



Spotlight

Mind the care gap Exposing the health system's vulnerability to the gap between family care provision and anticipated demand.

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Abstract

This *Spotlight* offers an analysis of family carers, those who provide care and support on an unpaid basis to people who are sick, disabled or frail in the community. It explores how demand for care at home is likely to increase dramatically while the future supply of family carers may be limited by demographic factors. High calculations of the monetary value of family care to the State underscore its vulnerability to any future shortage in family carers. Current developments which may have an impact on carers' lives and the future supply of carers are considered.



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Contents

Summary	3
Introduction	6
A profile of family carers.....	9
Counting carers	9
Gender and age profile of carers	12
Time spent caring	12
Who carers care for	14
Impact on carers' health and well being.....	16
Income supports to family carers	17
Gap between supply and demand.....	21
Ageing demographics and demand for care	21
Projected future demand for home care.....	22
Future supply of family carers.....	23
Calculating the value of family care	24
Key policy considerations.....	26
Gender and the care gap.....	26
Home care policy pressure on carers	28
Dedicated family carer policy	30
Disability and carer policy	32
Carers and employment	33
Catalysts for change	39
Increase home care, increase caring?	39
Carers Needs Assessment.....	41
The Assisted Decision Making (Capacity) Act (2015)	42
Care and the Constitution	44
Supporting employment and care	45
Conclusion	47

Summary

Gap between supply and demand

Family carers are the main source of care provision for those in need of care due to a long-term illness, disability or frailty living in the community^{1,2}. Demand for care at home is likely to increase dramatically due to a rising ageing population, the shift away from institutional care for people with disabilities³ and an increased emphasis on home-based care.

The ESRI's projection of the future demand for home care (and by proxy family care) is very high. Demand for home care from 2015 to 2030 is estimated to increase by between 48.4 per cent and 65.9 per cent.⁴

The future supply of family carers may be limited by demographic factors including a decline of fertility rates, delayed average age of starting a family and increased labour force participation by women.⁵

Calculations of the monetary value of family care to the State are very high (between €2.1 billion and €10 billion per annum depending on the valuation approach)^{6,7} and serve to underscore the dependency of the health system on family care and its vulnerability to any future shortage in family carers.

The estimated value of informal care in Ireland (€5.3 billion: OCABC) far exceeded the expenditure by Government on home-based long-term care (€1.34 billion: 2013) or long-term residential facilities (€2.69 billion: 2013) in Ireland (CSO, 2015), and equated to 3.8 per cent of Irish GNP in 2011.⁸

Key policy considerations

¹ Mosca et al. 'Sustainability of Long-term Care: Puzzling Tasks Ahead for Policy-Makers' International Journal of Health Policy and Management 6.4. (2017)

² F. Hoffmann & R. Rodrigues, 'Informal Carers: Who takes care of them?' Vienna: European Centre for Social Welfare Policy and Research (2010), 3 http://www.euro.centre.org/data/1274190382_99603.pdf

³ While the shift away from institutional care for people with disabilities is an influencing factor in the increased demand for care at home and the community an analysis of this issue is beyond the scope of this paper.

⁴ Maev-Ann Wren et al., *Projections of Demand for Healthcare in Ireland, 2015-2030: First Report from the Hippocrates Model* (Economic and Social Research Institute, 2017).

⁵ Dr Michael Browne, "Responding to the Support & Care Needs of Our Older Population" (SAGE Support & Advocacy for Older People, July 2016); Ricardo Rodrigues, *The Indirect Costs of Long-Term Care: Research Note, 8/2013* (European Commission, 2013); Hanley, Paul and Sheerin, Corina, "Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary," *The Economic and Social Review* 48, no. 3 (Autumn 2017).

⁶ Hanley, Paul and Sheerin, Corina, "Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary."

⁷ Family Carers Ireland, "Submission to Citizens Assembly on How We Best Respond to the Challenges and Opportunities of an Ageing Population," May 2013, <https://familycarers.ie/wp-content/uploads/2016/01/Family-Caring-in-Ireland-2013.pdf>.

⁸ Hanley, Paul and Sheerin, Corina, "Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary."

There are a range of policy factors at play in relation to demand for and supply of family care in Ireland.

It is factors affecting women that are most critical when considering the future supply of family carers. Most care in Ireland and worldwide is carried out by women and has often stereotypically been seen as part of a 'woman's role'.

The aim of numerous Irish health policy documents is to shift a greater proportion of care delivery to the home and community which will require a greater proportion of the population to take on family care roles. National policy relating to supporting family carers (*the National Carers Strategy*)⁹ while ambitious has been constrained through lack of dedicated funding. Minister Kathleen Lynch in her forward to the Strategy acknowledged that most of the actions were selected on the grounds of being 'cost neutral'.¹⁰ The stated goals of all of these policies are challenged by gaps in home care and respite care provision which have negative consequences for the family care role.

Disability policy too seems to be in tension with carer policy potentially to the detriment of implementing both.

