negate their potential need for support. Rummery (2011) argues that caregivers are optimally positioned to give attentive, competent and responsive care if they can exercise choice and control of the elements of care that they provide and how they provide that care. A society that conceptualises care as social participation and exercise in citizenship would enable individuals to give care through choice rather than from obligation or because of lack of formal services.

6.9: Positives and love labour

Many carers endorsed many of the statements about the positive aspects of caregiving. However, the level of endorsement of five of the eight positive statements was lower among those caregivers who were caring at **Wave 3** than those caring at **Wave 1**. This was most apparent in reference to the statements that caring made them “feel appreciated” (-15.6%), “feel good” about themselves (-14.2%) and “feel useful” (-12.7%) indicating an overall declining level of benefit finding among the caregivers. This trend may be associated with an increased endorsement of many of the difficulties of caregiving; the caregivers in **Wave 3** more frequently reported upsetting caregiver behaviour (**Wave 1**: 24%; **Wave 3**: 29%); emotional adjustment (**Wave 1**: 24.4%; **Wave 3**: 47.7%) and sleep disturbance (**Wave 1**: 29.3%; **Wave 3**: 43.9%). Likewise, it may also be associated with the finding that the frequency with which care tasks had to be performed increased between the waves as did the level of support required for key tasks including providing partial of full support with medication, walking, bathing, oral care and getting in and out of bed.

Nonetheless, many of the text responses demonstrated a deep affective commitment to the family member with intellectual disability illustrating the “love labour”; “other-centred” (Lynch & Lyons 2009a) element of the caregiver/care recipient relationship. Carers wrote of the love that they had for their family member, the fact that this transcended the difficulties and their wish to maintain their current role for as long as possible. However, it was also clear that some caregivers want to relinquish the role of caregiver totally or partially either because they feel that they can now longer fulfil the role or because they had not chosen not to take it on. The National Carer’s Strategy (2012) makes passing reference to carers “who choose to care” (p. 9) however in the absence of real choice and when the same strategy presents family care as normative, barriers are created to family members choosing not to provide this care, or choosing to relinquish care or share the care with formal services. Lifelong caring is different: lifelong caring is a life sentence if it does not involve choice and the fact that formal care services are perceived to be crisis-driven and residualist feeds into a perception that not to cope is to fail. Instead, Todd and Shearn’s (1996) “captivated” caregivers should be supported to sustain and continue to enjoy and benefit from their role and the “captured” caregivers should be released from the role secure in their confidence that their family member will thrive in a different care setting. It is also important to note the evidence that informal care is more prevalent in countries with higher levels of formal care provision and that the sustainability of family care may be enhanced by ensuring that adequate, proactive supports protect caregivers and enable them to live the lives of their choosing while maximising their capacity to give affective love and care to their family member.

6.10: Future planning

More than half the **Wave 1** carers (53.1%) and **Wave 2** (62.9%) carers reported that they had considered long-term planning for their family member and 61.4% of **Wave 3** carers reported that they had thought about where their family member would be in five years time. The text responses indicated that some carers had firm plans with which they were happy. However, other text responses demonstrated palpable frustration on the part of the caregivers and their perception about the futility of engaging with voluntary and statutory services about future planning. High turnover of staff and red-tape were identified as barriers and carers wrote of repeatedly completing surveys about future needs without any further progression and of spending years “applying, applying, applying” for a service that they believed does not actually exist. The perception that there is no service available to meet future – or in some instances current – need re-occurred in the responses of the caregivers and 53% of **Wave 3** carers reported that they had concerns about what would happen when they themselves can no longer provide the care needed by their family member. Most commonly services are not proactive in initiating discussions about future planning and the responsibility is usually assumed by the parents (Walker & Hutchinson 2017) yet a number of studies have shown that family members participate in formal future planning initiatives when these are both sensitive and supportive (McCausland *et al.* 2020, Ryan *et al.* 2014, Heller & Caldwell 2006). However, similar to reports in previous studies (Pryce *et al.* 2015, Bibby 2013, Dillenburger & McKerr 2011, Bowey & McGlaughlin 2005) a number of carers identified their wish that their family member would die before them; indeed this finding has been reported so often that it has become normalised as a trope. Rather than an indication of over-protection by (mainly) parents and a belief in their care is unrivalled, this hope may be a reasonable response in light of the failure of services to engage with families, perceived bureaucracy, families’ previous negative experiences of services and the reality of inadequate alternative, community based residential options for older people with intellectual disability (Walker & Hutchinson 2018, Pryce *et al.* 2015, Weeks *et al.* 2009). Effective future planning should start at an early stage and be proactive rather than reactive and crisis driven (Ryan *et al.* 2014, Bigby 2000). Respite provision is also an important issue with regard to future planning as respite services frequently serve as starting points for family consideration of future care plans (Leane 2020). The increasing longevity of people with intellectual disability is an established fact and the onus should be on statutory and voluntary services to plan ahead to meet out-of-home accommodation and support needs (Ryan *et al.* 2014). It is important that supports for future planning are inclusive of siblings who have previously reported future planning

as a significant unmet need (Holl & Morano 2014). These services should be developed in a way and to a standard that will obviate the circumstances that lead family members hoping that their loved one will die before them. Such high quality alternative provision should include appropriate nursing home facilities for those who need this level of care particularly where the person with intellectual disability has dementia.

The disability and ageing sectors are distanced by both bureaucracy and funding models. People with disability straddle two client categories as they age with little policy attention to their particular needs (Leahy 2018). Intellectual disability services may be unprepared to meet the needs of older people with intellectual disability and general provision for older adults may be unsuitable (Bigby 2004). This was raised as an issue by a number of carers who expressed both concern and frustration about the uncertainty of provision for family member as the day service model became inappropriate. This concern was particularly acute for family carers who were dealing with the prospect of the older adult with disability developing dementia. Little evidence is available to indicate that progress in being made towards the implementation of the recommendations of the International Association for the Scientific Study of Intellectual Disabilities to improve services for ageing carers by combining expertise from different sectors (Ryan *et al.* 2014).

6.11 Limitations

The carers who participated in the IDS-TILDA study opted to do so. In **Wave 1**, eighty-three carers were eligible and invited to participate and forty-seven did so. The characteristics of those who chose not to participate are not known and therefore no conclusion can be drawn about the extent to which participating carers are representative of all family carers of older adult participants in the IDS-TILDA study.

Further, the sample of participants in the IDS-TILDA study was drawn from the National Intellectual Disability Database. This database may not be inclusive of adults with a milder level of intellectual disability who are not registered with intellectual disability services and therefore the experiences of family carers of this cohort of older adults with an intellectual disability are not included in this study.

As described in the Methodology chapter, the mode of questionnaire administration changed in **Wave 2** changed to a researcher administered mode. This appears to have impacted on the responses of many of the carers who were inclined to reflect more positively on the health, wellbeing and experiences that did the carers in **Wave 1** and **Wave 3**. This effect was mitigated by limiting the extent to which direct comparisons were made

between **Wave 2** responses and those in **Wave 1** and **Wave 2** in the cross-sectional data and by restricting the analysis of the longitudinal data to that of **Wave 1** and **Wave 3**.

The number of participants in the longitudinal sample was small and the extent to which the findings can be generalised is limited. However, this longitudinal study represents a unique insight of the trajectory of the health and wellbeing of an under-researched cohort of family caregivers.

6.12: Conclusion

Care is the most basic of human needs without which humans will not only fail to flourish but will fail to survive (Lynch & Walsh 2009). Accepting that care is a “universal activity that binds us all” (Williams 2002, p. 487) is to recognise that that dependency is a fundamental feature of being human. The neoliberal emphasis on the individual stands in sharp contrast to an ethic of care approach which envisions individuals as existing within interdependencies and with multiple responsibilities to each other and also to themselves (Hill 2015). Where the right to receive and give care has an ethical value, it also has an intrinsic value. And if the responsibility for care is equally distributed within societies rather than being located within individuals and families, then high quality and accessible formal care services will be a sine qua non of social policy (Hill 2015). A residualist approach to care ignores the obligation of society to not exploit individuals engage in dependency work but attend to attend to their wellbeing and to support them to survive and thrive (Kittay 1999) and to take their place as full and valued members of society.

Policymakers largely shape policy within existing paradigms as it is existing paradigms which shape their own cognitive understandings of the range of policy alternatives (Immergut & Anderson 2008). Unless existing paradigms are challenged and disrupted, policy proceeds along well-worn paths. Disability used to be framed as an individual and personal tragedy and the barriers and discrimination faced by persons with disability were generally accepted as an inevitable consequence of the person’s misfortunes. The current portrayal of carers in the public discourse through the media is either as selfless and heroic or as desperate and despairing. Individual carers who have reached the extremities of their resources find themselves sharing the most difficult details of their family lives through the media in an attempt to rally support and a service response. The fact that many parent carers feel strongly that they will not pass the primary care responsibility for their family member with intellectual disability on to the next generation indicates that these parents, with their decades of experience, do not foresee that the circumstances of carers will change.

The Irish National Carer's Strategy (2012) is now eight years old. Its stated focus was on the short to medium term thereby, self-evidently, lacking a long-term vision identifying the place of carers in Irish society. Its goals were admirable aiming to: 1. Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for 2. Support carers to manage their physical, mental and emotional health and well-being 3. Support carers to care with confidence through the provision of adequate information, training, services and supports 4. Empower carers to participate as fully as possible in economic and social life (National Carer's Strategy 2012, p. 10). The Strategy also claimed to recognise the reality that many carers may "be unable to do the day to day things that most people take for granted – to relax, to socialise or to work" (National Carer's Strategy, (2012, Goal 4, p. 18). Yet these goals were intended to be achieved on a cost-neutral basis and the Strategy was launched in a time of austerity and in the context of consistent decreases in the funding for disability services. The state benefits from the personal cost which carers pay for fulfilling their role (Smith 2012) and financial cuts to service providers inevitably lead to retrenchment of services resulting in greater care responsibilities falling to informal caregivers (Malli 2018).

