Guiding support for family carers

Family Caring in Ireland

May 2013

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Notes

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If you notice any inaccuracies or omissions please let us know, so we can rectify these as soon as possible.

If you are undertaking research in the area, we would be delighted to receive your final report so that we can consider it for inclusion in any updated versions. Please also let us know if you wish to be involved in our Family Carer Research Group, by emailing: **research@carealliance.ie**.

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1. What is a Family Carer?

The most recent Census of Population defines a 'carer' as someone who:

provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability (including problems which are due to old age). Personal help includes help with basic tasks such as feeding and dressing[1].

The vast majority of respondents (98.3%) in 2008 Care Alliance Ireland research on full-time carers in Ireland indicated that they were caring for a family member[2].
However, the term 'carer' is often used to refer to an array of health care workers. It is therefore considered appropriate to use the term 'Family Carer' to clearly differentiate paid care workers or health care professionals from unpaid Family Carers.

The term 'informal carer' is also used quite widely. This is somewhat problematic as Family Carers often say that there is nothing informal about the care they provide. Nonetheless, as the term is commonly used, we attempt to define it here. Informal carers are people who provide care to others in need of assistance or support on an unpaid basis. Generally, informal care is provided by family members or friends of the person receiving care. Informal care is distinguished from formal care services provided by people employed in the health and community sectors, because the care is generally provided free of charge and is not regulated by the state. Although informal care is provided freely, it is not free in an economic sense, as time spent caring is time that cannot be directed to other activities such as paid work, education, volunteering or leisure[3].

For the purposes of this report, the terms informal carer and Family Carer are used synonymously

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2. What do Family Carers do?

Caring can be described in a number of ways, such as hours per week spent, types of activities performed, or duration of the care period[4]. The roles played by Family Carers will differ depending on the condition of the person being cared for; as his/her situation changes, so too will the care provided[5]. The following categories[6] illustrate the different levels of care that Family Carers may be involved in:

- Low level caring – mainly companionship, with some caring assistance
- Medium level caring with chores – cooking, shopping, housework, driving
- Medium level caring – as above, plus some personal assistance with washing, dressing, lifting, use of toilet
- High level caring – all of the above, where the person receiving the care cannot be of much or any assistance to the Family Carer with his/her personal and social care.

There are also many 'sandwich' carers; those with a responsibility for both childcare and care for a disabled or older person[7].

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3. Statistics on Family Carers in the Republic of Ireland

Information on Family Carers is still relatively scarce. This is in part due to the nature of the subject itself, as informal care is usually provided by relatives and thus falls within the sphere of private family life. In addition, methodological issues make it difficult for informal care to be properly addressed in general population or household surveys[8]. Despite such concerns, a number of important studies have quantified the numbers and experiences of Family Carers in Ireland and these are outlined below.

3.1 Census of Population

A question about providing unpaid care was asked for the third time in Census 2011. Where particularly relevant, comparative data are shown for 2002, 2006 and 2011, which were the years those three censuses were held. The Central Statistics Office, which is responsible for managing the censuses, has recently produced a large number of interactive tables pertaining to Family Carers. This makes it much easier to analyse the relevant data[9].

3.1.1 Number of carers

There is a continuing upward trend in the number of Family Carers[10]. In Census 2002, 148,754 people indicated that they provided unpaid care. By 2006, the total number of carers aged 15 and over was 160,917, growing to 182,884 in 2011. This represents a 13.7% increase over that last five-year period alone. The most recent census showed that 4.1% of the total population was providing unpaid assistance to others in April 2011[11].

4.1% of the total population was providing unpaid assistance to others in April 2011

3.1.2 Time spent caring

For the first time in 2011, respondents were asked to write in the number of hours spent caring, rather than select

from set categories, as had been the case in the two previous censuses. However, around one in eight did not indicate the number of hours of care they provided, which highlights the difficulty in accurately quantifying caring[12].

Census 2011 indicated that a total of 6,287,510 hours of care was provided each week, giving an average of 33.6 hours per carer[13]. Females provided almost two-thirds (66.1%) of all care hours. Carers typically provided up to two hours of care per day; with more than 80,000 carers providing this level of care, this amounts to more than half a million hours of care per week. The numbers of carers decreased with increasing hours.

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However, at the tail end of the distribution, 15,175 people indicated that they gave '24/7' care, providing a total of 2,549,400 care hours every week.

A further review of these data by Care Alliance Ireland suggests that carers in Ireland provide an average of 35 hours per week of care, but for those who reported providing full-time care (43 hours or more) the average is 110 hours per week[14].

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3.1.3 Caring by geography

Proportionally more carers were found to live in rural areas. Overall, figures from Census 2011 show that the share of carers in rural areas (43.2%) was greater than the rural share of the population (38%), and there were proportionally fewer carers in urban areas (56.8%) compared with their share of the overall population (62%). On a county-by-county basis, the highest proportion of carers identified in Census 2011 was in Mayo, where 5% of people were involved in providing unpaid care. The lowest proportion was in Kildare and Fingal, with 3.4% of the population involved in providing care[15]. Similar figures were identified in Census 2006, ranging from a low of 4.2% in Kildare to a high of 5.5% in Mayo[16].

more carers were found to live in rural areas

3.1.4 Caring by employment status

According to figures from the 2011 Census, participation in the labour force by persons who provided unpaid care to others was 59.1%, compared with a marginally higher rate of 61.9% for the population generally. In 2006, there were 90,544 carers in Ireland who were also in paid employment outside of the home[17]. This represented 56% of the c. 161,000 carers in the country at that time. In 2011, labour force participation amongst carers was found to decline with increasing number of hours care provided. However, carers providing up to 14 hours of unpaid assistance per week had a participation rate of 70.6% (far higher than that of the general population) whilst those providing more than 43 hours of care a week had a labour force participation rate of just 38%.

labour force participation amongst carers was found to decline with increasing number of hours care provided

Census 2006 figures showed that carers came from all occupational groups, with a similar proportion of each group involved in the provision of unpaid care[18]. Data from the 2011 Census has not yet been analysed to this level, but it is considered unlikely that a significant change has occurred over the period 2006 to 2011.

3.1.5 Caring by marital status

carers in Census 2011 were more likely to be married

In terms of marital status, carers in Census 2011 were more likely to be married. Some 61.6% of female carers were married compared to just 46.5% of females generally, whilst for men the figures were 60.6% and 48.3% respectively. The proportion of carers who were separated or divorced was also higher than in the general population.

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3.1.6 Caring by gender

Women were found to be more likely to be carers than men

Women were found to be more likely to be carers than men. Figures from Census 2011 showed that whilst female carers continued to outnumber male carers

(114,113 and 72,999 respectively), the number of male carers showed the larger increase[19]. Women made up 61% of carers and 39% were men, representing a 16.8% increase in male carers aged 15 and over since 2006.

In comparison, in the 2006 Census data, the gender balance for carers overall was 62.3% female and 37.7% male and for full-time carers it was quite similar (65.7% and 34.3% respectively).

3.1.7 Caring by age

The greatest proportion of carers in Census 2011 was in the 40-55 age groups for both males and females, amounting to 27,504 carers in total[20].

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The peak age for caring amongst women was 45-49 with 11.2% of women in this age group providing unpaid care, amounting to 572,680 hours every week.

The number of carers aged 30-44 increased by 6% from 2006 to 2011, with further increases of 33.6% in the 60-74 age group and 39.5% in the group aged 75 and over, highlighting the increasing role of older persons in the provision of unpaid care. The reported increase may be partially explained by the introduction in 2007 of the Half-Rate Carer's Allowance for those full-time carers who were already in receipt of another social welfare payment. The biggest cohort of recipients of this half-rate allowance are those aged 65 and over, and as such, the payment may have impacted on the rate of self-reported caring amongst this group.

Although carers aged 65 years and over represented just 11% of the total population of carers in 2006, they represented 22% of those providing at least 43 hours of care per week[21]. Substantial amounts of care were provided by those aged 70+, who were giving 795,916 hours of unpaid care per week. Around a fifth of these

reported providing full-time care (39,982 individuals = 21%)[22]. This is significant, because the person being cared is not alone in having (possibly complex) health needs; so too has the Family Carer as s/he ages. Data from the 2011 Census has not yet been analysed to this level, but it is considered unlikely that a significant change has occurred over the period 2006 to 2011.

major shift upwards in the age profile of those being cared for, which is consistent with an ageing population

It is also important to point out that there is a major shift upwards in the age profile of those being cared for, which is consistent with an ageing population. Of particular note is the large absolute increase between 2006 and 2011 of those aged in their early fifties being cared for (4,523 = 21%) as well as the large relative increase in those aged 85 years and over being cared for (442 = 51%)[23].

3.1.8 Young carers

A significant number of younger carers were identified in Census 2011 (10,005 in the 15-24 year old category)[24]. However, based on the experiences of other countries, it is assumed that there is a greatly under-reported number of children (that is, those aged under 18 years) performing caring roles in Ireland. Carers aged under 15 years old were not previously accounted for in censuses. This changed in Census 2011, when for the first time the caring question was asked of children aged 14 and under. Census 2011 identified 4,228 children aged under 15 years who were engaged in providing care to others, accounting for 2.3% of all carers[25]. These data need to be treated with caution, however, as over 30% of those aged 14 and under did not indicate the number of hours of care they provided. This illustrates an inherent difficulty in reporting on young carers. The person who typically completes the census may nominally be the head of the family, but may in fact also be a recipient of care from their child(ren). Many such adults may not wish to report that their own child(ren) is/are providing care for them, as doing so raises fears around being judged, or at worst

that the state may intervene and break up their families.

Notwithstanding the less than comprehensive reporting, the majority of young carers who indicated their number of caring hours (82%), reported providing up to two hours of care per week, with decreasing numbers providing more hours. Interestingly, a less gendered picture of young carers emerges, with 50.9% of young carers being female and providing 53.1% of total care hours, and 49.1% being male and providing 46.9% of the total care hours. The total number of unpaid care hours provided by children on a weekly basis amounted to 38,496. Children aged nine and under provided a total of 13,738 hours of care, whilst the older 10-14 age group provided 24,758 hours. The majority of care was provided by two categories of young people, namely those caring for less than two hours and those caring for more than 12 hours daily. Overall, young carers provided an average of 9.2 hours care each per week, with girls providing 9.5 hours per week and boys providing slightly less at 8.8 hours on average[26].

a less gendered picture of young carers emerges

There appears to have been a fall of around 12% in the numbers providing care in the 15-29 year age group[27]. Recent high levels of youth emigration may account for this reduction, but this contention has not yet been empirically validated.

3.2 Quarterly National Household Survey

It is difficult to pinpoint the exact number and nature of Family Carers in the Republic of Ireland. In pursuit of a more in-depth understanding of the issues, and after representation by carers' organisations, Family Carer related questions were included for the first time in the Quarterly National Household Survey in the third quarter of 2009[28]. This survey asked the following question of 21,500 people:

Some people have extra responsibilities because they look after someone who has long-term physical or mental ill health

or disability, or problems related to old age. May I just check, is there anyone living with you/not living with you who is sick, disabled or elderly whom you look after or give special help to, other than in a professional or paid capacity (for example, a sick or disabled (or elderly) relative/husband/wife/child/friend/parent etc?).