Most family carers combine a caring role with paid employment and this is likely to be increasingly a feature of our workplace. There are challenges and benefits to juggling both roles. Irish legislation aimed at supporting carers to leave the workplace temporarily to take up a caring role is progressive compared to other European countries but take up is low. There is a knowledge and research gap relating to this. In the absence of a firm evidence base organisations representing carers have suggested that the low take up of Carer's Leave may be due to: a poor fit between the structure of the scheme and people's caring needs; a fear of negative career consequences of availing of the scheme; the high economic, psychological and social costs of leaving work for an extended period; and low awareness about the scheme among employers and employees.

Catalysts for Change

There are a number of factors that directly relate to the predicted care gap. They may positively or negatively impact the future demand for family carers or the future supply of carers.

Will enhancing funding to home care increase the numbers of family carers in the future? Surprisingly the literature is not clear on this. One interpretation indicates that it may lead to a more sustainable caring population. More generous home and long term care provision may reduce the number of carers with intensive caring roles but may lead to more carers with sustainable caring roles.

A Carers Needs Assessment has been developed in addendum to a tool to assess older people's care needs. If adopted, mainstreamed and broadened to include all full-time carers this may have the potential to dramatically alter how carers are supported in Ireland.

[The Assisted Decision-Making \(Capacity\) Act 2015](#) has the potential to dramatically change caring relationships. Those with cognitive impairment which challenges their capacity to make decisions about their finances, healthcare, living arrangements etc. will be encouraged to put in place

⁹ Department of Health, "National Carers' Strategy. Recognised, Supported, Empowered.," July 2012.

¹⁰ Department of Health.

supports to assist their decision making. Currently family members and carers are operating in a legal vacuum when making day to day decisions, including decisions on the spending of money, on behalf of people who do not have capacity. This legislation, if implemented as intended will remove this vacuum and may help to clarify some of the tensions referenced above in relation to disability policy and carer policy.

There is currently a debate on amending the Constitution, Article 41.2.1, to recognise the value of caring work in gender neutral terms. A constitutional amendment could offer a mechanism for responding to calls for the need for care work to be valued and for the encouragement of a greater distribution of care work between genders.

There are a number of initiatives that may improve the situation of carers trying to combine employment and caring. These include:

- an EU proposal which aims to improve the access for working parents and carers to work-life balance arrangements, such as leave and flexible working arrangements.
- a HRB funded four year study has begun focusing on self-care behaviours among working carers. It will investigate how better to support carers in maintaining their health and wellbeing, creating a programme to help working family carers to improve their physical and mental health.
- a Family Carers Ireland project aimed at encouraging employers to offer greater flexibility and support to employees juggling paid employment and family care. It is suggested that by doing so employers could significantly reduce costs caused by staff turnover, absenteeism and stress.

Introduction

Care and caring are: central to human life and relations; associated with a wide range of emotions (e.g. spanning grief to joy, patience to exasperation, fear to security, and living and dying); and also – especially as the capacity to extend and save lives increases – have profound implications for the distribution of human, economic and other resources, in global, national and local contexts¹¹

It is recognised that family carers are the main source of care provision for those in need of care due to a long-term illness, disability or frailty living in the community^{12,13}. In a range of countries the demand for care at home is set to increase while the potential pool of available family carers is narrowing significantly. An unpaid ‘care gap’ is predicted^{14,15,16,17}.

At the very time the demand for long-term care services is increasing, the traditional supply of both paid caregivers and unpaid caregivers is shrinking.¹⁸

Groups representing Irish family carers have presented the gap between future demand and future supply of family carers in stark terms:

“We believe that the current crisis [in manpower planning relating to home care] will increase markedly over the next decade unless policy reflects the fact that in order for the current level of ‘co-production’ of home care to be sustained the ratio of family carers will have to increase from one in 10 to one in 5 by 2030”.¹⁹

Demand for care at home is likely to increase dramatically due to a rising ageing population, the shift away from institutional care for people with disabilities and an increased emphasis on home-

¹¹ Sue Yeandle et al., “Care and Caring: Interdisciplinary Perspectives on a Societal Issue of Global Significance,” Text, March 2017, <https://doi.org/info:doi/10.1332/239788217X14866278171183>.

¹² Mosca et al. ‘Sustainability of Long-term Care: Puzzling Tasks Ahead for Policy-Makers’ International Journal of Health Policy and Management 6.4. (2017)

¹³ F. Hoffmann & R. Rodrigues, ‘Informal Carers: Who takes care of them?’ Vienna: European Centre for Social Welfare Policy and Research (2010), 3 http://www.euro.centre.org/data/1274190382_99603.pdf

¹⁴ Pickard, L. ‘A Growing Care Gap?’ Ageing and Society (2015)

¹⁵ Browne, M ‘Report of Forum on Long Term Care for Older People’, SAGE Support & Advocacy Service for Older People (2016)

¹⁶ Joyce Outshoorn, “Gendering the ‘Graying’ of Society: A Discourse Analysis of the Care Gap,” *Public Administration Review* 62, no. 2 (January 1, 2002): 185–96, <https://doi.org/10.1111/0033-3352.00169>.

¹⁷ Nora Super, “Who Will Be There to Care? The Growing Gap between Caregiver Supply and Demand,” *National Health Policy Forum*, January 23, 2002, https://hsrc.himmelfarb.gwu.edu/sphhs_centers_nhpf/89.