This thesis is being completed at a time of extreme social and economic upheaval due to the Coronavirus Covid-19. Mark Carney (From Covid Crisis to Renaissance 2020) suggested that as societies responded to the crisis by prioritising health over the economy, it has demonstrated that

We know that we need to act as an interdependent community, not as independent individuals. The values of economic dynamism and efficiency have been joined by those of solidarity, fairness, responsibility and compassion.

The approach to those who respond to dependency should reflect the same values. The prevailing paradigm around care and caring must be changed with dependency framed as a social risk to be met as a collective societal responsibility. Family caring can bring great personal benefit, satisfaction and joy but it can also compromise and even destroy the lives of carers and their families. Disability activists reframed the "problem" of disability from an individual one to a rights-based issue and thus changed the context within which people with disability can claim their right to equality. An inclusionary model of citizenship, which acknowledges caregiving as a key attribute of citizenship, may offer a similarly effective framework through which the rights of caregivers could be asserted. Otherwise caregivers may continue to be politically and socially invisible.

6.12: Recommendations

6.12.1: Research

1. Given the large variation in results from extant generic caregiver research, it is important to continue to develop a body of knowledge about the lives of caregivers of older adults with intellectual disability in Ireland. The Irish context is different from that in other countries including other countries with a Liberal welfare system therefore much of the existing research is of only limited value. Likewise, caring for an older person with intellectual disability is a caring experience which differs in many important aspects to caring for people with other support needs or whose support needs are differently originated.
2. Findings indicate the imperative for future research focussing specifically on siblings of older adults with intellectual disability. Sibling carers are a specific and increasing category of carers and it is important to understand their experiences in order to support them with their care responsibilities enhancing both their lives and the lives of those for whom the care.
3. The disproportionately (compared to other studies) low level of engagement in the paid workforce requires exploration to investigate whether there are particular barriers to employment for carers of older people with intellectual disability and the supports required to overcome any such barriers. However, carers must also have the freedom to choose not to combine care with paid employment and to be valued as an equal citizen for the contribution they make to the public good.
4. As Ireland becomes an increasingly multi-cultural society, it is timely to explore the accessibility and appropriateness of the statutory and voluntary intellectual disability support services to ensure that they are inclusive of ethnic minority people. The experience from other countries indicate that barriers faced by ethnic minority communities include language and communication difficulties, different cultural expectations and assumptions and implicit or explicit prejudice and discrimination (Henwood *et al.* 2017).
5. A body of literature is developing which highlights specific issues relating to ageing and disability in rural areas including disparities in the availability of formal services and supports and the scarcity of residential options for people ageing with intellectual disability (Garnham & Bryant 2019). Despite increasing urbanisation Ireland still has one of the most rural populations in Western Europe suggesting the importance of research to identify issues specific to rurality and caring for older people with an intellectual disability.

6.12.2: Practice

1. The international literature indicates that the most frequently identified need expressed by sibling carers of people with intellectual disability is for information particularly with respect to providing care, navigating the disability and older persons systems and accessing support for themselves (Arnold & Heller 2018). Ireland lacks a national sibling specific support network such as The Sibling Collaborative in Canada, Siblings Australia in Australia and Sibs in the United Kingdom; the establishment of such a network in Ireland would be a positive step towards the provision of support for sibling caregivers in Ireland.
2. Clarity is required about whose role it is to support carers or identify their needs. The UK's Care Act (2014), is a clear legal framework which explicitly locates the responsibilities for addressing the needs of caregivers and their quality of life with the local authorities. A similar statutory right to an assessment of need is overdue in Ireland but such an assessment must be made meaningful through the availability of appropriate services and supports.

6.12.3: Policy

1. The poor financial circumstances of many carers should be considered untenable. Carers should not be financially penalised because of their care responsibilities. If a moral or citizenship argument is not persuasive with regard to the need to support caregivers, a pragmatic, financial one should be. It is in the interest of the state to protect the health and wellbeing of informal caregivers in order maintain them as caregivers. Caregivers are an asset to the state and their health and wellbeing should be protected as such. Different models of financial support for care should be explored at a policy level.
2. An all-of-government approach should be taken to promoting the wellbeing of caregiver. All new policies should be "caregiver-proofed". The paradigmatic movement of disability policy towards independence, empowerment, autonomy and choice are to be welcomed however some policy initiatives will also impact, positively or negatively, on family caregivers of individuals who need support. Disability policy, in particular, risks being in tension with carer policy (Oireachtas Library & Research Service 2019) whereas they should blend together to the benefit of both.

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Appendix 1:
IDS-TILDA Carer's Study
Wave 3 Questionnaire



**Intellectual Disability Supplement to The Irish
Longitudinal Study on Ageing (IDS-TILDA)**

**Wave 3 Carer's Self Completion
Questionnaire: CONFIDENTIAL**

IDS-TILDA would like to convey to the reader that no part of tis protocol may be replicated reproduced or copied in any form without the explicit permission of the principal investigator of IDS-TILDA ©



IDS-TILDA

Working to Make Ireland the Best

Place to Grow Old

IDS-TILDA would like to convey to the reader that no part of this protocol may be replicated reproduced or copied in any form without the explicit permission of the principle investigator of IDS-TILDA ©

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Section 5	Your Health	26
Section 6	Health services for the person you support	33
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About this Questionnaire

This Carer's Self-Completion Questionnaire is about your experience as a carer and as a carer, your views are very important to us. Carers play a vital role in supporting older adults with intellectual disability in the home. [We recognise that you may be caring for more than one member of your family but this](#) questionnaire will assess your experience of caring for an older adult with intellectual disability and the impact your caring role had had on your health and well-being.

We would like to ask you some questions about the support you provide to the person selected to take part in this study.

For the purpose of the study, we will refer to the person selected to take part in this study as the 'person you support'.

Please complete this questionnaire and return it to the interviewer before s/he leaves.

All your answers will remain strictly confidential.

How to complete this Questionnaire

Please answer the questions by :

Ticking a box like this



OR

Writing a number in a box like this

Sometimes you will find an instruction telling you which question to answer next like this:

PLEASE TICK ONE BOX ONLY

YES	<input type="checkbox"/>	Go to Question 6
No	<input type="checkbox"/>	Go to Question 10

- ❖ If there are no instructions just answer the next question
- ❖ Please try to answer each question as best you can.
- ❖ The questionnaire should take you about 15 to 20 minutes to complete.

What to do if you need support

If you need any support completing the questionnaire please ask the interviewer if he/she is still in your home. Otherwise, please contact the research team at: 01-8962771 or 01-8963186 or email dstilda@tcd.ie

How to return the Questionnaire

When the interviewer visits your home please hand it back to them.

Please start the questionnaire at Question 1 on the next page

Thank you for taking part in this study

Section 1: About Yourself

1

Are you male or female?

PLEASE TICK ONE BOX ONLY

Male	<input type="checkbox"/>
Female	<input type="checkbox"/>

2

How old are you? **Please let us know your age**

_____ Years.

OR

Please tick one box only

16 – 25 yrs	<input type="checkbox"/>
26 – 35 yrs	<input type="checkbox"/>
36 – 45 yrs	<input type="checkbox"/>
46 – 55 yrs	<input type="checkbox"/>
56 – 65 yrs	<input type="checkbox"/>
66 – 75 yrs	<input type="checkbox"/>
76 – 85 yrs	<input type="checkbox"/>
86+ yrs	<input type="checkbox"/>

3	<p>What is your marital status?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1"> <tr> <td data-bbox="459 562 831 622">Single/never married</td> <td data-bbox="831 562 948 622"></td> </tr> <tr> <td data-bbox="459 622 831 683">Married/living with partner</td> <td data-bbox="831 622 948 683"></td> </tr> <tr> <td data-bbox="459 683 831 743">Separated</td> <td data-bbox="831 683 948 743"></td> </tr> <tr> <td data-bbox="459 743 831 804">Divorced</td> <td data-bbox="831 743 948 804"></td> </tr> <tr> <td data-bbox="459 804 831 864">Widow/widower</td> <td data-bbox="831 804 948 864"></td> </tr> </table>	Single/never married		Married/living with partner		Separated		Divorced		Widow/widower									
Single/never married																			
Married/living with partner																			
Separated																			
Divorced																			
Widow/widower																			
4	<p>What is the highest level of education you have completed?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1"> <tr> <td data-bbox="459 1070 1090 1111">Some primary (not complete)</td> <td data-bbox="1090 1070 1177 1111"></td> </tr> <tr> <td data-bbox="459 1111 1090 1151">Primary or equivalent</td> <td data-bbox="1090 1111 1177 1151"></td> </tr> <tr> <td data-bbox="459 1151 1090 1191">Intermediate/junior/group certificate or equivalent</td> <td data-bbox="1090 1151 1177 1191"></td> </tr> <tr> <td data-bbox="459 1191 1090 1232">Leaving certificate or equivalent</td> <td data-bbox="1090 1191 1177 1232"></td> </tr> <tr> <td data-bbox="459 1232 1090 1272">Diploma/certificate</td> <td data-bbox="1090 1232 1177 1272"></td> </tr> <tr> <td data-bbox="459 1272 1090 1312">Primary degree</td> <td data-bbox="1090 1272 1177 1312"></td> </tr> <tr> <td data-bbox="459 1312 1090 1352">Postgraduate/higher degree</td> <td data-bbox="1090 1312 1177 1352"></td> </tr> <tr> <td data-bbox="459 1352 1090 1393">None</td> <td data-bbox="1090 1352 1177 1393"></td> </tr> <tr> <td data-bbox="459 1393 1090 1722">Other (Please specify)</td> <td data-bbox="1090 1393 1177 1722"></td> </tr> </table>	Some primary (not complete)		Primary or equivalent		Intermediate/junior/group certificate or equivalent		Leaving certificate or equivalent		Diploma/certificate		Primary degree		Postgraduate/higher degree		None		Other (Please specify)	
Some primary (not complete)																			
Primary or equivalent																			
Intermediate/junior/group certificate or equivalent																			
Leaving certificate or equivalent																			
Diploma/certificate																			
Primary degree																			
Postgraduate/higher degree																			
None																			
Other (Please specify)																			