The authors point out that the definition of caring used in their survey (looking after or giving special help to) is broader than the concept of regular unpaid personal help used in the census, so it would be expected that a higher prevalence of caring would be observed.

8% of respondents aged 15 and over provided some level of unpaid care

In summary, the survey found that 8% of respondents aged 15 and over provided some level of unpaid care. Generalised to the estimated population at the time[29], the survey suggests that in the region of 274,000 people aged 15 and over were providing unpaid informal care. The survey identified that at least 21% of carers provided 57 or more hours of care per week; c. 50,000 of whom lived with the person and c. 3,000 who did not. A further c. 13,000 reported providing variable amounts of care[30]. Some other key findings include:

A fifth of all carers reported no formal education

- 13% of adults aged 45-64 were carers
- Nearly half (48%) of all carers was aged 45-64
- 64% of carers were female
- Men with no formal education or educated only to primary level were the most likely category of male carers
- A fifth of all carers reported no formal education
- A third of carers worked full-time
- Four in ten carers were the sole carer for the person they looked after
- Four in ten carers looked after a parent or parent-in-law
- A third of respondents was caring for someone who needed care due to old age
- Half of all carers cared for someone in the same household

- A third of carers looking after someone in the same household had been caring for ten years or more
- 47% of all carers spent more than 15 hours per week providing care and 21% spent more than 57 hours per week
- Two-thirds of carers reported that their own life had been impacted by their caring responsibilities
- 38% of carers who looked after someone in the same household reported feeling completely over whelmed by their caring responsibilities
- 27% of carers scored seven or higher on the Caregiver Strain Index[31]
- 40% described their own health as very good, 40% as good, 14% as fair, 2% as bad and 0% as very bad[32].

38% of carers who looked after someone in the same household reported feeling completely overwhelmed by their caring responsibilities

3.3 The Irish Longitudinal Study on Ageing (TILDA)

TILDA was launched in 2006 to study a representative cohort of at least 8,000 people aged 50 and over and resident in the Republic of Ireland, charting their health, social and economic circumstances over a ten-year period[33]. Initial TILDA project results were published in May 2011 and important references to Family Carers and caregiving were made. For instance, half of 50-64 year olds with surviving parents provided help with household tasks to their parents (for ten hours per week on average) and over a quarter provided their parents with personal care (18 hours per week on average). In addition, only 3.5% of people aged over 50 were found to receive state-provided home help services[34].

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A 2012 TILDA report provides important information on the social care received by community-dwelling older people who report difficulty with at least one 'activity of daily living' or one 'instrumental activity of daily living'[35]. The report also characterises the main caregivers. The key findings of this study include:

- Amongst community-dwelling older people in Ireland, 11% of men and 14% of women aged 50

or over had at least one limitation in daily activities. This translates into 164,000 older adults with care and support needs living in communities across Ireland.

- The vast majority of caregivers for community-dwelling older people were unpaid (89.5%). The remaining 10.5% were paid caregivers.
- Amongst older people who got help with personal care and household tasks, assistance from family members and friends amounted to 30 hours per week on average.
- The majority of main caregivers was aged 50 and over. This reflects the enormous contribution that the ageing population is making to the care of older family members.
- Spouses were most frequently identified as the main caregiver.
- Seven out of ten main caregivers were women.
- Of paid caregivers, 62% were contracted through the formal home care sector and 38% were not affiliated to any organisation or company.
- Amongst spouse carers, 11.7% received Carer's Allowance or Carer's Benefit. This finding calls for discussion on additional ways of supporting ageing spouse carers[36].

First results from the Intellectual Disability Supplement to TILDA have also captured the experiences of Family Carers[37]. Although they are not specifically reported, it is envisaged that carer data will be provided in a separate future report.

Upcoming Irish research

The Carers Association of Ireland is proposing to commission a significant piece of new research to quantify the contribution of Family Carers (funding dependent). It is essential that the deficit of information about the extent and nature of the contributions of Family Carers to the care of different groups in society is addressed. The research will: document who is cared for by Family Carers in Ireland, by illness, disability and/or condition; describe the principal medical, nursing and personal care needs of the care recipients by category; describe the nature and extent of care provided by Family Carers and the health service provisions available; and describe Family Carers' needs as contributors to the caring process. The research will make recommendations regarding the recognition of the work of Family Carers and the integration of that work in the planning and delivery of care services. A scoping study that will develop a framework for undertaking the research and give a clear understanding of the parameters and components involved should be complete by mid-2013. For further information, please contact Clare Duffy, Social Policy Manager at the Carers Association of Ireland: **cduffy@carersireland.com**.

It is essential that the deficit of information about the extent and nature of the contributions of Family Carers to the care of different groups in society is addressed

4. Family Carers in Northern Ireland

The 2001 UK Census of Population was the first to include a question on carers[38]. A carer in the UK is defined someone who gives:

help or support to family members, friends, neighbours or others because of long-term physical or mental health or disability, or problems relating to old age.

Census 2001 identified 185,086 carers in Northern Ireland, representing 11% of the total population. 59% of carers from Northern Ireland were female and 41% were male[39]. Three-fifths were providing care for one to ten hours per week and 15% for 20-49 hours. Around 93,000 carers were aged 60+, representing almost half of the total population of carers in Northern Ireland. In addition, 30,000 individuals were caring for more than one person, and 83,000 carers (45%) were found to combine caring with paid employment[40]. The 2001 Census identified carers as an at-risk group for poor health. Those caring for 50 hours were twice as likely to report poor health as the non-carer population and this was true across all age ranges[41].

Ten years on, the 2011 Census revealed that the number of carers in Northern Ireland had increased to 213,980 people, or nearly 12% of the population[42]. The number of people providing over 20 hours of care per week – the point at which caring is reported as starting to significantly impact on a carer's health and wellbeing and their ability to hold down paid employment alongside their caring responsibilities – had increased to almost 92,000[43]. More than a quarter of carers stated that they were looking after someone for over 50 hours a week (56,310 people = 26%). It is interesting to note that in 2011, nearly three times the proportion of the population in Northern Ireland identified themselves as carers in comparison with the Republic of Ireland (11.8% versus 4.1%). Some of the reasons for this may be the somewhat different wording of questions between the two, a different cultural view of the term carer and/or different

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expectations around state social services. Demographics and disability rates between the two jurisdictions, whilst not identical (Northern Ireland, for example, having an older population with 13% aged 65 and over, compared to 11% in the Republic) are not sufficiently different to explain the significant differences in reported levels of caring.

Other research, using face-to-face interviewing and a much smaller sample (c. 1,200) asked similar questions on caring, yet yielded significantly different numbers reporting caring responsibilities[44]. The 2010 Northern Ireland Life and Times Survey identified that 26% of adults had caring responsibilities. Some 22% of men and 30% of women said they were carers and almost half (49%) of those identified were aged between 35 and 54 years. Around 30% of carers were found to spend 30 hours per week or more caring, and 18% spent 60 hours per week or more providing care. This compares with a figure of 23% from the 2006 Northern Ireland Life and Times Survey. Over one-quarter of carers (27%) reported having a long-standing illness, disability or infirmity, compared with one in five of other respondents (21%)[45].

18% spent 60 hours per week or more providing care

Carers' issues have in recent years risen higher on the political agenda. This is illustrated by, for example: the passage of the Carers and Direct Payments Act (Northern Ireland) 2002, the Northern Ireland Act 1998 (Section 75), the Work and Families (Northern Ireland) Order 2006, and Employment Rights (Northern Ireland) Order 2006; the formation of a Carers Strategy: *Caring for Carers: Recognising, Valuing and Supporting the Caring Role* (2006); and the inclusion of Family Carers in numerous other policy initiatives including *The Review of Community Care* (2002)[46].

the provision and receipt of care are seldom considered together

Limitations of census data

Limitations of census data have already been alluded to (for example, under-reporting by young carers). Importantly, researchers have commented that despite the inclusion of questions in the censuses (since 2001 in the UK and 2002 in the Republic of Ireland) on whether an individual provides care and the amount of time typically devoted to this over a week, the provision and receipt of care are seldom considered together[47]. Current debate centres on older people as recipients of care and the failure to capture data on the amount of care provided by older people is significant[48]. For instance, levels of informal care provided by community-dwelling older adults in samples taken from both the Republic of Ireland and Northern Ireland were found to be notably higher than reported in single-item census questions in both jurisdictions[49]. In parallel, almost half of older people in the same study received some form of informal care in the previous year, mostly from relatives. There is therefore a need to evaluate factors that may facilitate or impede informal care delivery in census assessments in order to foster this essential societal resource.

5. The economic importance of Family Carers

The economic value of informal caring activities is not officially captured and those Family Carers who are not in paid employment are registered in national statistics as being economically inactive. However, they are providing vital care to family members in the home. Some have estimated the value to be in the region of €4 billion per year. This figure, calculated from Census 2011 data, has increased significantly since the 2006 estimate which stood at €2.5 billion[50]. Calculations are based on the rate of €25 per hour, which is the average cost of home help provided through the HSE. This means that, on average, a full-time Family Carer saves the state €62,000 per year[51]. According to 2012 Carer's Allowance rates, a Family Carer aged 66 caring for one person would receive €12,525 per annum[52]. It could therefore be argued that Family Carers' contribution to society is equivalent to one-third of the total annual cost of the HSE (c. €13 billion) and five times what Family Carers cost the Department of Social Protection in income supports (c. €850 million)[53].

Some have estimated the value to be in the region of €4 billion per year

When one considers the cost of nursing home care at €800-€1,500 per week, and the cost of acute hospital care, which is in the region of €7,000 per week, the above savings become even more apparent[54]. Both nursing home and acute hospital care options have often become the default provision, as opposed to the appropriate provision in all cases. There are many reasons for this, including a lack of appropriate, timely and comprehensive care planning. Insufficient home care packages and the lack of a statutory entitlement to home care are also contributing factors. Such statutory entitlement has been called for by many, but there is little evidence that it will be forthcoming. Enhancing the capacity of family care, with adequate community-based supports for such care, can directly contribute to a reduction in demand for expensive and inappropriate institutional care[55].

Informal care for those with dementia is estimated to have a value of €807 million

Indeed, recent demographic, social and policy developments across Europe have raised the question of whether 'care gaps' are increasingly likely to occur as informal care may become less available, which in turn could lead to an increase in demand for formal long-term care. In particular, the numbers of people with dementia is set to increase dramatically in the coming years due to an ageing population, and this will have resultant implications for care burden, care provision and public expenditure[56]. Specifically in relation to dementia, it is estimated that a total of 81 million hours of care is provided by family and friends each year. Informal care for those with dementia is estimated to have a value of €807 million[57].

6. The impacts of caring

Providing care can be an enriching and rewarding experience, in cases where expectations placed on Family Carers are reasonable and adequate supports are provided. However, caring can also be a source of burden and stress. Research in Ireland carried out on the impacts of informal caring has been relatively limited to date. However, it is probably fair to assume that the experiences of carers elsewhere apply to a large extent in Ireland also. Where appropriate, therefore, references are made in the sections below to the international experience.