¹⁸ Donald Redfoot, Lynn Feinberg, and Ari N. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* (AARP Public Policy Institute Washington, DC, 2013).

¹⁹ Family Carers Ireland, “Family Carers Ireland’s Submission to the Health Committee,” December 12, 2018, https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/joint_committee_on_health/submissions/2018/2018-12-12_opening-statement-john-dunne-chief-executive-family-carers-ireland_en.pdf.

based care. On the supply side the potential pool of available carers may be narrowing significantly because of demographic factors and increasing labour force participation of women.

This *Spotlight* frames these issues using demographic and statistical data, considers how national policy is influencing the gap between demand for family carers and their predicted supply and highlights key issues that may positively or negatively impact the situation. The *Spotlight* is structured as follows:

A profile of family carers

- Counting carers
- Gender and age profile of carers
- Time spent caring
- Who carers care for
- Impact on carers' health and wellbeing
- Income supports to family carers

Gap between supply and demand

- Ageing demographics and demand for care
- Projected future demand for home care
- Future supply of family carers
- Calculating the value of family care

Key policy considerations

- Gender and the Care Gap
- Home care policy pressures on carers
- Dedicated family carer policy
- Disability and carer policy
- Carers and employment

Catalysts for change

- Increase home care, increase caring?
- Carers Need Assessment
- The Assisted Decision-Making (Capacity) Act
- Care and the constitution
- Supporting employment and care

Note on data sources and methodology

This *Spotlight* aims to synthesise and assess the available evidence in relation to the future supply of family carers as it relates to a predicted increase in demand for care at home. The methodological approach is, therefore, primarily an analysis of available research and does not seek to present any new or primary research. To this end the author has extensively reviewed existing reports and research including; government policy, independent academic analysis, stakeholder commentary and reports of administrative bodies. The author is grateful to the Carers' Section within the Department of Employment Affairs and Social Protection for supplying key social welfare data relating to family carers.

The final section of this *Spotlight* considers a number of factors that may impact family care into the future. Organisations representing family carers are prominent in the literature relating to initiatives that may offer greater support to family carers. For clarity the author frames these perspectives as coming from organisations representing family carers or names the organisations individually.

A profile of family carers

Counting carers

Before considering the future supply of family carers an understanding of how many carers there are and how much they contribute is important. Estimates of the proportion of Irish population engaged in family caring varies from 4.1% to 10% depending on the research method used.²⁰ This section considers the way in which carers have been counted and what this tells us how Ireland compares to other countries.

The 2016 census recorded 195,263 carers providing 6,608,515 hours of care each week, averaging 38.7 hours of unpaid care per carer.²¹ This represents 4.1% of the population, the same proportion as in the 2011 census.

A question on family carer prevalence has been included in the Irish census since 2002. Since then two other nationally representative surveys using different questions to identify carers suggest much larger proportions of the population engaged in unpaid care. A 2009 Quarterly National Household Survey (QNHS) found that 8% of respondents aged 15 and over provided some level of unpaid care.²² Furthermore, the Irish Health Survey 2015 found that

*“10% of the population are providing care to someone with a chronic condition or an infirmity due to old age. In 86% of these cases, the person being cared for is a family member. The average number of hours spent providing care is 44.7 hours per week.”*²³

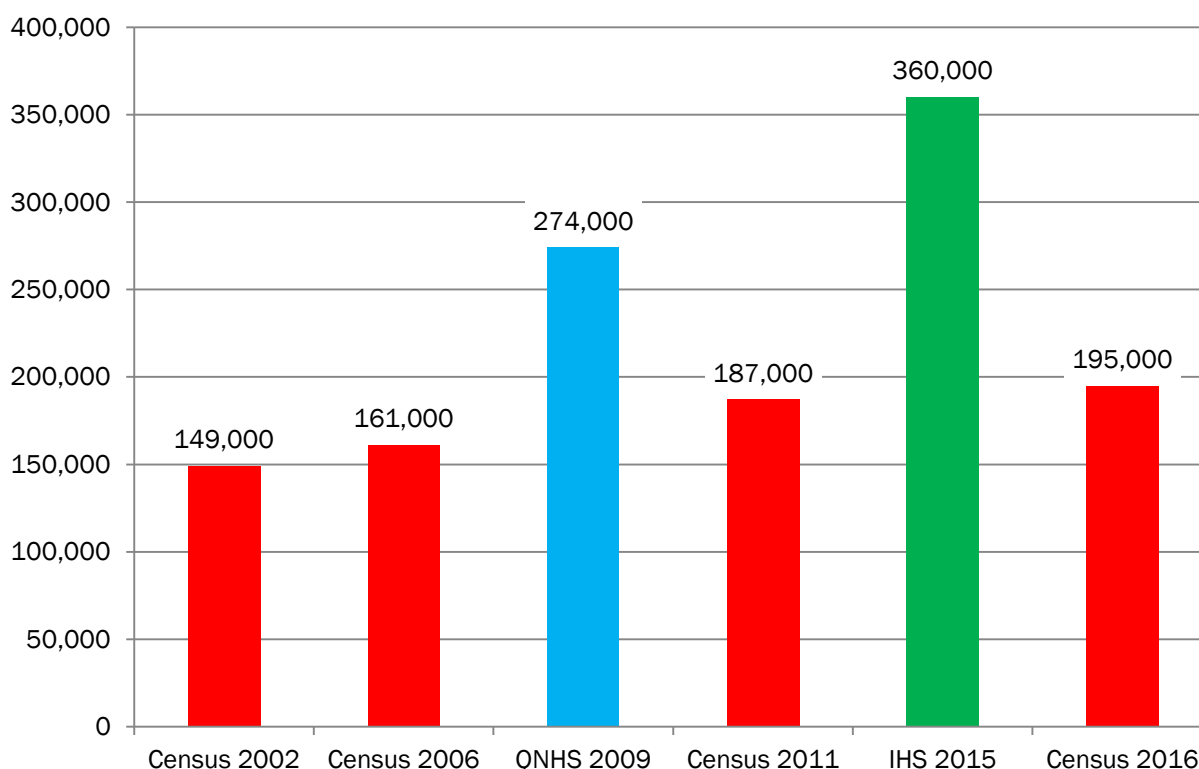
The differences between the numbers of carers captured by these different methodologies is represented in the chart below.