5	<p>What is your employment status?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="459 555 1257 902"> <tr> <td>Employed/Self employed</td> <td><input type="checkbox"/></td> <td>(Go to Question 6)</td> </tr> <tr> <td>Self employed</td> <td><input type="checkbox"/></td> <td>(Go to Question 6)</td> </tr> <tr> <td>Unemployed</td> <td><input type="checkbox"/></td> <td>(Go to Question 10)</td> </tr> <tr> <td>Looking after home or family</td> <td><input type="checkbox"/></td> <td>(Go to Question 10)</td> </tr> <tr> <td>Actively seeking work</td> <td><input type="checkbox"/></td> <td>(Go to Question 10)</td> </tr> <tr> <td>Retired</td> <td><input type="checkbox"/></td> <td>(Go to Question 10)</td> </tr> <tr> <td>In education or training</td> <td><input type="checkbox"/></td> <td>(Go to Question 10)</td> </tr> <tr> <td>Permanently sick or disabled</td> <td><input type="checkbox"/></td> <td>(Go to Question 10)</td> </tr> <tr> <td>Other</td> <td><input type="checkbox"/></td> <td>(Go to Question 10)</td> </tr> </table>	Employed/Self employed	<input type="checkbox"/>	(Go to Question 6)	Self employed	<input type="checkbox"/>	(Go to Question 6)	Unemployed	<input type="checkbox"/>	(Go to Question 10)	Looking after home or family	<input type="checkbox"/>	(Go to Question 10)	Actively seeking work	<input type="checkbox"/>	(Go to Question 10)	Retired	<input type="checkbox"/>	(Go to Question 10)	In education or training	<input type="checkbox"/>	(Go to Question 10)	Permanently sick or disabled	<input type="checkbox"/>	(Go to Question 10)	Other	<input type="checkbox"/>	(Go to Question 10)
Employed/Self employed	<input type="checkbox"/>	(Go to Question 6)																										
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Permanently sick or disabled	<input type="checkbox"/>	(Go to Question 10)																										
Other	<input type="checkbox"/>	(Go to Question 10)																										
6	<p>If employed/self-employed, How many hours per week are you in paid employment?</p> <p>_____ hours per week</p>																											
7	<p>Have you given up or cut down on work in order to care for the person you support?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="459 1384 1257 1507"> <tr> <td>Yes, given up work</td> <td><input type="checkbox"/></td> <td>(Go to Question 7A)</td> </tr> <tr> <td>Yes, cut down on work</td> <td><input type="checkbox"/></td> <td>(Go to Question 7A)</td> </tr> <tr> <td>No</td> <td><input type="checkbox"/></td> <td>(Go to Question 10)</td> </tr> </table>	Yes, given up work	<input type="checkbox"/>	(Go to Question 7A)	Yes, cut down on work	<input type="checkbox"/>	(Go to Question 7A)	No	<input type="checkbox"/>	(Go to Question 10)																		
Yes, given up work	<input type="checkbox"/>	(Go to Question 7A)																										
Yes, cut down on work	<input type="checkbox"/>	(Go to Question 7A)																										
No	<input type="checkbox"/>	(Go to Question 10)																										
7A	<p>If Yes, please give details when this happened (MM/YYYY)</p> <table border="1" data-bbox="459 1704 965 1767"> <tr> <td><input type="text"/></td> <td><input type="text"/></td> <td>/</td> <td><input type="text"/></td> <td><input type="text"/></td> <td><input type="text"/></td> <td><input type="text"/></td> </tr> </table>	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>																				
<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>																						

8	<p>Was there any particular reason why work was given up or cut down at that time? (e.g. accommodation arrangements changed for the person you support, stress)</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="459 640 1114 719"> <tr> <td data-bbox="459 640 660 674">Yes</td> <td data-bbox="660 640 756 674"><input type="checkbox"/></td> <td data-bbox="756 640 1114 674">(Go to Question 8A)</td> </tr> <tr> <td data-bbox="459 674 660 719">No</td> <td data-bbox="660 674 756 719"><input type="checkbox"/></td> <td data-bbox="756 674 1114 719">(Go to Question 9)</td> </tr> </table>	Yes	<input type="checkbox"/>	(Go to Question 8A)	No	<input type="checkbox"/>	(Go to Question 9)				
Yes	<input type="checkbox"/>	(Go to Question 8A)									
No	<input type="checkbox"/>	(Go to Question 9)									
8A	<p>If Yes, please give details:</p> <div data-bbox="459 891 1251 1189" style="border: 1px solid black; height: 133px; width: 496px;"></div>										
9	<p>By how many hours did you cut down on your work?</p> <p>_____ hours per week</p>										
10	<p>Do you receive any monetary allowance from the state to support your caring?</p> <p>PLEASE TICK ALL THAT APPLY</p> <table border="1" data-bbox="459 1615 1174 1805"> <tr> <td data-bbox="459 1615 1086 1648">Carer's Allowance</td> <td data-bbox="1086 1615 1174 1648"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="459 1648 1086 1682">Half Carer's Allowance</td> <td data-bbox="1086 1648 1174 1682"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="459 1682 1086 1715">Carer's Benefit</td> <td data-bbox="1086 1682 1174 1715"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="459 1715 1086 1749">Respite grant</td> <td data-bbox="1086 1715 1174 1749"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="459 1749 1086 1783">No</td> <td data-bbox="1086 1749 1174 1783"><input type="checkbox"/></td> </tr> </table>	Carer's Allowance	<input type="checkbox"/>	Half Carer's Allowance	<input type="checkbox"/>	Carer's Benefit	<input type="checkbox"/>	Respite grant	<input type="checkbox"/>	No	<input type="checkbox"/>
Carer's Allowance	<input type="checkbox"/>										
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Carer's Benefit	<input type="checkbox"/>										
Respite grant	<input type="checkbox"/>										
No	<input type="checkbox"/>										

	Other Please tell us	<input type="checkbox"/>																
11	<p>How well would you say you are managing financially (could insert time period here e.g. last 3 months, last 12 months, at present etc.)</p> <table border="1"> <tr> <td data-bbox="456 837 1075 875">Living comfortably</td> <td data-bbox="1075 837 1161 875"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 875 1075 913">Doing alright</td> <td data-bbox="1075 875 1161 913"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 913 1075 952">Just about getting by</td> <td data-bbox="1075 913 1161 952"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 952 1075 990">Finding it quite difficult</td> <td data-bbox="1075 952 1161 990"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 990 1075 1028">Finding it very difficult</td> <td data-bbox="1075 990 1161 1028"><input type="checkbox"/></td> </tr> </table>	Living comfortably	<input type="checkbox"/>	Doing alright	<input type="checkbox"/>	Just about getting by	<input type="checkbox"/>	Finding it quite difficult	<input type="checkbox"/>	Finding it very difficult	<input type="checkbox"/>							
Living comfortably	<input type="checkbox"/>																	
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Just about getting by	<input type="checkbox"/>																	
Finding it quite difficult	<input type="checkbox"/>																	
Finding it very difficult	<input type="checkbox"/>																	
12	<p>Which of the following descriptions comes closest to how you feel about your household's income nowadays?</p> <table border="1"> <tr> <td data-bbox="456 1198 1075 1236">Living comfortably on present income</td> <td data-bbox="1075 1198 1161 1236"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1236 1075 1274">Coping on present income</td> <td data-bbox="1075 1236 1161 1274"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1274 1075 1312">Difficult on present income</td> <td data-bbox="1075 1274 1161 1312"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1312 1075 1350">Very difficult on present income</td> <td data-bbox="1075 1312 1161 1350"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1350 1075 1386">Don't Know refusal / prefer not to say</td> <td data-bbox="1075 1350 1161 1386"><input type="checkbox"/></td> </tr> </table>	Living comfortably on present income	<input type="checkbox"/>	Coping on present income	<input type="checkbox"/>	Difficult on present income	<input type="checkbox"/>	Very difficult on present income	<input type="checkbox"/>	Don't Know refusal / prefer not to say	<input type="checkbox"/>							
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Very difficult on present income	<input type="checkbox"/>																	
Don't Know refusal / prefer not to say	<input type="checkbox"/>																	
13	<p>Thinking about the total amount of household income in the last year, please tick the box for the range in which your household income falls (in Euro):</p> <table border="1"> <tr> <td data-bbox="456 1500 1075 1538">Nil or Loss</td> <td data-bbox="1075 1500 1161 1538"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1538 1075 1576">1 to 9,999</td> <td data-bbox="1075 1538 1161 1576"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1576 1075 1615">10,000 to 14,999</td> <td data-bbox="1075 1576 1161 1615"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1615 1075 1653">15,000 to 19,999</td> <td data-bbox="1075 1615 1161 1653"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1653 1075 1691">20,000 to 29,999</td> <td data-bbox="1075 1653 1161 1691"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1691 1075 1729">30,000 to 39,999</td> <td data-bbox="1075 1691 1161 1729"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1729 1075 1767">40,000 to 49,999</td> <td data-bbox="1075 1729 1161 1767"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1767 1075 1805">50,000 or more</td> <td data-bbox="1075 1767 1161 1805"><input type="checkbox"/></td> </tr> </table>	Nil or Loss	<input type="checkbox"/>	1 to 9,999	<input type="checkbox"/>	10,000 to 14,999	<input type="checkbox"/>	15,000 to 19,999	<input type="checkbox"/>	20,000 to 29,999	<input type="checkbox"/>	30,000 to 39,999	<input type="checkbox"/>	40,000 to 49,999	<input type="checkbox"/>	50,000 or more	<input type="checkbox"/>	
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30,000 to 39,999	<input type="checkbox"/>																	
40,000 to 49,999	<input type="checkbox"/>																	
50,000 or more	<input type="checkbox"/>																	