6.1 Health impacts

Family Carers' health is of fundamental importance for the sustainability of care. It has been shown in Ireland that caring for a loved one at home can take a toll on the Family Carer's mental, emotional and physical health[58]. However, reported ill-health or disability cannot necessarily be linked to the caring role[59]. There is some recent evidence to support the contention that older carers may be more vulnerable to the negative health consequences associated with caring[60].

caring for a loved one at home can take a toll on the Family Carer's mental, emotional and physical health

2008 research by Care Alliance Ireland examining the health status of 1,411 Family Carers found that, in comparison with the general population, Family Carers were less likely to report themselves in excellent or very good health[61]. They also reported comparatively high levels of depression, back pain and anxiety. Other negative aspects associated with caring included restricted leisure hours and a high risk of being exposed to stress, emotional strain and social isolation. The extent of the limitation imposed by caring on leisure and recreation appeared to be a key factor both in the likelihood of health suffering due to caring and of low quality of life for Family Carers.

A 2009 Irish study of Family Carers found that 71% reported their health as 'quite good' or 'very good', but that well over half experienced being mentally and physically 'drained' by their

caring role. The types of caring tasks most reported to cause ill-health were: dealing with verbal/emotional abuse; coping with bizarre/inconsistent behaviour; and getting up in the night. Over half reported having a medical problem, the most frequent being back injury, and over half also reported a significant mental health problem, the most frequent being anxiety disorder. Most carers stated that they had no time for themselves and worried how the person they cared for would cope if they had to stop caregiving due to illness or death[62].

Irish research undertaken in 2009 exploring the health and wellbeing of Family Carers of people with Parkinson's disease found that the role of Family Carer is both physically and emotionally demanding, particularly as the person's condition deteriorates and their caring needs intensify[63]. High blood pressure, tiredness, lack of physical energy, back problems and arthritis were all seen as negative consequences of caring. Feelings of loneliness, anxiety and depression were directly associated with the demands of caring.

In the UK, researchers found that Family Carers were three times more likely to report ill-health than the non-carer population[64]. More recent research in the UK found that caring had a negative impact on the physical health of carers aged over 60, whilst four out of ten respondents said that their mental health had deteriorated in the last year[65]. In Australia, Family Carers were found to be unable to participate in social and health activities due to the burden of care[66]. The greater the intensity in the type or quantity of assistance provided, the greater the magnitude of health effects on the caregiver, which were largely due to chronic stress[67]. Cross-country comparison by the OECD found that the prevalence of mental health problems amongst carers was 20% higher than amongst non-carers[68].

Internationally, the physical health of Family Carers has been found to be more likely to decline after their first year of caring

Internationally, the physical health of Family Carers has been found to be more likely to decline after their first year of caring[69]. In addition, spousal carers and mothers caring for a disabled child have been found to be most at risk of psychological distress, and the period immediately following the cessation of caring has been

identified as a time when ill-health was likely to increase[70]. Other factors which have been found to contribute to poor health amongst Family Carers are low income and lack of respite breaks[71]. When compared with both older carers and non-carers of the same age, a US study found that middle-aged carers were more likely to binge drink (25.5%), smoke (15.9%) and/or be obese (30.1%)[72]. In the UK, 60% of carers worried about the nutrition of the person they cared for. They were found to be under stress and struggling to care without the right advice and support[73]. Irish researchers have recently found that low social support in parents of children with developmental disabilities is associated with higher blood pressure[74].

A recent study undertaken in Scotland[75] found that unpaid carers had twice the prevalence of long-term illness and disability as the rest of the Scottish population. More than half (57%) of respondents had a long-term illness or disability, even those who rated their health as average or good. Many had more than one (and in some cases three or four) long-term conditions and 45% (had) suffered from significant illness including cancer, depression, diabetes or fibromyalgia. Over two-thirds experienced physical problems such as joint, hip, back and/or neck pain, with more than a third suffering from arthritis, osteoarthritis or osteoporosis. Some 13% had respiratory problems, including asthma and chronic obstructive pulmonary disease, and 11% had neurological problems including epilepsy, stroke or acquired brain injury. A third had high blood pressure. Carers reported other significant impacts on their health and wellbeing including back and shoulder pain (70%), stress, anxiety and depression (86%) and exhaustion (34%). Almost half of carers reported that their conditions had started after they began caring. Of those whose condition predated their caring role, a quarter said it had worsened since they started giving care. On the other hand, the same study found that people caring for ten years or more were less likely to be in poor health than those caring for a shorter period of time. This suggests that carers may adapt to their responsibilities so as not to adversely affect their health[76]. This reflects the results of the Irish study of carers of people with Parkinson's disease[77], which indicated that stress

carers may adapt to their responsibilities so as not to adversely affect their health

does not build up over time and is not related to the length of time spent caring. Rather, it is based on other factors such as the intensity of care, the type of condition of the person receiving care and/or the personality of the carer.

6.2 Social impacts

As a result of providing care, Family Carers may suffer barriers to social participation as well as a lack of recognition and respect for their role.The Irish Government's strategic response to tackling poverty and social exclusion, as set out in the National Action Plan for Social Inclusion 2007-2016, is underpinned by this definition:

People are living in poverty if their income and resources (material, cultural and social) are so inadequate as to preclude them from having a standard of living which is regarded as acceptable by Irish society generally. As a result of inadequate income and resources people may be excluded and marginalised from participating in activities which are considered the norm for other people in society[78].

Family Carers are not identified as a priority target group within current social inclusion policy

Family Carers are not identified as a priority target group within current social inclusion policy. However, the recent publication of the National Carers' Strategy 2012 has the potential to provide a roadmap for the future (see later).

major restrictions on their social or leisure activities

Caring responsibilities often limit the time available for Family Carers to have a life of their own. Many do not have access to supports to allow them significant time off from their caring duties to have a social life or to more generally participate in the community and wider society[79]. The majority of Family Carers in an Irish study reported major restrictions on their social or leisure activities, with isolation being a problem for many. Other Irish research confirmed these findings, showing that providing care resulted in significant limitations to personal interests and hobbies[80]. Both carers and care recipients have been found to experience social isolation[81]. The study recommends promoting awareness of Family Carers and their support needs to combat such feelings.

In a recent US study[82], approximately one-third of carers who lived with care recipients were found to spend an average of 36 hours per week on caring, which almost equates to a full-time job. In a Scottish study, 54% of carers felt isolated and could not meet friends and family or take part in leisure or social activities[83]. In the UK, more than one-third of carers aged 60 and over was found not to get breaks from caring, with a further one-third getting a break only once every two to three months[84].

Other research from the UK suggests that carers in rural areas have the same needs as carers living elsewhere[85]. However, social problems can be particularly acute for carers living in rural areas because of: lack of specialist services; lack of respite; difficulty in accessing medical support; isolation and lack of companionship; lack of privacy; information gaps; lack of alternatives to family care; poverty and the additional cost of living in a rural area; and difficulties with transport and employment. Research undertaken in Australia proposes that reducing social isolation in rural older carers is a two-stage process. Firstly, barriers to attendance, both logistical and perceived, must be addressed, and the focus of the intervention must be relevant to the carer. Secondly, opportunities for informal social interaction must be maximised within the intervention. However, a secondary focus may be necessary to ensure attendance, and the provision of education is also integral to achieving long-term outcomes. Integration of service providers in an informal capacity is also important in providing long-term support options to rural older carers[86].

6.3 Financial impacts

Working-age carers are at a higher risk of poverty according to OECD analysis on data available from both the European Survey on Health and Ageing and the United States Health and Retirement Survey[87]. Caregiving was found to be associated with a higher probability of experiencing poverty across all 16 countries in the survey, except in southern Europe. Female carers appear to be especially vulnerable to poverty risks. Research in the UK found that 72% of Family Carers were

Female carers appear to be especially vulnerable to poverty risks

financially worse off as a consequence of becoming caregivers[88]. The reasons given included the additional costs of disability, giving up paid employment to provide care, the inadequacy of current benefits, and charges for services. Family Carers may face higher bills than the non-carer population, such as extra heating, laundry and transport costs. More recent UK work[89] documented that over 45% of Family Carers were cutting back on essentials. More than four in ten surveyed said they had been in debt as a result of caring. Financial hardship, debt and worries about money were found to take their toll, with almost half reporting that their financial circumstances were affecting their health. Other UK research outlined that two-thirds of Family Carers were spending their own income or savings to pay for care[90]. Many were found to be suffering from financial hardships, including: experiencing debt; struggling to pay essential bills; not being able to afford house repairs; cutting back on food; and having difficulties paying their rent or mortgage.

over two-thirds of Family Carers interviewed expressed difficulty in making ends meet

An Irish study that examined the relationship between caring and financial situation[91] found that over two-thirds of Family Carers interviewed expressed difficulty in making ends meet.

Another recent Irish report[92] estimated the value of informal care time for people with visual impairment and blindness. It recognised that there are significant further costs in addition to the value of lost time. Three potential methods were considered in an attempt to place a monetary value on informal/family care:

- The replacement valuation method estimates the cost of buying a similar amount of services from the formal care sector.
- The self-valuation method sums the costs of what carers themselves feel they should be paid for the care provided to a person.
- The opportunity cost method values earnings forgone by the carer in caring for a person.

The report argued that the replacement valuation method may over-estimate the value of informal care as it assumes the

person receiving care, or society, is willing to pay for the services typically provided by a family or friend. This may not be the case due to budget constraints faced by individual and community service funders. Additionally, this method does not account for differences in quality of care and may over-estimate value if formal care is of a higher quality. There may also be differences in time-utilisation during caring, if a formal carer is more efficient. If an informal carer receives utility or satisfaction from providing care, this method does not account for this in valuation. The self-valuation method also has weaknesses, including subjectivity, inconsistency and respondent biases.

The opportunity cost method, on the other hand, measures the value in alternative use of time spent caring, which is typically valued by productivity losses (or value of leisure time) associated with caring. This is based on the assumption that time spent providing informal care could be alternatively used within the paid workforce or in leisure activities. The value of informal care using the opportunity cost method can be represented as ti × wi, where ti is the time provided by individual i on providing care, and wi is the net market wage rate of individual i. It has been argued that informal carers forgo significant earnings because they have less opportunity to undertake higher paid employment and therefore earn less than equally qualified non-carers[93]. This is because informal carers may require more flexible working arrangements, which may reduce the likelihood of promotion. For those who provide informal care but are not in paid work (for example, children or retirees), the value of providing informal care is the value of the lost opportunity of undertaking leisure time. This can be approximated by the willingness to pay to undertake leisure, or to avoid work. Therefore, the value of leisure time is often proxied by an average age and gender-specific wage rate[94 95]. If the value of non-work is more (or less) than the average wage rate, the opportunity cost method will under- (or over-) estimate the value of informal care.

informal carers forgo significant earnings because they have less opportunity to undertake higher paid employment

The opportunity cost method was applied in the visual impairments/blindness study using the availability of earnings data for the Republic of Ireland. The report estimated that in

in 2010, in the region of €109 million worth of informal care was provided to approximately 4,800 people with visual impairments/blindness

2010, in the region of €109 million worth of informal care was provided to approximately 4,800 people with visual impairments/ blindness[96].