²⁰ Central Statistics Office, “Census of Population 2016 – Profile 9 Health, Disability and Carers,” accessed February 5, 2019, <https://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9cr/>; Central Statistics Office, “Irish Health Survey 2015” (Central Statistics Office, 2015), <https://www.cso.ie/en/releasesandpublications/ep/p-ihs/irishhealthsurvey2015/ct/>.

²¹ Central Statistics Office, “Census of Population 2016 – Profile 9 Health, Disability and Carers.”

²² Central Statistics Office, “Quarterly National Household Survey” (Central Statistics Office, 2009), www.cso.ie/en/media/csoie/releasespublications/documents/labourmarket/2009/carersq32009.pdf.

²³ Central Statistics Office, “Irish Health Survey 2015.”

Figure 1: Numbers of carers in Ireland

Source: [Trends in Family Caring in Ireland in 2017](#), Care Alliance Ireland (2017)

Capturing the total population who are caring for another family member, neighbour or friend is challenging. The degree to which people self-identify as a carer or recognise the support they provide as caring work varies greatly.

All three surveys displayed in the chart above have robust methodologies but due to wording of the questions used and varying methods of data gathering different proportions of the population are identifying as carers.

The language used in the census ‘personal help ... including feeding or dressing’ may contribute to the lower census prevalence figure. The wording of the 2015 health survey and the 2009 QNHS is broader than that used in the census. Indeed authors of the 2009 Quarterly National Household Survey (QNHS) acknowledge this fact and explicitly state that it is expected that their terminology would elicit a higher prevalence rate of caring.²⁴

It has been suggested that the census captures those who are more likely to be providing support for ‘Activities of Daily Living’ (ADLs) such as eating, bathing, dressing, toileting and moving in and out of bed.²⁵ While those captured by the Irish Health Survey and QNHS are more likely to be primarily providing support for ‘Instrumental Activities of Daily Living’ (IADLs) including preparing

²⁴ Central Statistics Office, “Quarterly National Household Survey.”

²⁵ Hughes, Zoey, “Trends in Family Caring in Ireland in 2017: Review of Awareness, Self-Identification, Official Surveys and Income Supports” (Care Alliance Ireland, January 9, 2017), [https://www.carealliance.ie/userfiles/file/Overview%20Report\(1\).pdf](https://www.carealliance.ie/userfiles/file/Overview%20Report(1).pdf).

meals, managing money, shopping for groceries or personal items, performing housework, doing laundry and using the telephone.

Some weaknesses in the census question relating to caring have been highlighted. Family Carers Ireland argue that use of the term ‘unpaid’ may discourage recipients of social welfare supports (i.e. Carers Allowance, Carers Benefit, Carer Support Grant or Domiciliary Care Allowance) from responding positively as some may consider these social transfers as payment for care work and therefore not ‘unpaid’.²⁶ Also the framing of the question may not be sufficiently broad and may deter carers of adults or children with an intellectual disability (e.g. autism, Asperger’s) or indeed those caring for a loved one with a mental health difficulty from responding.

Few countries capture nationally representative data on the proportion of carers. A selection of those that do are represented in the chart below. As this table makes clear, in contrast to the census figures, the QNHS survey and Irish Health Survey 2015 observe a similar proportion of carers to other developed countries.

Table1: Proportion of the population who are family carers

Country	Data Source	Proportion of Population Caring
Ireland	Census 2016 ²⁷	4.1%
Ireland	Irish Health Survey 2015 ²⁸	10%
Ireland	QNHS 2015 ²⁹	8%
England & Wales	Census 2011 ³⁰	10%
Northern Ireland	Census 2011 ³¹	12%
Australia	SDAC 2015 ³²	11.6%

Source: Library & Research Service using data from the CSO, UK Office for National Statistics, Northern Irish Assembly and the Australian Bureau of Statistics.

In this *Spotlight* we will switch between census data and other survey data as the former gives robust data over time facilitating the tracking of trends in the carer population while the latter allows greater detail about the caring role.