14	<p>Please indicate (tick) the various sources of your household income</p> <table border="1"> <tr> <td data-bbox="456 528 1091 566">My own wages</td> <td data-bbox="1091 528 1179 566"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 566 1091 604">Spouses wages</td> <td data-bbox="1091 566 1179 604"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 604 1091 642">Carers allowance</td> <td data-bbox="1091 604 1179 642"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 642 1091 680">Social welfare</td> <td data-bbox="1091 642 1179 680"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 680 1091 719">Disability benefit</td> <td data-bbox="1091 680 1179 719"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 719 1091 1211">Other (Please specify e.g. from other household members / grants / bursaries)</td> <td data-bbox="1091 719 1179 1211"><input type="checkbox"/></td> </tr> </table>	My own wages	<input type="checkbox"/>	Spouses wages	<input type="checkbox"/>	Carers allowance	<input type="checkbox"/>	Social welfare	<input type="checkbox"/>	Disability benefit	<input type="checkbox"/>	Other (Please specify e.g. from other household members / grants / bursaries)	<input type="checkbox"/>						
My own wages	<input type="checkbox"/>																		
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Disability benefit	<input type="checkbox"/>																		
Other (Please specify e.g. from other household members / grants / bursaries)	<input type="checkbox"/>																		
15	<p>What is your relationship to the person you support?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1"> <tr> <td data-bbox="456 1417 1091 1456">Partner/Spouse</td> <td data-bbox="1091 1417 1179 1456"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1456 1091 1494">Parent</td> <td data-bbox="1091 1456 1179 1494"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1494 1091 1532">Sibling</td> <td data-bbox="1091 1494 1179 1532"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1532 1091 1570">Grandparent</td> <td data-bbox="1091 1532 1179 1570"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1570 1091 1608">Aunt/Uncle</td> <td data-bbox="1091 1570 1179 1608"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1608 1091 1646">Cousin</td> <td data-bbox="1091 1608 1179 1646"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1646 1091 1684">Friend</td> <td data-bbox="1091 1646 1179 1684"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1684 1091 1722">Neighbour</td> <td data-bbox="1091 1684 1179 1722"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="456 1722 1091 1760">Other (please specify)</td> <td data-bbox="1091 1722 1179 1760"><input type="checkbox"/></td> </tr> </table>	Partner/Spouse	<input type="checkbox"/>	Parent	<input type="checkbox"/>	Sibling	<input type="checkbox"/>	Grandparent	<input type="checkbox"/>	Aunt/Uncle	<input type="checkbox"/>	Cousin	<input type="checkbox"/>	Friend	<input type="checkbox"/>	Neighbour	<input type="checkbox"/>	Other (please specify)	<input type="checkbox"/>
Partner/Spouse	<input type="checkbox"/>																		
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Cousin	<input type="checkbox"/>																		
Friend	<input type="checkbox"/>																		
Neighbour	<input type="checkbox"/>																		
Other (please specify)	<input type="checkbox"/>																		

	Please specify															
16	<p>What are the reasons for you providing this support?</p> <p>PLEASE TICK ALL THAT APPLY</p> <table border="1" data-bbox="464 943 1182 1211"> <tr> <td>I'm the parent</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Because I've always done so</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Because I am needed</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Because I feel obliged to</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Because services not available</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Because I enjoy this and want to</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Other (Please provide detail in the box below</td> <td><input type="checkbox"/></td> </tr> </table> <div data-bbox="464 1272 1259 1476" style="border: 1px solid black; height: 90px; margin-top: 10px;"></div>		I'm the parent	<input type="checkbox"/>	Because I've always done so	<input type="checkbox"/>	Because I am needed	<input type="checkbox"/>	Because I feel obliged to	<input type="checkbox"/>	Because services not available	<input type="checkbox"/>	Because I enjoy this and want to	<input type="checkbox"/>	Other (Please provide detail in the box below	<input type="checkbox"/>
I'm the parent	<input type="checkbox"/>															
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Because I am needed	<input type="checkbox"/>															
Because I feel obliged to	<input type="checkbox"/>															
Because services not available	<input type="checkbox"/>															
Because I enjoy this and want to	<input type="checkbox"/>															
Other (Please provide detail in the box below	<input type="checkbox"/>															
17	<p>How long have you been in the carer role?</p> <p>Please give your best estimate in number of years and/or number of months</p> <p>_____ Years _____ Months</p>															

18	<p>Do you provide care for another person other than the person you support?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 10px;"> <tr> <td style="width: 30%; padding: 2px;">Yes</td> <td style="width: 10%; text-align: center; padding: 2px;"><input type="checkbox"/></td> <td style="padding: 2px;">(Go to Question 18A)</td> </tr> <tr> <td style="padding: 2px;">No</td> <td style="text-align: center; padding: 2px;"><input type="checkbox"/></td> <td style="padding: 2px;">(Go to Question 19)</td> </tr> </table>	Yes	<input type="checkbox"/>	(Go to Question 18A)	No	<input type="checkbox"/>	(Go to Question 19)												
Yes	<input type="checkbox"/>	(Go to Question 18A)																	
No	<input type="checkbox"/>	(Go to Question 19)																	
18A	<p>If Yes, please give details</p> <div style="border: 1px solid black; height: 100px; width: 100%; margin-top: 10px;"></div>																		
19	<p>How old are each of the children who are living in your household?</p> <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 10px;"> <thead> <tr> <th style="width: 70%; text-align: left; padding: 5px;">Number of Children</th> <th style="width: 30%; text-align: center; padding: 5px;">AGE</th> </tr> </thead> <tbody> <tr><td style="padding: 5px;">Child 1</td><td style="padding: 5px;"></td></tr> <tr><td style="padding: 5px;">Child 2</td><td style="padding: 5px;"></td></tr> <tr><td style="padding: 5px;">Child 3</td><td style="padding: 5px;"></td></tr> <tr><td style="padding: 5px;">Child 4</td><td style="padding: 5px;"></td></tr> <tr><td style="padding: 5px;">Child 5</td><td style="padding: 5px;"></td></tr> <tr><td style="padding: 5px;">Child 6</td><td style="padding: 5px;"></td></tr> <tr><td style="padding: 5px;">Child 7</td><td style="padding: 5px;"></td></tr> <tr><td style="padding: 5px;">Child 8</td><td style="padding: 5px;"></td></tr> </tbody> </table>	Number of Children	AGE	Child 1		Child 2		Child 3		Child 4		Child 5		Child 6		Child 7		Child 8	
Number of Children	AGE																		
Child 1																			
Child 2																			
Child 3																			
Child 4																			
Child 5																			
Child 6																			
Child 7																			
Child 8																			

20

In general would you say your health is?

PLEASE TICK ONE BOX ONLY

Excellent	<input type="checkbox"/>
Very good	<input type="checkbox"/>
Good	<input type="checkbox"/>
Fair	<input type="checkbox"/>
Poor	<input type="checkbox"/>

Section 2: Support you provide to the Person

21

How often do you provide support with.....?

PLEASE TICK ONE BOX ON EACH LINE

	No Support Needed	More than once a day	Once a Day	More than once a week	Once a week	Less often
1 Medication						
2 Dressing						
3 Walking						
4 Bathing or showering						
5 Cleaning teeth/taking care of dentures						
6 Eating						
7 Getting in and out of bed						
8 Using the toilet						
9 Socialising and activities within the home						
10 Behavioural needs (e.g. wandering off, aggression, self-injury etc.)						
11 Preparing a hot meal						
12 Shopping for groceries						
13 Making telephone calls						
14 Managing money and bills						

NOTE: If no support is provided with any of the above, please go directly to question 23

On a typical day, when you provide this support, how much time do you provide with...?