6.4 Potential for elder abuse

In Ireland, elder abuse is defined as:

a single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person or violates their human and civil rights[97].

there is a necessity to support both older people and their carers in order to avoid adverse outcomes such as carer depression and isolation, neglect and abuse

Older people with significant physical or cognitive impairment who are dependent on others for care have been identified as being particularly vulnerable to elder abuse[98]. Therefore, there is a necessity to support both older people and their carers in order to avoid adverse outcomes such as carer depression and isolation, neglect and abuse[99]. Current Irish research by the National Centre for the Protection of Older People at University College Dublin[100] is examining caregiver experiences and aims to identify conflict in their caring role. It is envisaged that once complete, this important work will provide an empirical description of caregiver experiences, including the identification of conflict and stress. The data will also provide a basis for the development of methods of caregiver support and best practice guidelines for carers in the community.

6.5 Positive impacts

It has been argued that with the right support, resources and information, caring can be a very rewarding experience[101]. Research undertaken in Northern Ireland supports the growing body of literature which suggests that the positive aspects of caring have, until recently, been under-reported. It examined the health of caregivers recorded in the 2001 Census and their subsequent mortality over the following four years. Caregivers were found to be a heterogeneous group, with those providing fewer hours of care being relatively more affluent than those

providing care at great intensities. Overall, caregivers had lower mortality risks than non-carers and effects were more pronounced for women, older people, and for those reporting poorer health at the start of the study period[102]. A recent US study examined how men, women, spouses, and children experience caring and how risk factors are different for these groups[103]. Negative caring, positive caring, care recipient problem behaviour, carer involvement, reciprocal help from care recipient, availability of other carers, family conflict, support from friends or relatives, and carer demographics were all measured. Female and adult-child carers generally reported having more negative experiences than male and spousal carers, with wife carers the least likely to report positive experiences. Care recipient's problem behaviour was the most important risk factor for wife carers having a negative experience, whereas positive experience was correlated with reciprocal help from care recipients.

caregivers had lower mortality risks than non-carers

Qualitative research undertaken by Care Alliance Ireland on the health of carers of individuals with Parkinson's disease found that whilst the focus of much discussion was on the negative impact of family caregiving, positive aspects of the role were also highlighted. For instance, several participants believed that they had become closer to the individual with Parkinson's disease as a result of providing care and that it had therefore had a beneficial influence on their relationship. A training programme for Family Carers was singled out as a crucial intervention that would assist participants in their role and in so doing, have a positive impact on their health status[104].

several participants believed that they had become closer to the individual

Recent research undertaken in Scotland has also found that three-quarters of Family Carers were happy most of the time that they were able to help someone, and only 6% did not feel this. Some 58% of respondents felt that they were giving something back most of the time in caring, and 28% felt this sometimes. The findings demonstrate the satisfaction many carers feel in being able to support people that they care about and it is therefore crucial that they are given adequate assistance in their role[105].

7. Specific caring situations

7.1 Family Carers and disability

7.1.1 A complex picture Census 2011 figures tell us that 13% of the population has a disability, which equates to almost 600,000 people living with disabilities in the state. It is impossible to infer, however, what percentage of people with disabilities are reliant on Family Carers for everyday living. The figures do highlight that 6% of the population has a disability connected with pain, breathing or another chronic illness or condition. When the 2006 and 2011 census figures are compared, they show a marked increase in the number of people aged 85 and older living with a disability (72.3%) and the most dramatic increase in carers has also been in the 75 plus age group (see earlier).

Scottish research has indicated that unpaid carers have twice the prevalence of long-term illness and disability as the rest of the population and that almost half of the carers studied had acquired their disability or disabling condition after they commenced caring (including pain, arthritis, asthma, chronic obstructive pulmonary disease, epilepsy, stroke or acquired brain injury). It is clear then, that not only are able-bodied adults caring for people with disabilities, and parents caring for children with disabilities, but in many instances people with disabilities are providing care for other family members who are ill, frail or have disabilities themselves.

in many instances people with disabilities are providing care for other family members who are ill, frail or have disabilities themselves

Whilst this blurring of boundaries between Family Carer and person with a disability creates a complex picture that is difficult to unpick, it does not imply an exclusive relationship between the two. Many people with a disability do not require assistance with everyday activities, and others may choose not to have a family member provide supports, instead using paid supports in the form of Personal Assistants. With tightening resources,

however, it is difficult to discern the degree to which both Family Carers and disabled people are increasingly compelled into this dynamic, where one or either might have chosen differently had circumstances been different.

A recently published report[106] indicated that working-age people with disabilities were less than half as likely to be active in the labour market as other adults and had a much higher unemployment rate than those without a disability. This, combined with Eurofound[107] research that young people with disabilities are more likely to have difficulty accessing employment and are being missed out on by both policy and practice, indicates further the extent and the institutionalisation of disadvantage. More than 20% of people with a disability are at risk of income poverty; this, compounded with the cost of caring as depicted earlier, points to a cumulative loss of living standard for both Family Carer and person with a disability.

7.1.2 National Disability Strategy

The National Disability Strategy (NDS), first announced in 2004, was reaffirmed in the present Programme for Government. The NDS adopts a whole government approach, recognising that to achieve good outcomes for people with disabilities, coordinated effort across public services is essential. A framework for the Plan relates departmental implementation to four person-centred goals for the equality, independence, participation and potential-maximisation of persons with disabilities. The relevant minister has committed to publishing an NDS Implementation Plan early in 2013. An NDS Implementation Group consisting of senior officials and representatives of people with disabilities and their voluntary organisations is working to develop the Plan. The United Nations Convention on the Rights of Persons with Disabilities, which Ireland has promised to ratify, is a major influence on the Strategy and, once

The United Nations Convention on the Rights of Persons with Disabilities, which Ireland has promised to ratify, is a major influence on the Strategy

published, on the monitoring of the NDS Implementation Plan. Family Carers are incorporated into the Strategy in various ways, for example, in relation to the provision of appropriate housing and accessing services that enable independence.

7.1.3 Disability organisations

Disability organisations have an excellent understanding of the importance of Family Carers and their role in supporting people with disabilities to live full and independent lives

Many disability organisations were set up by family members as well as by people with disabilities themselves, to support individuals with specific conditions and their families. This is true of long-established service provider organisations as well as of newer organisations that have a very strong independent living ethos. Disability organisations have an excellent understanding of the importance of Family Carers and their role in supporting people with disabilities to live full and independent lives, and Family Carers are included in assessment processes and where appropriate, in setting goals and making plans. Some organisations centre services around family supports, helplines are often open to people with disabilities, family members and carers, and information sessions and materials are often aimed at Family Carers. Parents are enlisted and trained to provide therapeutic services to children as an extension of professional services as a matter of course. Respite services offered by disability organisations also recognise the importance of taking a whole family approach. Respite may be a planned or an emergency service, it may take place in the person's home or involve innovative responses such as residential camps for either the person with a disability or in the case of younger Family Carers, holiday camps.

7.2 Young carers

7.2.1 2009 research

A lot of children and young people help look after a family member who has a disability and/or health problems.

In 2009, the Child and Family Research Centre at the National University of Ireland, Galway completed a study of these young people throughout the country, funded by the Office of the Minister for Children. The report found that the majority of respondents were providing care for someone with an intellectual disability. Significant proportions of those interviewed were the primary carer of a family member, with their caring roles including intimate and emotional care as well as domestic tasks and childcare. Respondents looked for more information, advice and home help to support them in their caring. The report considered the impact of caring and concluded that any policy response designed to support and assist young carers should be guided by the principles of: the protection of children's rights; a family support approach; and a multi-agency and multi-departmental response. The report also recommended that a National Forum take place, guided by the findings of this research[108].

the majority of respondents were providing care for someone with an intellectual disability

7.2.2 Response to 2009 research

Care Alliance Ireland is keen to ensure that the findings of this research are widely distributed, reflected on and acted upon.

The Carers Association of Ireland has already demonstrated its interest in and commitment to the area by way of an annual award for young carers. The theme for its 2010 conference was young carers and the research report was in fact formally launched at that event. More recently the organisation has developed an outreach and support service for young carers and a website specifically dedicated to young carers in Ireland **www.youngcarers.ie**.

a website specifically dedicated to young carers in Ireland www.youngcarers.ie

The Crosscare Carer Support programme in Dublin also set up a pilot project for young carers in the autumn of 2010. As a consequence, it co-facilitated a seminar in 2011 with Care Alliance Ireland entitled 'Young Carers Support Initiative'[109]. Following this event, Care Alliance

Ireland, the Crosscare Carer Support Programme and the Carers Association co-facilitated a further seminar and information exchange in 2012 on young people with caring responsibilities entitled 'Current Practice, Future Direction'[110]. This was aimed at those who work with young people and their families in a range of settings with a view to gaining:

- A better understanding of issues facing young carers
- Connection with leading practitioners in this emerging area
- Enhanced collaboration between organisations
- A movement to set up and develop additional local young carer support projects.

7.2.3 Further research

Care Alliance Ireland is currently involved in a project under the European Union Lifelong Programme entitled 'Together for Young Adult Carers' and will, amongst many other activities, host the European partner organisations in an exchange visit to Ireland. Care Alliance Ireland is leading the investigation that looks at the impact informal/family caring has on young adult carers' participation in third level education. It is guided in its initial exploration by a number of key international studies[111 112 113]. Research has found that the nature of caring means that transitions between education and employment are difficult and that the application of a 'life course' model in assisting young carers is very useful. Social media has been found to be an important resource for young adult carers and there is potential to use social media tools for engaging and helping young carers through online peer support.

Social media has been found to be an important resource for young adult carers

7.2.4 Policy response

Young carers have also been identified in the National Carers' Strategy published in 2012 (see later). Young carers are seen as a priority area with the objective to support children and young people with caring responsibilities and protect them from adverse impacts of caring. To this end, the Strategy aims to ensure that carers' needs are considered in the development of any policies that might affect them such as the Review of Disability Policy, the National Positive Ageing Strategy and the Children and Young People's Policy Framework 2012-2017 (forthcoming).

7.3 Male carers

In the US, approximately 37% of all caregivers of individuals 50 and older are men[114] and in the UK, men are just as likely as women to be caring for someone in their own home[115].

In Ireland, there was a 16% increase in the numbers of male carers between 2006 and 2011[116 117]. Male carers now represent a growing minority of the overall population of informal carers. The Department of Health's National Men's Policy 2008-2013 acknowledges that one in three carers in Ireland is male[118]. Its strategic aim is:

to target specific men's health policy initiatives in the home that accommodate diversity within family structures and that reflect the multiple roles of men as husbands/partners, fathers and carers.

16% increase in the numbers of male carers between 2006 and 2011

Irish census data reveals that male carers are more likely to report full-time caring as well as being in paid employment[119].

The lack of studies on male informal carers means that we know relatively little about their experiences and needs[120].

Whilst the numerical predominance of female caregivers cannot be ignored, diversity amongst male caregivers has been overlooked[121]. This has led to what has been called the 'gender comparative' approach, in which there is a tendency to compare men's caregiving against a female norm[122]. We have some evidence that men are assuming increasingly important roles as caregivers[123]. It is vital, therefore, that we learn to understand the dynamics and changing nature of such informal caring[124].

male carers go through transitions in their gender identity in providing care

To date, international research has shown that men as carers often have to make the difficult transition from work in the public arena to the private, largely invisible, world of family care[125]. It has been found that older men caring for their impaired wives undertake a negotiation with the dominant masculine ideology in order to maintain their sense of masculinity and legitimatise their presence in a feminine role[126]. Other international work has also found an interrelationship between masculinities, a sense of personal control and the experiences of suffering within caregiving[127]. Other researchers have found male carers go through transitions in their gender identity in providing care in dementia[128]. However, men are particularly under-represented in the literature pertaining to family caregiving in dementia[129].