²⁶ Family Carers Ireland, “Submission to the Central Statistics Office on Questionnaire Content for Census 2021,” November 2017, <http://familycarers.ie/wp-content/uploads/2017/11/CSO-Census-2021.pdf>.

²⁷ Central Statistics Office, “Census of Population 2016 – Profile 9 Health, Disability and Carers.”

²⁸ Central Statistics Office, “Irish Health Survey 2015.”

²⁹ Central Statistics Office, “Quarterly National Household Survey.”

³⁰ Office for National Statistics, “Unpaid Care 2011 Census Analysis,” accessed February 5, 2019, <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/articles/2011censusanalysisunpaidcareinenglandandwales2011andcomparisonwith2001/2013-02-15>.

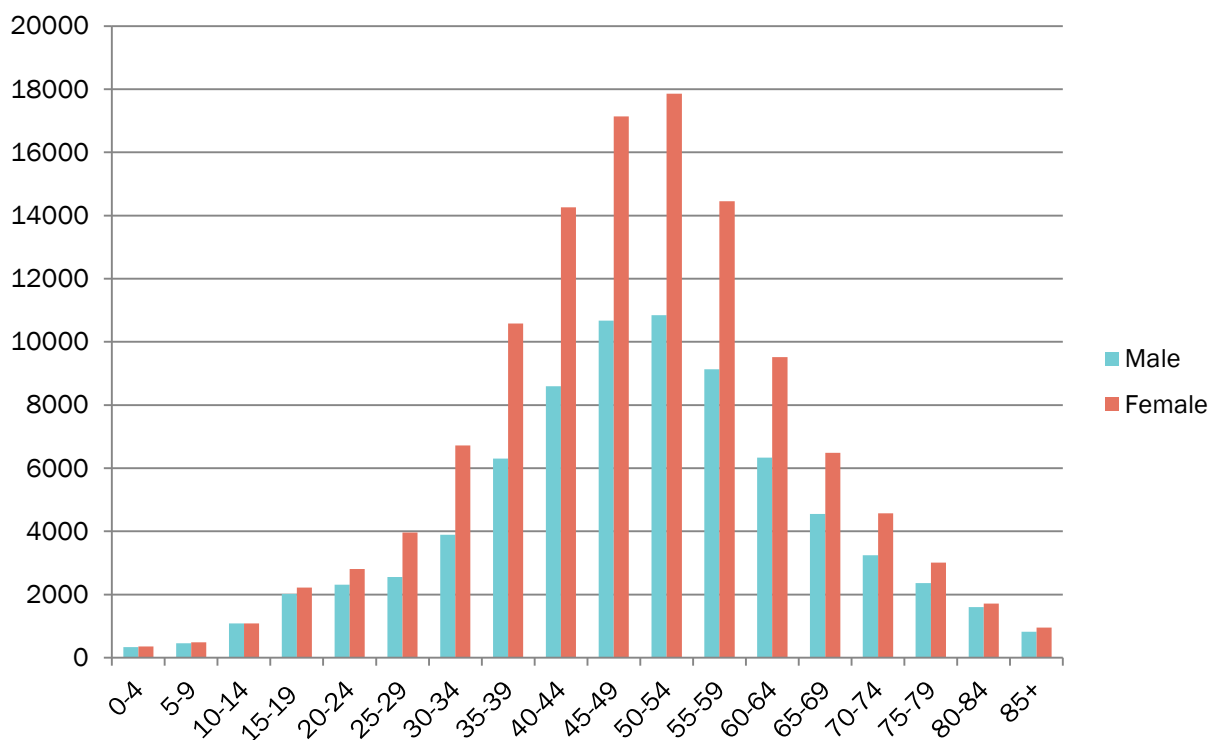
³¹ Ray Russell, “Carers in Northern Ireland: Some Key Statistics,” Research Matters, July 26, 2018, <https://www.assemblyresearchmatters.org/2018/07/26/carers-in-northern-ireland-key-statistics/>.

³² Australian Bureau of Statistics, “Disability, Ageing and Carers, Australia: Summary of Findings, 2015,” accessed February 5, 2019, <https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>.

Gender and age profile of carers

The majority (60.5%, 118,151 carers) of carers are women and as illustrated in figure 1 below there is a particular caring demand on women in the 40 to 59 age group.

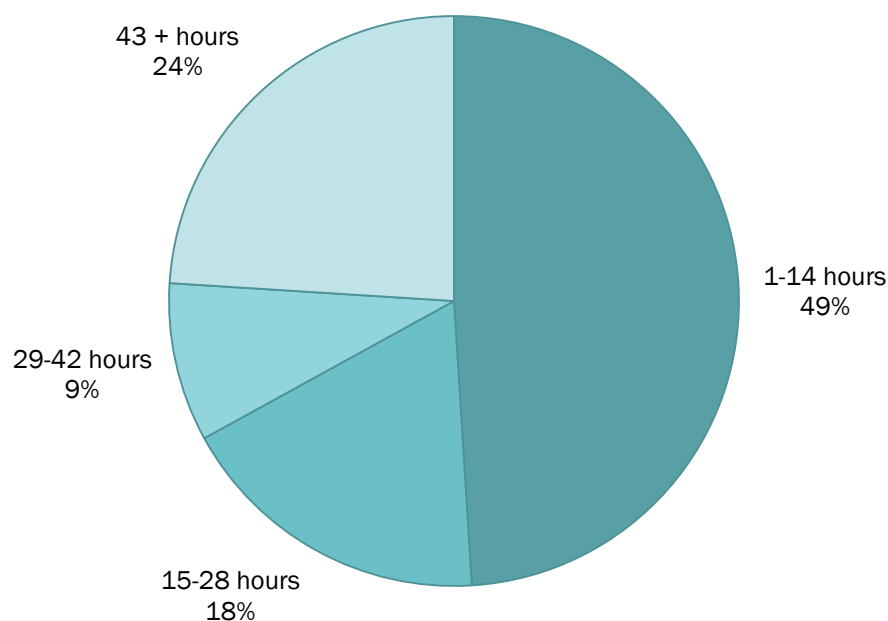
Figure 2: Carers by gender and age group (census 2016)