PLEASE TICK ONE BOX ON EACH LINE

	No Support Needed	Less than 30 minutes	30 minutes to less than 2 hours	2 hours to less than 4 hours	4 hours or more
1 Medication					
2 Dressing					
3 Walking					
4 Bathing or showering					
5 Cleaning teeth/taking care of dentures					
6 Eating					
7 Getting in and out of bed					
8 Using the toilet					
9 Socialising and activities within the home					
10 Behavioural needs (e.g. wandering off, aggression, self-injury etc.)					
11 Preparing a hot meal					
12 Shopping for groceries					
13 Making telephone calls					
14 Managing money and bills					

23 How many hours of care do you provide to the person you support **EACH DAY**?

Number of hours per day

24 What type of support do you provide with.....? ?

An example – dressing
Monitoring: dresses/undresses independently but needs some supervision from time to time.
Verbal/gesture prompting: physically able to get dressed/undressed but needs prompting or guidance.
Partial physical assistance: needs some physical assistance getting dressed/undresses e.g. with zippers, buttons etc.
Full physical assistance; completely dependent on others to get dressed/undressed.

TICK ONE BOX ON EACH LINE

		No Support Needed	Monitoring	Verbal/ gestural prompting	Partial physical assistance	Full physical assistance
1	Medication					
2	Dressing					
3	Walking					
4	Bathing or showering					
5	Cleaning teeth/taking care of dentures					
6	Eating					
7	Getting in and out of bed					
8	Using the toilet					

		No Support Needed	Monitoring	Verbal/gestural prompting	Partial physical assistance	Full physical assistance
9	Socialising and activities within the home					
10	Behavioural needs (e.g. wandering off, aggression, self-injury etc.)					
11	Preparing a hot meal					
12	Shopping for groceries					
13	Making telephone calls					
14	Managing money and bills					

Section 3: Understanding your experience of Care giving

25 When providing care to the person you support, you may find it difficult from time to time.

Please tell us if any of the following apply to you

PLEASE TICK ONE BOX ON EACH LINE

	YES	NO
Sleep is disturbed (e.g. because the person you support is in and out of bed or wanders around at night)		
It is inconvenient (e.g. because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g. because of lifting in and out of a chair, effort or concentration is required)		
It is confining (e.g. helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g. because helping has disrupted routing, there has been no privacy)		
There have been changes in personal plans (e.g. had to turn down a job: could not go on vacation)		
There have been emotional adjustments (e.g. because of severe arguments)		
Some behaviour is upsetting (e.g. because the person you support is incontinent, has trouble remembering things, or accuses people of taking things)		
It is upsetting to find the person you support has changed so much from his/her former self (e.g. he/she is a different person than he/she used to be)		
There have been work adjustments (e.g. because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g. because of worry about the person you support, concerns about how you will manage)		

25A	<p>What are the most difficult things about caring?</p> <p>PLEASE TICK ALL THAT APPLY</p> <table border="1"> <tr><td>Lack of Sleep</td><td><input type="checkbox"/></td></tr> <tr><td>Isolation</td><td><input type="checkbox"/></td></tr> <tr><td>Stress</td><td><input type="checkbox"/></td></tr> <tr><td>Emotional Strain</td><td><input type="checkbox"/></td></tr> <tr><td>Being constantly on Call</td><td><input type="checkbox"/></td></tr> <tr><td>Frustration</td><td><input type="checkbox"/></td></tr> <tr><td>Sadness for the person I care for</td><td><input type="checkbox"/></td></tr> <tr><td>Guilt</td><td><input type="checkbox"/></td></tr> <tr><td>None of these</td><td><input type="checkbox"/></td></tr> <tr><td>Don't know</td><td><input type="checkbox"/></td></tr> </table> <p>Other (Please specify in box below)</p> <div style="border: 1px solid black; height: 60px; width: 500px;"></div>	Lack of Sleep	<input type="checkbox"/>	Isolation	<input type="checkbox"/>	Stress	<input type="checkbox"/>	Emotional Strain	<input type="checkbox"/>	Being constantly on Call	<input type="checkbox"/>	Frustration	<input type="checkbox"/>	Sadness for the person I care for	<input type="checkbox"/>	Guilt	<input type="checkbox"/>	None of these	<input type="checkbox"/>	Don't know	<input type="checkbox"/>
Lack of Sleep	<input type="checkbox"/>																				
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Sadness for the person I care for	<input type="checkbox"/>																				
Guilt	<input type="checkbox"/>																				
None of these	<input type="checkbox"/>																				
Don't know	<input type="checkbox"/>																				
25B	<p>Which one is the most difficult?</p> <hr/>																				

26

Some caregivers report positive aspects related to this supportive role.

Please tell us how much you agree or disagree with the following statements

PLEASE TICK ONE BOX ON EACH LINE

	Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
1 Providing support has made me feel more useful					
2 Providing support has made me feel good about myself					
3 Providing support has made me feel needed					
4 Providing support has made me feel appreciated					
5 Providing support has made me feel strong and confident					
6 Providing support has enabled me appreciate life more					
7 Providing support has enabled me to develop a more positive attitude toward life					
8 Providing support has strengthened my relationship with others					

27	<p>Please record any other positive aspects of the caregiving role in the box below</p> <div style="border: 1px solid black; height: 60px; margin-top: 10px;"></div>																										
28	<p>What strategies do you use to help keep you going in your caring role?</p> <p>PLEASE TICK ALL THAT APPLY</p> <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 10px;"> <tr><td style="padding: 2px;">Talk to friends</td><td style="width: 30px; text-align: center;"><input type="checkbox"/></td></tr> <tr><td style="padding: 2px;">Watch TV</td><td style="text-align: center;"><input type="checkbox"/></td></tr> <tr><td style="padding: 2px;">Exercise</td><td style="text-align: center;"><input type="checkbox"/></td></tr> <tr><td style="padding: 2px;">Drink alcohol</td><td style="text-align: center;"><input type="checkbox"/></td></tr> <tr><td style="padding: 2px;">Smoke</td><td style="text-align: center;"><input type="checkbox"/></td></tr> <tr><td style="padding: 2px;">Take medication</td><td style="text-align: center;"><input type="checkbox"/></td></tr> <tr><td style="padding: 2px;">Use respite</td><td style="text-align: center;"><input type="checkbox"/></td></tr> <tr><td style="padding: 2px;">Attend support group</td><td style="text-align: center;"><input type="checkbox"/></td></tr> <tr><td style="padding: 2px;">Use phone line support</td><td style="text-align: center;"><input type="checkbox"/></td></tr> <tr><td style="padding: 2px;">Alternative medicine</td><td style="text-align: center;"><input type="checkbox"/></td></tr> <tr><td style="padding: 2px;">Praying / Faith</td><td style="text-align: center;"><input type="checkbox"/></td></tr> <tr><td style="padding: 2px;">None of these</td><td style="text-align: center;"><input type="checkbox"/></td></tr> <tr><td style="padding: 2px;">Don't know</td><td style="text-align: center;"><input type="checkbox"/></td></tr> </table> <div style="border: 1px solid black; padding: 5px; margin-top: 10px; min-height: 60px;"> <p>Other (Please specify)</p> </div>	Talk to friends	<input type="checkbox"/>	Watch TV	<input type="checkbox"/>	Exercise	<input type="checkbox"/>	Drink alcohol	<input type="checkbox"/>	Smoke	<input type="checkbox"/>	Take medication	<input type="checkbox"/>	Use respite	<input type="checkbox"/>	Attend support group	<input type="checkbox"/>	Use phone line support	<input type="checkbox"/>	Alternative medicine	<input type="checkbox"/>	Praying / Faith	<input type="checkbox"/>	None of these	<input type="checkbox"/>	Don't know	<input type="checkbox"/>
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Praying / Faith	<input type="checkbox"/>																										
None of these	<input type="checkbox"/>																										
Don't know	<input type="checkbox"/>																										

Section 4: Family and Social Networks

29 How would you rate the support you are getting from those within your household, wider family, friends and people in your workplace?

PLEASE TICK ONE BOX ON EACH LINE

	Not Applicable	Very Little Support	So-So Support	Some Support	A Lot of Support
1 From your spouse/partner					
2 From parents					
3 From your children					
4 From other close relatives					
5 From friends					
6 From employer/boss					
7 From others in workplace					

30	<p>Do other relatives or friends regularly support or assist you in caring for the person you support?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="418 571 1040 645"> <tr> <td data-bbox="418 571 609 607">Yes</td> <td data-bbox="609 571 703 607"><input type="checkbox"/></td> <td data-bbox="703 571 1040 607">(Go to Question 30A)</td> </tr> <tr> <td data-bbox="418 607 609 645">No</td> <td data-bbox="609 607 703 645"><input type="checkbox"/></td> <td data-bbox="703 607 1040 645">(Go to Question 31)</td> </tr> </table>	Yes	<input type="checkbox"/>	(Go to Question 30A)	No	<input type="checkbox"/>	(Go to Question 31)				
Yes	<input type="checkbox"/>	(Go to Question 30A)									
No	<input type="checkbox"/>	(Go to Question 31)									
30A	<p>If yes, thinking about a typical week, for how many hours do they support or assist you in caring for the person you support?</p> <p>_____ hours per week</p>										
<p>Section 5: Your Health</p>											
31	<p>In the past 4 weeks would you say your health is...?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="418 1142 925 1438"> <tr> <td data-bbox="418 1142 845 1200">Excellent</td> <td data-bbox="845 1142 925 1200"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="418 1200 845 1258">Very Good</td> <td data-bbox="845 1200 925 1258"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="418 1258 845 1317">Good</td> <td data-bbox="845 1258 925 1317"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="418 1317 845 1375">Fair</td> <td data-bbox="845 1317 925 1375"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="418 1375 845 1438">Poor</td> <td data-bbox="845 1375 925 1438"><input type="checkbox"/></td> </tr> </table>	Excellent	<input type="checkbox"/>	Very Good	<input type="checkbox"/>	Good	<input type="checkbox"/>	Fair	<input type="checkbox"/>	Poor	<input type="checkbox"/>
Excellent	<input type="checkbox"/>										
Very Good	<input type="checkbox"/>										
Good	<input type="checkbox"/>										
Fair	<input type="checkbox"/>										
Poor	<input type="checkbox"/>										
32	<p>Is your daily activity limited by a long-term illness, health problem or disability?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="418 1653 1040 1727"> <tr> <td data-bbox="418 1653 609 1688">Yes</td> <td data-bbox="609 1653 703 1688"><input type="checkbox"/></td> <td data-bbox="703 1653 1040 1688">(Go to Question 33)</td> </tr> <tr> <td data-bbox="418 1688 609 1727">No</td> <td data-bbox="609 1688 703 1727"><input type="checkbox"/></td> <td data-bbox="703 1688 1040 1727">(Go to Question 34)</td> </tr> </table>	Yes	<input type="checkbox"/>	(Go to Question 33)	No	<input type="checkbox"/>	(Go to Question 34)				
Yes	<input type="checkbox"/>	(Go to Question 33)									
No	<input type="checkbox"/>	(Go to Question 34)									