Research specific to the experiences of men providing care in an Irish context is extremely limited to date. A study undertaken by Care Alliance Ireland in 2008[130] showed that male carers were 1.6 times more likely to have a lower quality of life than female carers. Many of the Irish research reports have repeatedly highlighted the need to conduct specific research into the male carer experience. To this end, in 2010, Crosscare undertook an evaluation of its Pilot Male Carers Support Programme based in Dublin[131]. The objectives of this pilot project were multifaceted: to break isolation; to build new social contacts; to provide the opportunity to learn new skills; and to promote self-care. The evaluation aimed to acknowledge the contribution of the male carers and to better understand their perspective. Their insights are being used to develop a strategy and support framework to assist male carers, both as individuals and as a group. In addition, a doctoral researcher from the School of Nursing

and Midwifery, Trinity College Dublin is currently exploring the experiences of men providing care to a loved one or close relative in chronic illness within an Irish context. It is envisaged that this project will be completed by the end of 2013[132].

A recent report in Northern Ireland provides a summary of statistics on male caring[133].

- 41% of carers are male.
- Men are mostly caring for family members, for example, one-third are caring for a parent or a parent-in-law.
- The main activities are companionship and practical help (such as housework or shopping).
- While half of men spend under 10 hours a week caring, 15% of men spend at least 60 hours a week doing so.
- Most men (95%) are happy some or most of the time that they are able to help someone. However, 56% feels pressure most or some of the time.

7.4 Cultural and ethnic diversity amongst Family Carers

Overall, 7% of carers in Ireland are of non-Irish nationality. Over half of these are European Union (EU) citizens. A lower proportion of non-Irish people are carers (2.8%), compared to 5.1% for Irish persons. However, 40% of non-Irish carers provide at least 29 hours per week of unpaid care compared with 30% of Irish[134].

No Irish research to date has examined the specific experiences and needs of Family Carers across different cultures and/or ethnicities. In light of current increases in non-Irish nationalities living in Ireland[135] and social and health exclusion among ethnic minority groups (including Travellers[136]) this points to a clear research gap.

No Irish research to date has examined the specific experiences and needs of Family Carers across different cultures and/or ethnicities

In the UK, however, significant progress has been made into documenting the caregiving role amongst minority groups. For

example, research on ethnic minority carers[137] found that they were especially likely to say that they felt restricted in using services because they lacked information, or because services were too expensive, lacked flexibility, or were not suitable for their individual needs. In addition, a 2011 Carers UK survey of over 4,000 carers[138], including over 300 black, Asian and other minority ethnic carers, showed 69% of those surveyed said they had suffered physical ill-health as a result of caring and 78% said their mental health had suffered. A range of UK research[139] sets out the challenges faced by these specific groups of carers in getting support, including: the stigma of caring for particular conditions such as HIV or mental illness; misconceptions linked to cultural duties around care; as well as language and literacy barriers, combined with a lack of knowledge of entitlements and culturally appropriate practical services.

7.5 Family Carers in the workplace

Combining paid employment outside of the home and providing care can prove to be very difficult

The vast majority of Family Carers are of working age. Combining paid employment outside of the home and providing care can prove to be very difficult; even so, many Family Carers may have to juggle both due to financial constraints.

The importance of work for many Family Carers may not only be financial. Paid employment may also be vital for their wellbeing, including maintaining social contact. Carers who choose to give up paid work or reduce their working hours may compromise their future employability and this may lead to permanent exclusion from the labour market[140]. A 2004 Equality Authority report provides a good analysis of the issues faced by Family Carers in balancing their caring and working responsibilities[141].

An Irish survey of carers providing care to an individual with dementia found that while 63% of respondents were below retirement age, half had stopped working in order to care. Of those in full-time employment, 61% had reduced their working hours and 71% of carers in part-time employment had reduced their weekly working hours to below 20[142]. This research also noted that such levels of carer burden are

avoidable, through appropriate services and intervention.

Findings of research on a sample of working carers in Ireland[143] illustrated that they struggled to deal with the numerous pressures involved in managing both employment and caring. A quarter of respondents were providing full-time care for a person outside of their normal work hours and a fifth were providing care to two people. Some 18% of care provided took place at weekends. All had to take holiday time to provide care, leaving less time for their own recuperation and leisure activities; a likely contributor to poor health outcomes in carers. Around 15% described their own health as not very good and 56% were unaware of the services and supports available to assist them in their caring role. Moreover, providing care was shown to cost the carers, on average, €110 per week.

All had to take holiday time to provide care, leaving less time for their own recuperation and leisure activities; a likely contributor to poor health outcomes in carers

The findings of a survey of carers of working age in the UK[144] found that over a third had considered giving up work to care, but that many stressed that they were keen to continue to work. Almost half of those working part-time said they were only in work of this type because of their caring responsibilities. Most acknowledged that their caring responsibility affected their job. Other research highlighted that nearly one in five carers in the UK had left a job or had been unable to accept a job because of their caring responsibilities[145]. Important work carried by Carers UK[146] found immense pressure placed on what they term 'the sandwich generation' – people, often women in the age group 40-54, who combine care for an older relative with a range of other responsibilities including looking after their own children. They reported the cumulative pressures of caring, not just the physical component but the mental aspect associated with stress, anxiety and tiredness.

The OECD found in its review of 16 countries, including Ireland, that carers were less likely to be employed and 50% more likely than non-carers to be homemakers[147]. It found that limited labour force participation did not only translate into lower employment rates, but also into less time in full-time employment. When they were employed, carers were found to work on average two hours

less per week than non-carers and they tended to be over-represented in part-time work.

Evidence from Employers for Carers in the UK[148] shows that simple and effective actions from industry can reduce staff turnover and absence, thereby cutting employment costs, with an associated increase in loyalty and commitment. However, the challenge of caregiving is so great that it cannot possibly be addressed by any one sector. Community, government and business all play a role in establishing solutions to meet the challenges of the ageing population and the increased caregiver needs of society. Only by working together will we increase the accessibility of services to caregivers[149]. The OECD points out that whilst promoting options to combine care and work and provide support to carers are crucial, the availability of formal care is also important[150]. Differences in access to formal care services are likely to influence the possibility of carers to choose the amount and intensity of caregiving provided. It is therefore vital that Family Carers who want to work outside the home are supported to do so; both in the workplace and at home, through the provision of additional supports. Family Carers need flexible working arrangements, tailored supports and understanding employers. At home, there is a need for significant expansion of flexible, mostly home-based services, especially respite and home help, as well as occupational therapy, chiropody, social work and counselling services[151]. It is of equal importance that Family Carers who are unable to work receive adequate financial support in their role.

Family Carers need flexible working arrangements, tailored supports and understanding employers

Countries such as the UK, New Zealand and Australia are among the leaders in understanding and supporting citizens in their caring role and consider the financial and social investment as part of a long-term strategy across many portfolios including labour market, health and social services[152]. Ireland should therefore use the lessons learned in these countries in order to support and enable citizens to manage multiple care and work roles and responsibilities. A study on the cost and benefits of possible EU measures on Carers' Leave, covering all 27 member states, is currently being finalised by the European

Commission[153]. This is important for a number of reasons:

- It can enhance family welfare; in the context of Europe's ageing population, the need for people to care for older family members is increasing and it is crucial for them to be able to conciliate work and care for dependants.
- It can increase female employment rates which are, as stated in the Europe 2020 strategy[154], vital to Europe's economy, as a better utilisation of women's skills and potential will increase Europe's productivity and competitiveness.
- It can increase fertility rates, as countries where women are able to combine work and family life tend to have higher fertility rates.
- It can contribute to reduce the gender pay gap and labour market segregation.
- It can facilitate a more equal distribution of domestic responsibilities[155].

A study on the cost and benefits of possible EU measures on Carers' Leave, covering all 27 member states, is currently being finalised by the European Commission

8. When caring changes or ends

8.1 Life post-care

Looking after a loved one may have taken up a significant part of many Family Carers' lives, with the needs of the person being cared for taking priority. When this caring reduces or ends, for example, because of moving into residential care or due to the death of the person, many Family Carers find it difficult to deal with this significant change to their life circumstances. There is strong evidence to show that the psychological, social and physical health consequences of caring may leave some Family Carers poorly equipped for life after care[156]. Many former carers' lives have been found to involve three distinct phases: the post-caring void, closing down 'the caring time', and constructing life post-caring[157]. Many Family Carers find themselves totally unprepared for life after caring. It is of vital importance that former Family Carers are adequately supported in the period immediately following the cessation of care through counselling services (including bereavement counselling), social inclusion programmes and returning to education, training and work programmes.

Many Family Carers find themselves totally unprepared for life after caring

Following a successful joint research bid in late 2009 between Care Alliance Ireland and the School of Nursing and Midwifery, Trinity College Dublin, to the Irish Research Council for Humanities and Social Sciences, an important qualitative research project was undertaken in the area of post-care, specifically the experiences of Family Carers after their caring at home has ceased. The findings were published in 2011[158]. It explored the needs and experiences of 40 former Family Carers whose loved ones had recently died, or moved to either a nursing home or hospice. The length of time spent caring ranged from six months to 27 years and most people were caring for parents or a spouse. They described how becoming a full-time carer had meant losing the life they had with all its social contacts, work and other opportunities. Subsequently, when the person they cared for died or moved to a care home, they experienced further

losses associated with their role and identity as a full-time carer. Losing both these worlds was found to create a profound sense of emptiness and they felt caught 'between worlds'. The factors found to help former carers to move on (caring for themselves, getting out of the house, keeping active, becoming involved in their community, etc) included family support and support from carers' organisations. For some former carers, 'moving on' involved taking on other informal and/or formal caring roles using the skills they had acquired while being full-time carers.

An important issue identified in this study was that there are no statutory health or social care services in place for former carers. This is a major issue and there appears to be a need for a formalised system of support that addresses the potential poverty trap and the risk of long-term unemployment as a consequence of opportunities lost during full-time caring.

there are no statutory health or social care services in place for former carers

8.2 Moving into a formal care situation

The importance of a smooth transition from the family home or hospital to long-term care for the wellbeing of both the individual with dementia and carer was highlighted in a recent research conducted by the Alzheimer Society of Ireland[159]. On the one hand, carers in this study felt a sense of relief from the practical demands of caring, whilst on the other they experienced painful emotions including guilt, sadness, loss and loneliness. Adjustment to the transition was facilitated by the perceived quality of care provided in the long-stay setting, familiarity with the long stay setting, and the provision of emotional support. It was also affected by the nature of the caring relationship, the attitudes of others (including the perceived disapproval of society) and the passage of time. All carers were committed to ensuring quality of care and quality of life for their relatives. They were keen to stay involved in their relatives' life and care. This they thought could be facilitated by an accessible and welcoming care home, a communicative staff group that acknowledges and utilises its expertise, and the provision of information and emotional support to families, including mentoring and peer support groups.