Source: Library & Research Service using census 2016 data

Time spent caring

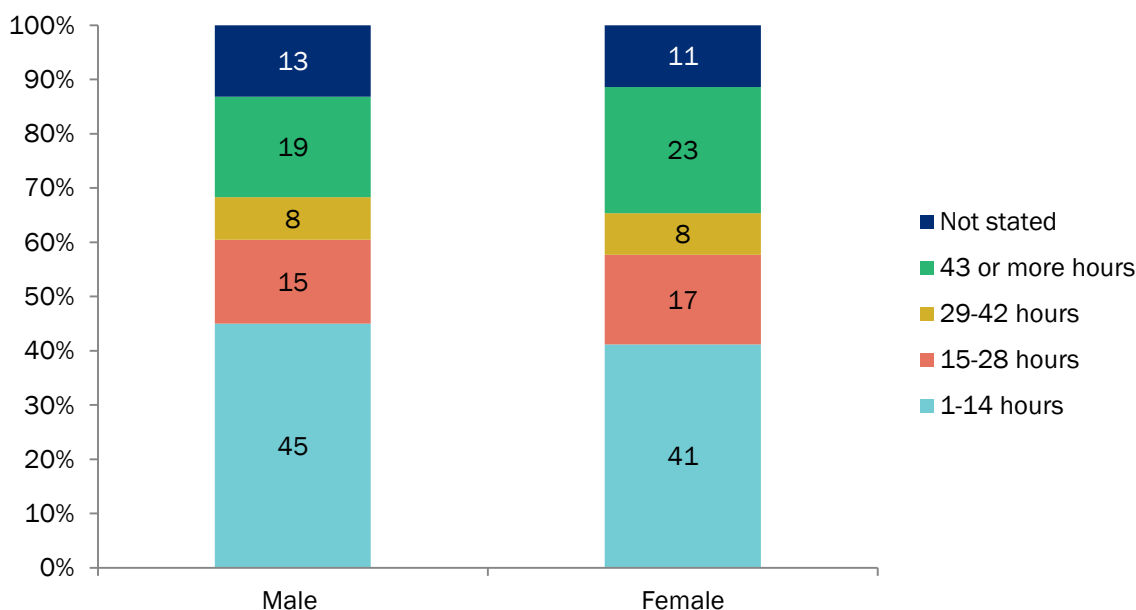
According to census 2016 just under half of those who identified as a carer were providing between 1-14 hours of unpaid care per week (n=83,734; 49%). Eighteen per cent provided 15-28 hours of care per week (n=31,129); 9% provided between 29-42 hours per week (n=14,868); and nearly a quarter provided 43 or more hours of care per week (n=41,185; 24%).

Figure 3: Hours per week spent caring (census 2016)

Source: Library & Research Service using census 2016 data

International literature indicates a propensity for women to care for longer hours and be involved in more demanding care³³ and this is reflected in census 2016 data where 23% of women who care reported caring for 43 or more hours per week compared to 19% of men while on the other end of the scale 45% of men who care reported caring for 1-14 hours per week compared to 41% of women (see figure 4 below).

³³ Eurocarers, "The Gender Dimension of Informal Care.Pdf" (Eurocarers, 2017), <http://eurocarers.org/userfiles/files/The%20gender%20dimension%20of%20informal%20care.pdf>.

Figure 4: Hours per week spent caring by gender (census 2016)

Source: Library & Research Service using census 2016 data. These values are a percentage of hours of care per week by male and female carers respectively.

The Irish Health Survey also highlights a greater proportion of women providing care and a greater proportion of people in middle age engaged in family care. The Irish Health Survey records ten per cent of the population as providing unpaid care and on average carers provide 44.7 hours per week. Not only are a greater proportion of the female population providing care compare to men (13% versus 8%) but they are also caring for a greater number of hours per week (48.7 hours per week versus 37.7 hours per week). Similar to the census data there is a distinct peak in the proportion of people providing care who are aged between 45 and 54. At 18% this is nearly double the average of the total population (10%).

According to the Irish Health Survey the age cohort providing the greatest number of hours of care are those over 65. Those aged between 65-74 reported caring for an average of 62.3 hours per week and those aged 75 and over reported caring for an average of 87.7 hours. This rise in hours spent caring is possibly because many of those in older age cohorts are likely caring for a partner of a similar age with whom they are living.