33	<p>If yes, please state the nature of your long-term illness, health problem or disability</p> <div style="border: 1px solid black; height: 50px; width: 100%;"></div>										
34	<p>During the past 4 weeks how much did physical health problems limit your usual physical activities (such as walking or climbing stairs?)</p> <p>PLEASE TICK THE ONE THAT APPLIES</p> <table border="1" data-bbox="416 909 924 1205"> <tr> <td>Not at all</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Very Little</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Somewhat</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Quite a lot</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Could not do physical activities</td> <td><input type="checkbox"/></td> </tr> </table>	Not at all	<input type="checkbox"/>	Very Little	<input type="checkbox"/>	Somewhat	<input type="checkbox"/>	Quite a lot	<input type="checkbox"/>	Could not do physical activities	<input type="checkbox"/>
Not at all	<input type="checkbox"/>										
Very Little	<input type="checkbox"/>										
Somewhat	<input type="checkbox"/>										
Quite a lot	<input type="checkbox"/>										
Could not do physical activities	<input type="checkbox"/>										
35	<p>During the past 4 weeks how much difficulty did you have doing your daily work, both at home and away from home, because of your physical health?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="416 1449 924 1619"> <tr> <td>None at all</td> <td><input type="checkbox"/></td> </tr> <tr> <td>A little bit</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Some</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Quite a lot</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Could not do daily work</td> <td><input type="checkbox"/></td> </tr> </table>	None at all	<input type="checkbox"/>	A little bit	<input type="checkbox"/>	Some	<input type="checkbox"/>	Quite a lot	<input type="checkbox"/>	Could not do daily work	<input type="checkbox"/>
None at all	<input type="checkbox"/>										
A little bit	<input type="checkbox"/>										
Some	<input type="checkbox"/>										
Quite a lot	<input type="checkbox"/>										
Could not do daily work	<input type="checkbox"/>										

36	<p>How would you rate your quality of life?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1"> <tr><td>Very good</td><td><input type="checkbox"/></td></tr> <tr><td>Good</td><td><input type="checkbox"/></td></tr> <tr><td>Neither good nor poor</td><td><input type="checkbox"/></td></tr> <tr><td>Poor</td><td><input type="checkbox"/></td></tr> <tr><td>Very Poor</td><td><input type="checkbox"/></td></tr> </table>	Very good	<input type="checkbox"/>	Good	<input type="checkbox"/>	Neither good nor poor	<input type="checkbox"/>	Poor	<input type="checkbox"/>	Very Poor	<input type="checkbox"/>
Very good	<input type="checkbox"/>										
Good	<input type="checkbox"/>										
Neither good nor poor	<input type="checkbox"/>										
Poor	<input type="checkbox"/>										
Very Poor	<input type="checkbox"/>										
37	<p>How much bodily pain have you had in the past 4 weeks?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1"> <tr><td>None</td><td><input type="checkbox"/></td></tr> <tr><td>Mild</td><td><input type="checkbox"/></td></tr> <tr><td>Moderate</td><td><input type="checkbox"/></td></tr> <tr><td>Severe</td><td><input type="checkbox"/></td></tr> <tr><td>Very Severe</td><td><input type="checkbox"/></td></tr> </table>	None	<input type="checkbox"/>	Mild	<input type="checkbox"/>	Moderate	<input type="checkbox"/>	Severe	<input type="checkbox"/>	Very Severe	<input type="checkbox"/>
None	<input type="checkbox"/>										
Mild	<input type="checkbox"/>										
Moderate	<input type="checkbox"/>										
Severe	<input type="checkbox"/>										
Very Severe	<input type="checkbox"/>										
38	<p>During the past 4 weeks how much energy did you have?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1"> <tr><td>A Lot</td><td><input type="checkbox"/></td></tr> <tr><td>Quite a lot</td><td><input type="checkbox"/></td></tr> <tr><td>Some</td><td><input type="checkbox"/></td></tr> <tr><td>A Little</td><td><input type="checkbox"/></td></tr> <tr><td>None</td><td><input type="checkbox"/></td></tr> </table>	A Lot	<input type="checkbox"/>	Quite a lot	<input type="checkbox"/>	Some	<input type="checkbox"/>	A Little	<input type="checkbox"/>	None	<input type="checkbox"/>
A Lot	<input type="checkbox"/>										
Quite a lot	<input type="checkbox"/>										
Some	<input type="checkbox"/>										
A Little	<input type="checkbox"/>										
None	<input type="checkbox"/>										
39	<p>During the past 4 weeks how much did your physical health or emotional problems limit your usual social activities with family or friends?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1"> <tr><td>Not at all</td><td><input type="checkbox"/></td></tr> <tr><td>Very little</td><td><input type="checkbox"/></td></tr> <tr><td>Somewhat</td><td><input type="checkbox"/></td></tr> <tr><td>Quite a lot</td><td><input type="checkbox"/></td></tr> <tr><td>Could not do social activities</td><td><input type="checkbox"/></td></tr> </table>	Not at all	<input type="checkbox"/>	Very little	<input type="checkbox"/>	Somewhat	<input type="checkbox"/>	Quite a lot	<input type="checkbox"/>	Could not do social activities	<input type="checkbox"/>
Not at all	<input type="checkbox"/>										
Very little	<input type="checkbox"/>										
Somewhat	<input type="checkbox"/>										
Quite a lot	<input type="checkbox"/>										
Could not do social activities	<input type="checkbox"/>										

40	<p>During the past 4 weeks how much have you been bothered by emotional problems (Such as feeling anxious, depressed or irritable)?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="416 622 922 792"> <tr><td>Not at all</td><td><input type="checkbox"/></td></tr> <tr><td>Slightly</td><td><input type="checkbox"/></td></tr> <tr><td>Moderately</td><td><input type="checkbox"/></td></tr> <tr><td>Quite a lot</td><td><input type="checkbox"/></td></tr> <tr><td>Extremely</td><td><input type="checkbox"/></td></tr> </table>	Not at all	<input type="checkbox"/>	Slightly	<input type="checkbox"/>	Moderately	<input type="checkbox"/>	Quite a lot	<input type="checkbox"/>	Extremely	<input type="checkbox"/>
Not at all	<input type="checkbox"/>										
Slightly	<input type="checkbox"/>										
Moderately	<input type="checkbox"/>										
Quite a lot	<input type="checkbox"/>										
Extremely	<input type="checkbox"/>										
41	<p>During the past 4 weeks, how much did personal or emotional problems keep you from your usual work, school or other daily activities?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="416 1037 922 1207"> <tr><td>Not at all</td><td><input type="checkbox"/></td></tr> <tr><td>Very little</td><td><input type="checkbox"/></td></tr> <tr><td>Somewhat</td><td><input type="checkbox"/></td></tr> <tr><td>Quite a lot</td><td><input type="checkbox"/></td></tr> <tr><td>Could not to social activities</td><td><input type="checkbox"/></td></tr> </table>	Not at all	<input type="checkbox"/>	Very little	<input type="checkbox"/>	Somewhat	<input type="checkbox"/>	Quite a lot	<input type="checkbox"/>	Could not to social activities	<input type="checkbox"/>
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Very little	<input type="checkbox"/>										
Somewhat	<input type="checkbox"/>										
Quite a lot	<input type="checkbox"/>										
Could not to social activities	<input type="checkbox"/>										
42	<p>How would you rate the quality of life of the person with ID for whom you provide care?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="416 1420 922 1590"> <tr><td>Excellent</td><td><input type="checkbox"/></td></tr> <tr><td>Very Good</td><td><input type="checkbox"/></td></tr> <tr><td>Good</td><td><input type="checkbox"/></td></tr> <tr><td>Fair</td><td><input type="checkbox"/></td></tr> <tr><td>Poor</td><td><input type="checkbox"/></td></tr> </table>	Excellent	<input type="checkbox"/>	Very Good	<input type="checkbox"/>	Good	<input type="checkbox"/>	Fair	<input type="checkbox"/>	Poor	<input type="checkbox"/>
Excellent	<input type="checkbox"/>										
Very Good	<input type="checkbox"/>										
Good	<input type="checkbox"/>										
Fair	<input type="checkbox"/>										
Poor	<input type="checkbox"/>										