8.3 End of life care

as providers of care, the most important thing carers wanted was more support in knowing what to expect in the future

As recipients of care for carers their primary support need was assistance with their own feelings and worries

Family Carers of individuals with a terminal illness face a particular set of serious issues: managing complex and unpredictable conditions that may change daily; recognising the impending onset of the terminal phase; planning for the future in the face of uncertainties; the emotional demands of preparing themselves (and the ill person) for the coming death; and, sometimes, dealing with complex family relationships[160]. People who care for someone with a life-limiting or terminal illness have to deal with many of the same issues as other carers. However, their experiences can also be different as they face the emotional strain of knowing that the person they are caring for will die sooner rather than later. Research undertaken in the UK has highlighted the dual role that carers play in palliative care as both providers and recipients of care[161]. Findings from this research, which aimed to develop a carer assessment process for palliative care professionals to identify carer needs, found that as providers of care, the most important thing carers wanted was more support in knowing what to expect in the future. Other support needs in their role as Family Carers were: an understanding of the relative's illness; knowing who to contact when concerned; managing symptoms and medicines; talking to the relative about their illness; and equipment to provide care. As recipients of care for carers their primary support need was assistance with their own feelings and worries as well as: time for self in the day; help with concerns over their own physical health; practical help in the home; dealing with financial, legal and work issues; an overnight break from caring; and coping with their own beliefs/spiritual concerns.

In 2011, the Alzheimer Society of Ireland published a study on end of life care and people with dementia. This important study explored the development of a model of best practice for palliative care interventions for people with dementia and their carers[162].

In addition, Care Alliance Ireland and the Irish Hospice Foundation held a joint seminar in 2011 on providing care to a family member

at the end of life. The aim of the seminar was to seek the views and suggestions from those involved in supporting carers (both paid and family) who are working with people facing death. The seminar provided important feedback from the discussion groups and key recommendations necessary to support ongoing work and development in this area[163]. The Irish Hospice Foundation has also developed a website **www.carers.ie** to provide practical information and guidance for people who are caring for someone who has been diagnosed with a life-threatening illness and where there is a reasonable possibility that this person will die within six months either at home, in hospital or in another residential setting.

www.carers.ie provide practical information and guidance for people who are caring for someone who has been diagnosed with a life-threatening illness

Furthermore, Care Alliance Ireland was a recent partner in a transnational project on post-caring involving four other European organisations[164]. In 2011, the project published country-specific resources, entitled 'Life after Care: A handbook to assist in the transition to post-caring'[165].

9. Future trends

The need for Family Carers is growing and will continue to grow over the coming years due to societal and demographic changes and this poses serious challenges for the future

There is no doubt that the face and form of the family and the role of the family in caring is changing in an unsystematic, irregular and relatively unpredictable manner[166]. The need for Family Carers is growing and will continue to grow over the coming years due to societal and demographic changes and this poses serious challenges for the future. For instance, women, who traditionally performed most caring roles, are now more likely to be working outside of the home and their incomes are often vital. The overall number of Family Carers now in employment has increased from over one-third to over a half in the past ten years and this number is continuing to rise. In addition, in the current economic climate, financial demands on families are likely to grow, meaning that they will find it increasingly difficult to afford to provide care in the home[167].

Ireland's population is ageing rapidly. All-Ireland research conducted in 2010[168] showed that since the 1920s, the number of years a man can expect to live has risen by about 20, while women have extended their average life spans by about 24-25 years. Moreover, it forecasted that the number of people aged 65 and over will rise from around 700,000 now to nearly 1,900,000 in 2041. During the same time period, the number of people over the age of 85 will likely increase five-fold to around 355,000. The research also showed that the number of years a man in the Republic of Ireland can expect to live in poor health rose from 9.5 in 1999 to 14.7 in 2007. The same research found that the average woman's likely period in bad health increased from 11.3 years to 16.8 years over the same period. Another forecast shows that the share of the population aged over 65 years will rise to almost one-fifth by 2036 (18.4% or 1.24 million) from 2006 (when it was 11% or 462,000)[169].

The projected demand for Family Carers is determined significantly by the future population of those with a disability who are resident at home. It is estimated that from 2006, there will be an increase in demand for carers of more than 25,000 by 2016,

rising to more than 40,000 by 2021. This represents increases of 17% and 28% of respectively[170]. There are now fewer adult children available to share caregiving tasks than previously, which means that the responsibilities for providing care may place greater pressures on individuals within families.

A recent research project aimed to develop a predictive model of future long-term care demand in the Republic of Ireland and Northern Ireland, as a consequence of future demand for formal residential or home care across Ireland[171]. Amongst its key findings, the study points out that by 2021:

- The number of people aged 65+ using residential long-term care will rise by 12,270 in the Republic, which is an increase of 59% since 2006. In the North, the rise will be 4,270 (+45%).
- An additional 23,670 older people in the Republic will use formal home care (+57%). The extra demand for care from statutory providers in the North will be 4,200 (+37%).
- Demand for all-day/daily informal home care by people aged 65+ with disabilities will expand by 23,500 in the Republic (+57%) and the demand for informal care generally by 11,000 in the North (+26%).
- 2,833 extra people will require residential or formal home care each year in the Republic and 565 in the North.
- The numbers requiring formal residential or home care will increase further if informal carers are unable to provide the same rate of care as in 2006, which would require all-day/daily care for an additional 1,565 people each year in the Republic and 730 in the North.

The study also found that in 2006, 14% of older people with limiting disabilities living in the community in the Republic (8,020 people) were receiving no care, compared with only 2% in Northern Ireland (1,100 people).

in 2006, 14% of older people with limiting disabilities living in the community in the Republic (8,020 people) were receiving no care, compared with only 2% in Northern Ireland (1,100 people)

Public policies should not try to crystallise current informal care arrangements, but rather to adapt to the changing conditions

Public policies should not try to crystallise current informal care arrangements, but rather to adapt to the changing conditions. It has been legitimately argued:

it is not the same if care is provided by daughters, spouses, people of working age, retired or migrant carers as each comes with different challenges, but the main point should be that conditions are created for adequate informal care to be available in the future[172].

10. Supports for Family Carers

10.1 Social protection

The state supports Family Carers in Ireland in different ways. The Department of Social Protection has collated a full list of the supports that may be offered[173]. Many full-time Family Carers receive a weekly payment – either Carers Allowance or Carers Benefit – and all full-time Family Carers are eligible to receive a Respite Grant[174]. In 2011:

- 51,666 were in receipt of the Carer's Allowance (including 21,951 who received the half-rate allowance)
- 1,637 were in receipt of Carer's Benefit
- 69,847 were in receipt of the Respite Care Grant[175].

However, as the weekly Carer's Allowance and Carer's Benefit payments are means-tested, many Family Carers do not receive regular financial support in their caring role. Furthermore, it is proposed to cut the Respite Care Grant, payable annually in June, by 19% in 2013.

many Family Carers do not receive regular financial support in their caring role

10.2 Other supports

Whilst cash benefits for Family Carers provide compensation and recognition of their role, they should be seen in the context of a wider care plan, including basic training for the family member concerned, work reconciliation measures including flexible work arrangements and other forms of support[176]. The range of vital support services that can be offered to Family Carers include: information about available services; individual carer assessment; assistance in getting access to support services; individual counselling; support groups; respite care; and training to help with problem-solving related to their roles[177].

some carer support services – such as phone line support, outreach, training, support groups and home/institutional respite – are contracted out to not-for-profit organisations

In a number of regions, some carer support services – such as phone line support, outreach, training, support groups and

home/institutional respite – are contracted out to not-for-profit organisations (most of whom are members of Care Alliance Ireland). In addition, in some HSE areas a coordinator is employed to oversee carer support services[178].

10.3 Home care supports

Formal care in Ireland consists largely of home help and home care packages, and these are delivered mainly by the HSE, but also increasingly by voluntary and private for-profit organisations. From 2005, there was a significant increase in the resourcing of home care supports, but since 2010 it has been reported by many that accessing such supports has become more difficult and the allocation of same more restrictive. A review by Care Alliance Ireland of HSE service plans and associated ministerial statements and press releases over the period 2010-2013 indicates that cuts have indeed taken place in the overall provision of home care support, particularly in the area of home help provision.

In 2013, the HSE plans to support approximately 6,000 people (the majority aged over 65) with 10.3 million hours of home help and home care packages, either through direct provision or through contracted services[179]. Budget overruns in other areas of health spending resulted in acute pressure on home care supports towards the end of 2012, leading to noticeable cuts to overall home care services. Financial allocations in 2013 point to further pressure on these services, particularly in light of the age-related demographic pressures. Anecdotally, it would appear that more restrictive criteria are being used in assessing need, with a move away from supporting with general house chores towards a greater focus on the provision of physical care (washing and dressing in particular).

Downward pressure on the hourly rates being requested by the HSE through its procurement processes have raised significant concerns amongst not-for-profit providers about sustaining quality services

Downward pressure on the hourly rates being requested by the HSE through its procurement processes have raised significant concerns amongst not-for-profit providers about sustaining quality services. Whilst for-profit home care providers have claimed that they can offer equivalent services for less, the

evidence is not compelling in this regard, and this is particularly true in the provision of specialist home care (dementia care and palliative care, for example). Although difficult to evidence completely, home care staff directly employed by the HSE and those employed by not-for-profit organisations tend to be in receipt of higher wages and better overall terms and conditions compared to those employed in the for-profit sector. In addition, as a public sector employer, the HSE is in any case restricted by the Croke Park Agreement[180], which limits the degree to which such services can be contracted out.

Formal home care in Ireland is largely unregulated

Formal home care in Ireland is largely unregulated, although a variety of draft standards to promote quality services do exist. Some of these draft standards are being implemented, but they either cover only a proportion of home care, or are implemented on a voluntary basis. These developments were the subject of a recent report by National Economic and Social Council[181]. Northern Ireland, on the other hand, has minimum enforceable standards[182]. The Law Reform Commission has published a report that recommends that the Health Information and Quality Authority (HIQA) should be given additional regulatory and inspecting powers to ensure that appropriate legal standards are in place for providers of professional home care[183]. The report does not propose that HIQA regulation and inspection would apply to informal carers. The National Carers' Strategy (see later) includes actions to progress the development and implementation of national standards for home support services, which will be subject to inspection by HIQA[184]. A Department of Health official at the Annual Carer Consultation Forum in November 2012 confirmed that home care provision will be subject to regulation, but not before 2016.

10.4 Telecare

Telecare can be defined as the remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems. Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs,

emergencies and lifestyle changes. It uses information and communications technology to trigger human responses or shut down equipment to prevent hazards. As well as helping older people to live in their own homes for longer, telecare has the potential to support and assist Family Carers.

For example, telecare is most likely to benefit carers who feel under stress as a result of the work they undertake, or those who have leisure or recreational activities curtailed as a result of the time they put into caring. Isolated carers could benefit in particular, as could carers who have little or no support from friends or family[185]. A strategic approach to telecare across agencies and departments is lacking in Ireland; this is despite a commitment at a policy level for the use of information and communication technology to improve the quality of life of older people and to assist them in independent living[186].

Research evidence from Scotland shows that almost three-quarters of carers (74%) felt that telecare equipment had reduced their stress levels

Research evidence from Scotland shows that almost three-quarters of carers (74%) felt that telecare equipment had reduced their stress levels[187]. Similarly, work undertaken in the UK identifies that technology has a vital part to play in supporting families to care, in supporting health and care services to enable them to do so without penalties, and in supporting employers to help people combine work and care[188].