Who carers care for

When considering the demand for care it is useful to consider who Irish carers are caring for:

The Irish Health Survey 2015 observed that 10% of the population are providing care to someone with a chronic condition or an infirmity due to old age.³⁴ In 86% of these cases, the person being

³⁴ Central Statistics Office, "Irish Health Survey 2015."

cared for is a family member and the average number of hours spent providing care is 44.7 hours per week.

In 2009 the Quarterly National Household Survey (QNHS) carried a special segment on carers.³⁵ Though this data is nearly a decade old it is the most recent nationally representative data that delves deeper into carer and care recipient relationships. Bearing in mind that the QNHS captures a broader cohort of carers than the census the following are some of the key findings about caring relationships:

- Four in ten carers were the sole carer for the person they looked after.
- Half of all carers cared for someone in the same household.
- Just under half (47%) of all carers spent more than 15 hours per week providing care and 21% spent more than 57 hours per week.
- Four in ten carers look after a parent or parent-in-law.
- A third of carers looking after someone in the same household have been caring for 10 years or more.
- A third of carers are caring for someone who needs care due to old age.

The two most common relationships of carers to the person they were helping were intergenerational. Four out of out of ten carers are caring for a parent or parent-in-law (43%) and one in five carers are caring for a child with a disability (19%). Just over one in ten carers are caring for their spouse or partner and similar proportions are caring for other relatives (11%) or non relatives (10%).

The relationship of the carer to the person receiving help varies according to the age of the carer. Among carers aged 30-44, more than half (57%) were helping a parent or parent-in-law and 22% are caring for a child. Among carers aged 45-64 half were caring for a parent or parent-in-law and 10% are caring for their spouse or partner. Among those aged 65 and over 39% are caring for a spouse or partner.

Just over a third of carers are caring for someone who requires care due to old age and a further third are caring for someone with a physical disability only. One in ten carers are caring for someone with a mental disability only and 13% are caring for someone with both a physical and mental difficulty.

Carers living in a separate household to the person they were caring for are more likely to be caring for someone with difficulties due to old age (49%) than carers who lived in the same household as the person cared (19%).

Among carers living in the same household as the person cared for 37% are caring for someone who require help due to a physical disability, 16% due to a mental difficulty and 20% due to both physical and mental difficulties.

³⁵ Central Statistics Office, "Quarterly National Household Survey."

Impact on carers' health and well being.

The literature that looks at the impacts of caring on health and well-being is particularly concerned with the mental and physical burden of caring. It has been observed that highlighting burdens associated with caring without acknowledging potential benefits provides an incomplete picture and can “set up negative expectations, self-fulfilling prophecies and limit our conceptual treatment of caregiver adjustment and satisfaction”.³⁶

While caring intensively over a long period without support is known to negatively affect a carer's health, financial status and social integration some studies suggest that all or some of these impacts can be mitigated by effective recognition, services and policies, and that caring can have lasting benefits for the carer.³⁷ The latter may include: enhanced self-esteem and feelings of personal worth; strengthened ability to cope with grief and loss; and an enhanced sense of purpose and commitment.³⁸

This correlates with observations made by Care Alliance Ireland:

“Providing care can be both enriching and rewarding where expectations placed on Family Carers are reasonable and adequate supports are provided.”³⁹

However, for many carers the task may come at a significant cost – for instance loss of or reduced opportunities for employment and an increased risk of mental health problems (the OECD puts this at 20% greater than the general population).⁴⁰ Advocacy groups for carers highlight the physical, emotional, social and financial toll that caring can take.⁴¹ And indeed, the Department of Health has stated that more than one in four carers (27%) aged 50+ report a high level of stress or distress.⁴²

A number of Irish studies show that sample populations of carers struggle with psychological problems such as stress or depression more than the general population. Among a sample of spousal carers of people with dementia, anxiety and depression were common, with ‘37% of carers [reporting] clinically significant depressive symptoms, and a further 40% [reporting] levels of depressive symptoms that were not clinically significant’. Further: ‘About 35% reported anxiety symptoms indicating borderline (15%) or probable (20.6%) mood disorders’.⁴³

³⁶ Jensen, Ferrari, & Cavanaugh, 2004 cited in Mary Larkin, Melanie Henwood, and Alisoun Milne, “Carer-Related Research and Knowledge: Findings from a Scoping Review,” *Health & Social Care in the Community*, May 30, 2018, <https://doi.org/10.1111/hsc.12586>.

³⁷ Yeandle and Buckner, 2007; Gaugler and Kane, 2015 cited in Yeandle et al., “Care and Caring.”

³⁸ Kearns, 2015 cited in Yeandle et al.