43	<p>How satisfied are you with your health?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="416 568 922 734"> <tr> <td>Very Satisfied</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Satisfied</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Neither satisfied nor dissatisfied</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Dissatisfied</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Very dissatisfied</td> <td><input type="checkbox"/></td> </tr> </table>	Very Satisfied	<input type="checkbox"/>	Satisfied	<input type="checkbox"/>	Neither satisfied nor dissatisfied	<input type="checkbox"/>	Dissatisfied	<input type="checkbox"/>	Very dissatisfied	<input type="checkbox"/>
Very Satisfied	<input type="checkbox"/>										
Satisfied	<input type="checkbox"/>										
Neither satisfied nor dissatisfied	<input type="checkbox"/>										
Dissatisfied	<input type="checkbox"/>										
Very dissatisfied	<input type="checkbox"/>										
44	<p>How satisfied are you with the health services you receive? (E.g. GP, psychological/counselling services, physiotherapy.)</p> <table border="1" data-bbox="416 875 922 1039"> <tr> <td>Very Satisfied</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Satisfied</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Neither satisfied nor dissatisfied</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Dissatisfied</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Very dissatisfied</td> <td><input type="checkbox"/></td> </tr> </table>	Very Satisfied	<input type="checkbox"/>	Satisfied	<input type="checkbox"/>	Neither satisfied nor dissatisfied	<input type="checkbox"/>	Dissatisfied	<input type="checkbox"/>	Very dissatisfied	<input type="checkbox"/>
Very Satisfied	<input type="checkbox"/>										
Satisfied	<input type="checkbox"/>										
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Dissatisfied	<input type="checkbox"/>										
Very dissatisfied	<input type="checkbox"/>										
45	<p>How satisfied are you with other services you receive? (e.g. respite services, social work services, public health or community nurse)</p> <table border="1" data-bbox="416 1151 922 1317"> <tr> <td>Very Satisfied</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Satisfied</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Neither satisfied nor dissatisfied</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Dissatisfied</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Very dissatisfied</td> <td><input type="checkbox"/></td> </tr> </table>	Very Satisfied	<input type="checkbox"/>	Satisfied	<input type="checkbox"/>	Neither satisfied nor dissatisfied	<input type="checkbox"/>	Dissatisfied	<input type="checkbox"/>	Very dissatisfied	<input type="checkbox"/>
Very Satisfied	<input type="checkbox"/>										
Satisfied	<input type="checkbox"/>										
Neither satisfied nor dissatisfied	<input type="checkbox"/>										
Dissatisfied	<input type="checkbox"/>										
Very dissatisfied	<input type="checkbox"/>										
46	<p>Please tell us if you have any further comment regards the services you receive</p> <div data-bbox="416 1429 1270 1675" style="border: 1px solid black; height: 110px; width: 535px;"></div>										

47

Have you had any of the following in the last 12 months?

PLEASE TICK ALL THAT APPLY

Asthma, chronic bronchitis, chronic lung disease	
Chronic Obstructive Pulmonary Disease (COPD), emphysema	
Heart Attack	
Angina	
Stroke	
Rheumatoid arthritis (inflammation of joints)	
Osteo-arthritis (arthrosis, joint degeneration)	
Lower back pain or other chronic back condition	
Diabetes	
Cancer (malignant tumour, leukaemia or lymphoma)	
Urinary incontinence, problems in controlling the bladder	
Anxiety	
Depression	
Aching joints	
High Blood Pressure	
Headaches	
Stress / nervous tension	
Stomach ulcers	
Varicose ulcers (an ulcer due to varicose veins)	
Cirrhosis, or serious liver damage	
Osteoporosis, sometimes called brittle bones	
Parkinson's disease	
Cancer or a malignant tumour	
Any emotional, nervous or psychiatric problems	
Alcohol or substance abuse	
Alzheimer's disease	
Dementia, organic brain syndrome, senility	
Serious memory impairment	
Other (please specify)	

I have had none of these conditions in the last 12 months	
------------------------------------------------------------------	--

48	<p>Has your health suffered due to your caring responsibilities?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="416 595 1040 669"> <tr> <td data-bbox="416 595 609 629">Yes</td> <td data-bbox="609 595 699 629"><input type="checkbox"/></td> <td data-bbox="699 595 1040 629">(Go to Question 49)</td> </tr> <tr> <td data-bbox="416 629 609 669">No</td> <td data-bbox="609 629 699 669"><input type="checkbox"/></td> <td data-bbox="699 629 1040 669">(Go to Question 50)</td> </tr> </table>	Yes	<input type="checkbox"/>	(Go to Question 49)	No	<input type="checkbox"/>	(Go to Question 50)				
Yes	<input type="checkbox"/>	(Go to Question 49)									
No	<input type="checkbox"/>	(Go to Question 50)									
49	<p>If yes, please describe how it has affected your health?</p> <div data-bbox="416 833 1185 1043" style="border: 1px solid black; height: 94px; width: 482px;"></div>										
50	<p>In general, compared to other people your age, would you say your health is..?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="416 1261 925 1431"> <tr> <td data-bbox="416 1261 842 1294">Excellent</td> <td data-bbox="842 1261 925 1294"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="416 1294 842 1328">Very Good</td> <td data-bbox="842 1294 925 1328"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="416 1328 842 1361">Good</td> <td data-bbox="842 1328 925 1361"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="416 1361 842 1395">Fair</td> <td data-bbox="842 1361 925 1395"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="416 1395 842 1431">Poor</td> <td data-bbox="842 1395 925 1431"><input type="checkbox"/></td> </tr> </table>	Excellent	<input type="checkbox"/>	Very Good	<input type="checkbox"/>	Good	<input type="checkbox"/>	Fair	<input type="checkbox"/>	Poor	<input type="checkbox"/>
Excellent	<input type="checkbox"/>										
Very Good	<input type="checkbox"/>										
Good	<input type="checkbox"/>										
Fair	<input type="checkbox"/>										
Poor	<input type="checkbox"/>										
51	<p>Are your leisure/recreational activities limited by your caring work?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="416 1568 925 1702"> <tr> <td data-bbox="416 1568 842 1601">Not at all</td> <td data-bbox="842 1568 925 1601"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="416 1601 842 1635">A little</td> <td data-bbox="842 1601 925 1635"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="416 1635 842 1668">Quite a lot</td> <td data-bbox="842 1635 925 1668"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="416 1668 842 1702">A great deal</td> <td data-bbox="842 1668 925 1702"><input type="checkbox"/></td> </tr> </table>	Not at all	<input type="checkbox"/>	A little	<input type="checkbox"/>	Quite a lot	<input type="checkbox"/>	A great deal	<input type="checkbox"/>		
Not at all	<input type="checkbox"/>										
A little	<input type="checkbox"/>										
Quite a lot	<input type="checkbox"/>										
A great deal	<input type="checkbox"/>										

Section 6: Health Services for person you support

52	<p>How satisfied are you with the health services your family member with ID receives? (e.g. GP, speech and language, dietician services)</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="padding: 2px;">Very Satisfied</td> <td style="width: 30px; height: 15px;"></td> </tr> <tr> <td style="padding: 2px;">Satisfied</td> <td style="width: 30px; height: 15px;"></td> </tr> <tr> <td style="padding: 2px;">Neither satisfied nor dissatisfied</td> <td style="width: 30px; height: 15px;"></td> </tr> <tr> <td style="padding: 2px;">Dissatisfied</td> <td style="width: 30px; height: 15px;"></td> </tr> <tr> <td style="padding: 2px;">Very dissatisfied</td> <td style="width: 30px; height: 15px;"></td> </tr> </table>	Very Satisfied		Satisfied		Neither satisfied nor dissatisfied		Dissatisfied		Very dissatisfied	
Very Satisfied											
Satisfied											
Neither satisfied nor dissatisfied											
Dissatisfied											
Very dissatisfied											
53	<p>How satisfied are you with the other services your family member with ID receives? (E.g. employment support, day care services, respite services.)</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="padding: 2px;">Very Satisfied</td> <td style="width: 30px; height: 15px;"></td> </tr> <tr> <td style="padding: 2px;">Satisfied</td> <td style="width: 30px; height: 15px;"></td> </tr> <tr> <td style="padding: 2px;">Neither satisfied nor dissatisfied</td> <td style="width: 30px; height: 15px;"></td> </tr> <tr> <td style="padding: 2px;">Dissatisfied</td> <td style="width: 30px; height: 15px;"></td> </tr> <tr> <td style="padding: 2px;">Very dissatisfied</td> <td style="width: 30px; height: 15px;"></td> </tr> </table>	Very Satisfied		Satisfied		Neither satisfied nor dissatisfied		Dissatisfied		Very dissatisfied	
Very Satisfied											
Satisfied											
Neither satisfied nor dissatisfied											
Dissatisfied											
Very dissatisfied											
54	<p>Please tell us if you have any further comment regards the services your family member with ID receives</p> <div style="border: 1px solid black; height: 150px; width: 100%; margin-top: 10px;"></div>										