In recent times a number of initiatives have been taken in the wider telecare area including one involving a number of Irish organisations[189].

11. The policy context

11.1 European policy context

Informal caring is an issue that transcends national boundaries. One of our principal knowledge sources for Family Carers across Europe was the international Eurofamcare research project[190]. It has been found that caring for an elderly parent is more frequent in northern than in southern Europe, but that the care provided is far more intensive in the latter[191]. These results are influenced by living arrangements, as extended families are still more common in southern Europe, but also by the (un)availability of care services. Family Carers across the EU provide over 80% of all care, with women providing approximately two-thirds of care mainly as daughters (or daughters-in-law) and as wives/partners. Informal carers are most likely to be women of working age. However, as populations age, this portrait is likely to change. The projected support ratio – the number of women aged 45-64 (those more likely to provide informal care) for each person aged 80 and older (those more likely to be in need of care) – has already diminished for many countries in western Europe. This trend is likely to continue and to extend to eastern European countries in the future. Given the prospect of a potentially reduced number of informal carers of working age, spouses may find themselves as the main carers in the future. This depends, however, on the future living arrangements of older people, as well as on their health status. Data also show an increasing trend of older people living alone, particularly women once they reach the age of 80. Although partners can potentially take over some of the care tasks from their children, elderly women living alone seem more likely to have to rely on professional care services if they live far from their children, or if the latter are unable or unwilling to leave paid employment for the purposes of caregiving. Approximately 40% of informal carers are in gainful employment across Europe and this number is likely to rise in the future as more women enter the labour force. This leads to the key policy question as to whether informal care in its present form is likely to hold in the future across Europe[192].

Family Carers across the EU provide over 80% of all care

A European Parliament Special Interest Group on Carers was launched in June 2007. It has a membership of around 30 MEPs and has proven itself an effective platform for concrete contributions to health and social policy initiatives at European level. Following the European elections in June 2009, the group was re-established in February 2010 with the support of Eurocarers and Irish MEP, Marian Harkin.

11.2 Policy development Ireland 2001-2011

In 2001, the government's Primary Care Strategy emphasised the shift away from hospital to community-based care

In 2001, the government's Primary Care Strategy emphasised the shift away from hospital to community-based care[193].

A social policy report published by Comhairle (now the Citizens Information Board) gave a useful insight into some of the key issues facing carers, issues that are unlikely to have changed significantly since its publication in 2002[194]. It summarised the available research at the time and was informed by feedback from Citizens Information Centres on issues identified by their clients. It highlighted the demographic pressures that, whilst not yet urgent, were considered likely to lead to both an increase in the need for care services and a decrease in the supply of those services by the traditional care providers, Family Carers. It found that the relatively low proportion of older people in the Irish population and low labour market participation rates amongst women had provided the underpinnings of the informal care system in Ireland. However, changes in family structures, women's labour market participation and an ageing population were considered to be making this model of support less sustainable.

In 2005, the Equality Authority published the 'Implementing Equality for Carers' report which provided practical recommendations to ensure that carers would be adequately supported[195].

The National Development Plan 2007-2013 recognised that respite and day care service places need to be part of a

comprehensive community service to give a much-needed break to Family Carers[196].

The National Action Plan for Social Inclusion 2007-2016 recognised the role that Family Carers play in supporting the government's policy of caring in the home and community and suggested that carers require a range of supports including financial supports, education and training[197].

Furthermore, the government's 2008 chronic disease policy framework Tackling Chronic Disease[198] also recognised both the burden placed on families and carers of individuals with chronic disease, and the importance of reducing such responsibilities.

The National Partnership Agreement Towards 2016 contained a commitment to develop a National Carers' Strategy[199]. This was to set out the government's vision for Family Carers and establish a set of goals and actions in areas such as income support, health care and services, housing, transport, information services, labour market issues, programmes of training, social inclusion, and research and technology development. However, a decision was taken in early 2009 that the long-promised strategy would not be published; the economic situation was cited, which they claimed 'makes it difficult to commit to major advances in services for carers'[200]. Following lengthy delays, a general election and action by Family Carers, not-for-profit sector organisations, political leaders, and those within various government departments, government published the National Carers' Strategy in 2012 (see below).

Family Carers will form an important part of the National Positive Ageing Strategy, which is currently being worked on following a consultation (Care Alliance Ireland and the Carers Association of Ireland made a joint submission)[201]. The preparation of the National Positive Ageing Strategy takes forward the commitment in the Programme for Government 2007-2012 to better recognise the position of older people in Irish society. The intention is to put in place arrangements that will ensure that issues affecting older people are mainstreamed in policy-making at all levels and

The National Development Plan 2007-2013 recognised that respite and day care service places need to be part of a comprehensive community service to give a much-needed break to Family Carers

across all sectors and will contribute to the best quality of life for older people in the years to come[202].

Specifically in relation to carers of individuals with dementia, it has been recommended that investment in dementia-specific community support should address the imbalance of the burden of care and the over-reliance on informal care in Ireland. Insufficient funding is ultimately resulting in carer burnout and greater demand for long-term care[203]. Important issues relating to Family Carers are therefore highlighted in the recent research review for Ireland's National Dementia Strategy[204]. It is envisaged that the findings of this vital piece of research will ultimately form the basis for the creation of a National Dementia Strategy which may be published by government in 2013.

The National Dementia Strategy, combined with the National Positive Ageing Strategy and the National Carers' Strategy, will lead to the potential for Ireland to have world-class services and supports for those living with dementia

The National Dementia Strategy, combined with the National Positive Ageing Strategy and the National Carers' Strategy, will lead to the potential for Ireland to have world-class services and supports for those living with dementia[205].

11.3 The National Carers' Strategy 2012

The National Carers' Strategy is considered a significant milestone in advocacy for and in recognition of Family Carers in Ireland

July 19th 2012 marked the publication of the first ever National Carers' Strategy by government. The National Carers' Strategy is considered a significant milestone in advocacy for and in recognition of Family Carers in Ireland. Its vision is as follows:

Carers will be recognised and respected as key care partners. They will be supported to maintain their own health and wellbeing and to care with confidence. They will be empowered to participate as fully as possible in economic and social life.

The Strategy identifies three principles (recognition, support and empowerment) and also sets out four national goals:

- Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for
- Support carers to manage their physical, mental

and emotional health and wellbeing
- Support carers to care with confidence through the provision of adequate information, training, services and supports
- Empower carers to participate as fully as possible in economic and social life[206].

Importantly, it outlines which government department is responsible for implementing each specific action under each objective and over what time frame[207]. It also recognises Family Carers as equal partners in the delivery of health care and fully acknowledges their expertise, knowledge and the quality of care they provide.

However, the Strategy is weak in some areas, noticeably offering no guarantee to fully protect current income supports and no absolute right to carer assessments. Whilst the Strategy does not commit additional financial investment, many of its objectives can be progressed with better, rather than with more, spending[208]. Care Alliance Ireland is currently reviewing each commitment given in the Strategy and in collaboration with other carer organisations intends to put together a review and monitoring process, to ensure maximum impact into the future[209].

the Strategy is weak in some areas, noticeably offering no guarantee to fully protect current income supports and no absolute right to carer assessments

11.4 Carer assessments

The absence of comprehensive assessments of the care needs of Family Carers within the Irish policy context is a highly debated issue at present. A caregiver assessment has been defined as:

a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the ability of the caregiver to contribute to the needs of the care recipient[210].

With the movement toward person- and family-centered care, there is growing recognition of the need to expand assessment of the individual with chronic or disabling conditions to include assessment of the family[211]. In order to see Family Carers as

partners in health and social care, it is argued that they should be given access to an assessment process which would allow them to identify their needs, be given information and advice, explore difficulties they may experience, and make contingency plans if they are ill or are unable to continue to provide care[212].

To this end, Care Alliance Ireland, after a review of progressive practice internationally, has outlined a number of factors that may be considered in building the case for such assessments in an Irish context[213]:

Assessment builds carer morale and capacity

Assessment builds carer morale and capacity:

- Carers who have their needs assessed feel acknowledged, valued, and better understood by practitioners.
- Carers gain a better grasp of their role and the abilities required to carry out tasks.
- If the physical, emotional and financial strains on Family Carers become too great, care in the home may be seriously jeopardised.

Assessment is the key to care planning:

- Identifying service needs and unresolved problems is fundamental to a plan that supports and strengthens the family as a whole, where most care is given and received.
- Carer strain and health risks can impede the carer's ability to provide care, lead to higher health care costs, and affect the quality of life for carers and those for whom they care.
- The wellbeing of the Family Carer is often key to the care recipient getting the help needed at home or in the community, rather than placement in a nursing home.

Assessment opens doors for the carer and the care recipient:

- Assessment can establish eligibility/suitability for useful services, supporting the carer and the care recipient.
- Knowing carer needs and preferences triggers timely referrals.

Assessment is a way towards monitoring programme effectiveness and can inform policy:

Assessment is a way towards monitoring programme effectiveness and can inform policy

- Information from carers reveals what works and what does not.
- Carer feedback helps assure quality of care.
- Patterns seen across carers and over time reveal gaps and priorities for new services and better policies.

There is a wide range of carer assessment tools in use internationally, many of which have high levels of demonstrated reliability and validity. Important lessons for Ireland may therefore be learnt from recent developments at international level.

An audit of support services for carers in 2008[214] found that carer assessments in Northern Ireland, where such assessments have been on a statutory basis since 2002, were valuable in supporting carers in identifying unmet need, in developing a relationship with support staff, and in reviewing changing needs of both the carer and the dependent person. A further review of carer assessments found that the process itself acts as a support for carers, that it assists carer involvement in the delivery of support services and evaluation of same, and that it can help prevent the breakdown of the caring situation[215]. In 2011, a small scale survey with a sample of carers was undertaken by the Northern Health and Social Care Trust Carers Strategy

Group in order to identify issues influencing carers' decisions to refuse assessment and suggest solutions[216]. The main barrier to carers having an assessment was found to be a lack of clear understanding and a lack of clear information given to carers about what the assessment is, what it involves and why they should consider having one. In 21% of the carers interviewed, their main concern was that they thought their ability to care was being assessed and they were worried about the consequences of that.

Care Alliance Ireland contends that the introduction of carer assessments would not lead to a significant increase in demand for services. Rather, the experience internationally and the experience of the recent introduction of such assessments in two HSE areas (Sligo and the Midlands), is that the assessment process enhances the carer's relationship with the community nursing team and other health and social care professionals and leads to more integration of support services for both the dependent person and the carer. The process can be challenging for community nurses, but it can also be cathartic for Family Carers, for whom being asked questions about themselves rather than the dependent persons is likely to be a new and welcome experience. Whilst the limits on available resources are acknowledged, it is believed that the carer's experience of being supported can be improved without the provision of significant additional resources[217].

The carer's experience of being supported can be improved without the provision of significant additional resources

Care Alliance Ireland is aware of two carer assessment models that are currently being used in two HSE regions in Ireland, namely the CARENAP-D and COPE/Salford. There has been some very limited and sporadic used of the Carer Strain Index in hospital settings. We are also aware of two internal assessment/referral models used by national carers organisations[218]. As of early 2013, InterRAI[219], a single assessment tool for assessing care needs, has been introduced on a pilot basis within the HSE. Care Alliance Ireland is working with stakeholders to ensure that a new carer assessment supplement is incorporated into the suite of InterRAI assessment tools.