Section 7: Future Planning

55	<p>Are there any services you think that you as a carer would benefit from that you are not receiving at present?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1"><tr><td data-bbox="416 680 608 714">Yes</td><td data-bbox="608 680 699 714"><input type="checkbox"/></td><td data-bbox="699 680 1038 714">(Go to Question 56)</td></tr><tr><td data-bbox="416 714 608 748">No</td><td data-bbox="608 714 699 748"><input type="checkbox"/></td><td data-bbox="699 714 1038 748">(Go to Question 57)</td></tr></table>	Yes	<input type="checkbox"/>	(Go to Question 56)	No	<input type="checkbox"/>	(Go to Question 57)
Yes	<input type="checkbox"/>	(Go to Question 56)					
No	<input type="checkbox"/>	(Go to Question 57)					
56	<p>If yes, please give details.</p> <div data-bbox="416 893 1150 1070" style="border: 1px solid black; height: 79px;"></div>						
57	<p>Are there any services you think the person you support would benefit from that he/she is not receiving at present</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1"><tr><td data-bbox="416 1288 608 1321">Yes</td><td data-bbox="608 1288 699 1321"><input type="checkbox"/></td><td data-bbox="699 1288 1038 1321">(Go to Question 58)</td></tr><tr><td data-bbox="416 1321 608 1355">No</td><td data-bbox="608 1321 699 1355"><input type="checkbox"/></td><td data-bbox="699 1321 1038 1355">(Go to Question 59)</td></tr></table>	Yes	<input type="checkbox"/>	(Go to Question 58)	No	<input type="checkbox"/>	(Go to Question 59)
Yes	<input type="checkbox"/>	(Go to Question 58)					
No	<input type="checkbox"/>	(Go to Question 59)					
58	<p>If yes, please give details of what your ideal package of services and supports would be.</p> <div data-bbox="416 1525 1054 1680" style="border: 1px solid black; height: 69px;"></div>						

59	<p>Is there anything you worry about for the future for the person you support?</p> <div data-bbox="416 517 1222 676" style="border: 1px solid black; height: 71px; width: 505px;"></div>						
60	<p>Have you thought about where you see your family member with intellectual disability living in five years?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="416 972 1042 1048"> <tr> <td data-bbox="416 972 608 1010">Yes</td> <td data-bbox="608 972 699 1010" style="text-align: center;"><input type="checkbox"/></td> <td data-bbox="699 972 1042 1010">(Go to Question 61)</td> </tr> <tr> <td data-bbox="416 1010 608 1048">No</td> <td data-bbox="608 1010 699 1048" style="text-align: center;"><input type="checkbox"/></td> <td data-bbox="699 1010 1042 1048">(Go to Question 63)</td> </tr> </table>	Yes	<input type="checkbox"/>	(Go to Question 61)	No	<input type="checkbox"/>	(Go to Question 63)
Yes	<input type="checkbox"/>	(Go to Question 61)					
No	<input type="checkbox"/>	(Go to Question 63)					
61	<p>Have you discussed future plans for the person you support with any professional individual or group?</p> <p>PLEASE TICK ONE BOX ONLY</p> <table border="1" data-bbox="416 1290 1042 1366"> <tr> <td data-bbox="416 1290 608 1328">Yes</td> <td data-bbox="608 1290 699 1328" style="text-align: center;"><input type="checkbox"/></td> <td data-bbox="699 1290 1042 1328">(Go to Question 62)</td> </tr> <tr> <td data-bbox="416 1328 608 1366">No</td> <td data-bbox="608 1328 699 1366" style="text-align: center;"><input type="checkbox"/></td> <td data-bbox="699 1328 1042 1366">(Go to Question 63)</td> </tr> </table>	Yes	<input type="checkbox"/>	(Go to Question 62)	No	<input type="checkbox"/>	(Go to Question 63)
Yes	<input type="checkbox"/>	(Go to Question 62)					
No	<input type="checkbox"/>	(Go to Question 63)					
62	<p>If yes please give details. For example has this been discussed with the person with intellectual disability and with services, is there a written plan?</p> <div data-bbox="416 1532 1262 1671" style="border: 1px solid black; height: 62px; width: 530px;"></div>						

63	<p>What are your hopes and dreams for the future for the person you support?</p> <div data-bbox="416 519 1198 710" style="border: 1px solid black; height: 85px;"></div>
64	<p>What are your hopes and dreams for the future for yourself?</p> <div data-bbox="416 846 1278 1019" style="border: 1px solid black; height: 77px;"></div>
65	<p>Any other comments?</p> <div data-bbox="464 1279 1220 1621" style="border: 1px solid black; height: 153px;"></div>

The Intellectual Disability Supplement to TILDA

**The University of Dublin, Trinity College,
School of Nursing & Midwifery,
2 Clare Street, Dublin 2.**

General Inquiries: 01-8963187

Email: dstilda@tcd.ie

www.idstilda.tcd.ie

The Intellectual Disability Study to TILDA is funded and supported



Appendix 2: Measures

Relevant validated measures were among those used in the Carer's Survey, some questions were developed specifically for the IDS-TIDA Carer's Study and other questions were based on questions used by O' Sullivan (2008) in a survey for the Care Alliance Ireland. These questions in turn had been based on those used in the Slan 02 survey. The following table outlines the measures used in the Carer's Survey and their origins.

Demographics	<p>Carers were asked to provide a range of demographic information. Their responses to the questions on age, gender, marital status, employment status, relationship to the person the care supports, monetary allowances received to support caring, income and feelings about income.</p> <p>Carers were also asked how long they had been providing care, whether they were caring for another person apart from the older person with intellectual disability and for the reasons why they provide care. Seven reasons for providing care were included and carers were asked to indicate all that applied to them. The potential reasons offered were: I am the parent; because I've always done so; because I am needed; because I feel obliged to; because services are not available; because I enjoy this and want to. Carers were also offered the opportunity to provide detail of other reasons why they provide care.</p>
Support needs of care recipients	<p>The type, level and frequency of support given by the carers to the older person with intellectual disability was measured using items from the Lawton - Brody Instrumental Activities of Daily Living Scale (I.A.D.L.) (1969). The independent living skills included in the questionnaire were: medication, dressing, walking, bathing/showering, oral care, eating, getting in and out of bed, using the toilet, preparing a hot meal, shopping for groceries, making telephone calls and managing money and bills. The two items of support with socialising and behavioural needs were also included.</p> <p>Separate questions asked the carers to indicate how frequently they provided support with each item, how much time is required to give support with each item and the level of support required for each support.</p> <p>The frequency response options were: "no support needed", more than once a day", "once a day", "more than once a week", once a week" and "less often".</p> <p>The response options to the question "On a typical day, when you provide this support, how much time" to you spend on each of the tasks. The response options were: "no support needed", "less than 30 minutes", 30 minutes to less than 2 hours", 2 hours to less than 4 hours, and "4 hours of more".</p> <p>The response options to the question about the level of support required were: "monitoring", "verbal/gesturing prompting", "partial physical assistance" and "full physical assistance"</p>
Health	<p>Items from the 36-Item Short Form Survey (SF-36) were included in the IDS-TLIDA Carer's Survey. This measure assesses: limitations in physical activities because of health problems; limitations in social activities because of physical or emotional problems; limitations in usual role activities because of physical health problems; bodily pain; general mental health (psychological distress and well-being); limitations in usual role activities because of emotional problems; vitality (energy and fatigue); and general health perceptions. (Ware <i>et al.</i> 1992). Specific response options were offered for each item.</p> <p>The IDS-TILDA Carer's Study also included a list of 27 conditions and carers were asked indicate all of which applied to them</p>

Positive Aspects of Caring	<p>Tarlow <i>et al.</i>'s (2004) positive aspects of caring scale comprises 8 items: providing support has made me feel more useful; providing support has made me feel good about myself; providing support has made me feel needed; providing support has made me feel appreciated; providing support has made me feel strong and confident; providing support has enabled me to appreciate life more; providing support has enabled me to develop a more positive attitude toward life; providing support has strengthened my relationship with others</p> <p>Carers are offered 5 response choices: “disagree a lot”, “disagree a little”, neither agree nor disagree, “agree a lot” and are asked to respond to each of the questions.</p>
Caregiver Strain	<p>Twelve of the 13 items of the Caregiver Strain Index (Robinson 1983) were included to measure strain experienced by the caregivers. These items referred to: Sleep is disturbed; It is inconvenient; It is a physical strain; It is confining; There have been family adjustments; There have been changes in personal plans; There have been emotional adjustments; Some behaviour is upsetting; It is upsetting to find the person you support has changed so much from his/her former self; There have been work adjustments; It is a financial strain; Feeling completely overwhelmed.</p> <p>Carers were asked to indicate all items that applied to them.</p>
Coping	<p>The coping strategies itemised were those used by O' Sullivan (2008) and were based on questions used in SLÁN 02 plus a number of questions which are specific to carers (use of respite, use of support groups and phone line support).</p>
Quality of Life	<p>The self-reported Quality of Life question aligned with that used by O' Sullivan (2008) and SLÁN 02.</p> <p>The 5-point scale ranged through “very good” to “very poor”</p>
Self-reported general health	<p>The self-reported general health question aligned with that used by O' Sullivan (2008) and SLÁN 02.</p> <p>The 5-point scale ranged through “excellent”, “very good”, “good”, “fair” and “poor”</p>
Most difficult things about caring	<p>These questions were developed by O' Sullivan (2008) following a review of the literature. Eight items were included in the question and carers were asked to indicate all that applied to them</p>
Support from household, wider family, friends and people in the workplace	<p>These questions were based on those used by O' Sullivan (2008) who replicated those used in SLÁN 02.</p> <p>Using a scale which ranged through: “not applicable”, “very little support”, “so-so Support”, “some support” and “a lot of support” the carers were asked to indicate the support which they received from their spouse/partner, parents, children, other close relatives, friends, employer/boss, others in the workplace.</p>
IDS-TILDA Carer's Study	<p>Questions developed specifically for the study included questions about unmet services needs of the carer themselves and the person for whom they care. Carers were asked about their hopes, dreams and worries for their own future and that of the older person with intellectual disability. Questions about whether the carer had engaged in future planning and the extent of any such plans were also asked.</p> <p>Finally, carers were offered the opportunity to add a further comment.</p>