12. Carer organisations in Ireland

12.1 Care Alliance Ireland

12.1.1 About us

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. Our vision is that the role of Family Carers is fully recognised and valued by society in Ireland. We exist to enhance the quality of life for Family Carers. Our legitimacy derives from our 85-strong membership base, which comprises all the carer organisations and nearly all the disease/ disability-specific organisations currently providing services to Ireland's Family Carers at local, regional and national levels. We support our member organisations in their direct work with Family Carers through the provision of information, sharing resources, developing research and policy in the field, and instigating opportunities for working together. We bring cohesion to those organisations and we actively encourage collaboration in all of our work.

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers

12.1.2 National Carers Week

National Carers Week takes place in Ireland each June. Its aim is to deliver a vibrant week of celebration, leading to a fuller appreciation of the value and contribution of Family Carers. The objectives of the Week are to raise awareness of Family Carers in our communites, to deliver events for Family Carers throughout the country and to engage with Family Carers not yet availing of carer support services. The week is coordinated by Care Alliance Ireland with eight other non-governmental organisations that provide support to Family Carers and their dependants (Alzheimer Society of Ireland, Brí, Carers Association of Ireland, Parkinsons Association, Caring for Carers Ireland, Disability Federation of Ireland, Hospice Foundation and MS Ireland).

Each year, hundreds of events for Family Carers take place throughout Ireland. Full details are available on www.carersweek.ie.

12.1.3 Family Carer Research Group

Care Alliance Ireland established a national research alliance on Family Carer issues in 2007, with the following key aims:

- To progress and develop an agreed research agenda within the Family Carer sector.
- To facilitate relationship building between community and voluntary organisations, statutory agencies and academics in relation to Family Carer research issues.
- To act as a means of sharing research information relating to Family Carers.
- To inform and update members of the group on research being carried out in other organisations, which may be relevant to their own work.
- To work together to develop and promote evidence-based research and publications on Family Carers, that can be used to support policy and to develop appropriate services.
- To identify possible gaps in research and help set priorities for new work in the area of Family Carers.
- To identify possible relevant research funding opportunities.
- To develop partnerships for possible future research.
- To promote the use of research to inform policy and practice in the Family Carer arena.
- To support members of the group in

securing a more central recognition of Family Carers within their own organisations.

Membership, which currently stands at 15, is open to all organisations and individuals working on issues relating to Family Carers. The Family Carer Research Group meets on a quarterly basis in Dublin. Care Alliance Ireland maintains a database of recently published and current Irish caring related research.
www.carealliance.ie/publications_currentfamilycarerresearch

12.2 The Carers Association

The Carers Association is Ireland's national charity for and of Family Carers in the home. Its mission is to provide Family Carers with emotional and practical supports; to promote the interests of Family Carers and those receiving care in the home through effective partnership, lobbying and advocacy, and to gain recognition and social justice for carers' invaluable contribution to Irish society. The organisation reaches Family Carers through its National Care Line and drop-in Resource Centres across Ireland.
www.carersireland.com
www.youngcarers.ie

12.3 Caring for Carers Ireland

Caring for Carers Ireland is an independent voluntary support organisation working in partnership with Family Carers and those for whom they care. Currently there are 109 local Caring for Carer groups. Rooted in the Carers' Charter launched by Soroptimist International Republic of Ireland in the 1980s, Caring for Carers Ireland focuses on the recognition of the role of the Family Carer, the provision of respite care, information and training, whilst advocating for the rights and needs of carers at local, national and European levels.
www.caringforcarers.org

12.4 Other organisations supporting Family Carers

- Ability West **www.abilitywest.ie**
- Abode (Doorway to Life) **www.doorwaytolife.com**
- Acquired Brain Injury Ireland **www.abiireland.ie/services_carers.html**
- Age Action Ireland **www.ageaction.ie/home.htm**
- Alzheimer Society of Ireland **www.alzheimer.ie/Living-with-dementia/I-am-a-carer.aspx**
- Aware **www.aware.ie**
- Bloomfield Health Services **www.bloomfield.ie**
- Bodywhys **www.bodywhys.ie/supportingSomeone/family-friends-carers**
- Brí **www.briireland.ie**
- Brothers of Charity **www.brothersofcharity.ie**
- Carebright **www.carebright.ie**
- Cavan and Monaghan Caring for Carers **www.cavanmonaghancarers.com**
- Cheshire Ireland **www.cheshire.ie**
- Clarecare **www.clarecare.ie**
- Crosscare **www.crosscare.ie/community/index.php?option=com_content&view=article&id=83&Itemid=93**
- Cystic Fibrosis Ireland **www.cfireland.ie/index.php/informationnewparents**
- Extracare **www.extracare.ie**
- Galway Head Injury Support Group **www.galwayheadinjury.com**
- Haemophilia Society of Ireland **www.haemophilia.ie**
- Hand In Hand **www.handinhand.ie/family-supports**
- Headway **www.headway.ie/services/servicesbytype/familysupports.html**
- Health Training United Care **www.healthtrainingunitedcare.ie**
- Huntington's Disease Association of Ireland **www.huntingtons.ie/content/carers-support**
- Inclusion Ireland **www.inclusionireland.ie/content/page/carers**

- Independent Age **www.independentage.org/about-us/our-local-offices/ireland-office.aspx?highlight=ireland**
- IRD Duhallow **irdduhallow.com/community-supports/carers/39-carers-group**
- Irish Cancer Society **www.cancer.ie**
- Irish Hospice Foundation **www.hospicefoundation.ie/supporting-you/supporting-carers** and **www.carers.ie**
- Irish Kidney Association **www.ika.ie**
- Irish ME/CFS Association **www.irishmecfs.org**
- Irish Motor Neurone Disease Association **www.imnda.ie/carers.html**
- Irish Osteoporosis Society **www.irishosteoporosis.ie**
- Irish Red Cross **www.redcross.ie/our-work-in-ireland/community-services**
- Irish Wheelchair Association **www.iwa.ie**
- Kare Social Services **www.karesocialservices.ie**
- Mental Health Ireland **www.mentalhealthireland.ie/projects-a-activities/caring-for-the-carer.html**
- MS Ireland **www.ms-society.ie/pages/living-with-ms/carers-**
- Muscular Dystrophy Ireland **www.mdi.ie/family-support.html**
- Newry and Mourne Carers **www.carers-nm.org**
- Parkinson's Association of Ireland **www.parkinsons.ie/advice_carers**
- Rehab Care **www.rehab.ie/care/index.aspx**
- Roscommon Disability Support Group **www.rosdisabilities.ie**
- Rosses CDP **rossescdp.ie/carers.html**
- Special Olympics Ireland **www.specialolympics.ie/GETINVOLVED/FAMILIES.aspx**
- Spina Bifida Hydrocephalus Ireland **www.sbhi.ie/services.html#family**
- St. Aidan's Day Care Centre

www.saintaidansservices.com/index.html

- St Andrew's Resource Centre www.standrews.ie/elderlyservice
- Tír Boghaine Teo www.tirboghaine.com
- West Cork Carers Support Group www.westcorkcarers.ie
- Western Care www.westerncare.com
- Volunteer Stroke Scheme www.strokescheme.ie

12.5 Relevant government departments and statutory bodies

12.5.1 Citizens Information Board

Free information on public services available online, by telephone (0761 07 4000, Monday to Friday, 9am to 8pm), or by visiting a local Citizens Information Centre. www.citizensinformation.ie

12.5.2 Department of Health and Children

www.dohc.ie

12.5.3 Department of Social Protection

www.welfare.ie/EN/Pages/carers.aspx

12.5.4 Health Service Executive (HSE)

- Managers and Coordinators of HSE Care Services Services: www.hse.ie/eng/services/Find_a_Service/Older_People_Services/Carers_and_Relatives/HSE_Carer_Managers.html
- Outline of supports for carers: www.hse.ie/eng/services/Find_a_Service/Older_People_Services/Carers_and_Relatives/Support_for_Carers.html
- Outline of supports for family members of people with mental health conditions: www.hse.ie/eng/services/Find_a_Service/Mental_Health_Services/localmentalhealth/info

13. International carer organisations

13.1 International Alliance of Carers Organisations

The International Alliance of Carer Organizations (IACO) was incorporated in the USA in 2013 and is currently at an embryonic stage. It was set up to build a strong network of carer organisations across nations to share ideas, programmes and research that will bring visibility and support to Family Caregivers around the globe.
www.internationalcarers.org

13.2 Eurocarers

Eurocarers was officially established in Luxembourg in 2006. Its origin lies in two European networks: Carmen and The Eurofamcare Network. Since then the association has increased in size and reach and now includes over 60 organisations and several individual associates from all 27 EU Member States. It seeks to represent and act on behalf of all informal carers, irrespective of their age or the health needs of the person they are caring for.

Amongst its principal aims are:

- Contributing to policy development at national as well as European level supported by evidence-based research: by acting as a voice for informal carers and issues relevant to carers, and by translating relevant EU policy developments to members operating at national and regional level.

- The exchange, gathering and dissemination of experience, expertise and good practice, as well as innovations.

Many of the current EU policy initiatives have a bearing on care provision and carers, and Eurocarers endeavours to make informed submissions in this regard. Eurocarers also aims to collaborate with other interest and advocacy groups at national and EU level – including organisations representing disabled people and their families, women's organisations, organisations campaigning against social exclusion and poverty – in order to promote recognition of carers and carers' interests and shape a policy environment that is more favourable to carers. Other organisations such as AGE, Coface and Alzheimer Europe also have a keen interest in carers' issues, often acting as advocates for carers at a European level. In 2009 Eurocarers updated its factsheet entitled 'Caring in Europe' (available for free download from its website).
www.eurocarers.org

13.3 Other key carer organisations

- Canadian Caregiver Coalition **www.ccc-ccan.ca**
- Carers Australia **www.carersaustralia.com.au**
- Carers Northern Ireland **www.carersni.org**
- Carers Trust **www.carers.org**
- Carers UK **www.carersuk.org**
- Coalition of Carers in Scotland **www.carersnet.org**
- Family Caregiver Alliance (US) **www.caregiver.org/caregiver/jsp/home.jsp**
- Mezzo (Netherlands) **www.mezzo.nl**
- National Alliance for Caregiving (US) **www.caregiving.org**
- New Zealand Carers **www.carers.net.nz**
- Wir Pflegen (Germany) **www.wir-pflegen.net**

13.4 Family Carer research

- Centre for International Research on Care, Labour and Equalities (CIRCLE) **www.sociology.leeds.ac.uk/circle/about**
- Rosalyn Carter Institute for Caregiving (US) **www.rosalynncarter.org**

- Saul Becker (focus on young carers)
  www.saulbecker.co.uk/all_publications.html
- Social Policy Research Unit – Adults, Older People and Carers Team (UK)
  www.york.ac.uk/inst/spru/research/aoc.html
- Social Work Leadership Institute (carer focus) (US)
  www.nyam.org/about-us/social-work-leadership
- Young Carers Research Group, Loughborough University (UK)
  www.lboro.ac.uk/departments/ss/centres/YCRG

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