³⁹ Care Alliance Ireland [Budget 2017 – Recognising and Respecting Family Carers in Ireland as Key Partners in Care \(2016\)](#)

⁴⁰ Organisation for Economic Co-operation and Development [Preventing Ageing Unequally](#), OECD Publishing, Paris (2017)

⁴¹ Family Carers Ireland [Budget 2017 – Achieving Fairness for Family Carers](#) (2016)

⁴² HSE and Department of Health [Positive Ageing 2016 – Indicators Report](#). (2015)

⁴³ Brennan, S. et al. [De-stress: A study to assess the health and wellbeing of spousal carers of people with dementia in Ireland](#) Dublin: Alzheimer Society of Ireland (2017)

In a 2016 study of 247 full-time carers of children with an intellectual disability, ‘two fifths of respondents scored above the threshold for poor psychological distress (40.8%), which is a much higher proportion than that found among the general population (12%)’.⁴⁴

In a large survey of stress and coping skills in carers of older people published in 2014 (2,311 respondents, ranging in age from 19 to 92), it was found that 44% were at risk of developing clinical depression.⁴⁵ The chronic stress associated with caregiving has been shown to have a negative impact on the physical system, in particular the immune system, making carers more vulnerable to infection⁴⁶ and parents of children with significant developmental difficulties showed poor antibody responses to pneumococcal vaccination.⁴⁷ This echoes the findings of a previous study of carers of people with dementia, which also showed elevated salivary cortisol levels indicating emotional distress, as well as a poor antibody response to influenza.⁴⁸

Presented here is a sample of some of the literature on the cost of caring to a carer’s health, an extensive paper would be required to cover the literature comprehensively.

Currently a large scale study is being carried out on carers’ health and wellbeing by the College of Psychiatrists of Ireland, Family Carers Ireland and U.C.D. which when finalised will provide nationally representative data on this important issue.

Income supports to family carers

Current policy approaches to supporting family carers in Ireland primarily consist of direct income supports.⁴⁹ For those eligible, this includes either a means tested carer’s allowance, or carer’s benefit which is a form of social insurance benefit (dependent on employment related eligibility conditions). A half rate carer’s allowance is also available for people in receipt of another social welfare entitlement.

Full time carers are also eligible to receive the Carer’s Support Grant, an annual payment to carers, from the Department of Social Protection (previously titled the Respite Care Grant), while married couples or civil partners where one spouse or civil partner works in the home caring for a dependent person can apply for a home carer’s tax credit. Underpinning this range of supports is

⁴⁴ Lafferty, A., O’Sullivan, D., O’Mahoney, P., Van Bavel, B. [Resilience in Family Carers of Adults with an Intellectual Disability](#) Dublin: National Disability Authority (2016)

⁴⁵ Lafferty, A., Fealy, G., Downes, C., Drennan, J. [Family Carers of Older People: Results of a National Survey of Stress, Conflict and Coping](#) Dublin: National Centre for the Protection of Older People/UCD (2014)

⁴⁶ Gallagher, S., Phillips, A.C., Evans, P., Der, G., Hunt, K., Carroll, D. ‘Caregiving is associated with low secretion rates of immunoglobulin A in saliva’ *Brain, Behavior, and Immunity* 22, 565–72 (2008)

⁴⁷ Gallagher, S., Phillips, A.C., Drayson, M., Carroll, D. ‘Parental caregivers of children with developmental disabilities mount a poor antibody response to pneumococcal vaccination’ *Brain, Behavior & Immunity* 23, 338–46 (2009)

⁴⁸ Vedhara, K., Cox, N., Wilcock, G., Perks, P., Hunt, M., Anderson, S., Lightman, S., Shanks, N. ‘Chronic stress in elderly carers of dementia patients and antibody response to influenza vaccination’ *The Lancet* 353.9153, 627–31 (1999)

⁴⁹ Hanley, Paul and Sheerin, Corina, “Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary.”

the [Carer's Leave Act, 2001](#), which entitles employees to unpaid leave to provide full-time care and attention for a dependant up to a maximum of 104 weeks.⁵⁰

Table 2: Overview of family carer supports

Carer's Allowance (max weekly rate aged under 66 caring for one person is €214)

- Means tested
- Habitual residency condition

Carer's Benefit (max weekly rate caring for one person is €215)

- Give up work to be a full-time carer
- Habitual residency condition
- Meet PRSI contribution conditions

Carers' Leave (entitlement to take between 13-104 weeks leave to take up caring role. The leave is unpaid but people who take carer's leave have their jobs kept open for the duration of the leave)

- Have worked for employer for continuous period of 12 months

Carer's Support Grant (€1,700 is paid once each year for each person being cared for. It is not taxable)

- Paid automatically to those in receipt of Carer's Allowance, Carer's Benefit or Domiciliary Care Allowance*
- Those not in receipt of above are eligible if
 - Caring for someone on full time basis
 - Caring for the person for at least 6 months (including first Thursday in June)
 - Living with person requiring care or in direct, quick contact with them

Criteria that apply to all above-named supports

- Caring for someone on a full-time basis
- That person requires full time care and attention
- Not working more than 15 hours per week

Source: L&RS table sourced from Citizen's Information website. This is a non-exhaustive list of family carer social welfare supports and eligibility criteria. * [Domiciliary Care Allowance](#) is a monthly payment for a child aged under 16 with a severe disability, who requires ongoing care and attention, substantially over and above the care and attention usually required by a child of the same age. It is not means tested.

This is not an exhaustive list of social welfare supports for family carers, a full list can be found on the Citizen's Information website.⁵¹ Described below is a selection of the larger supports which offer an insight into the current population of family carers.

The number of full-time Irish family carers in receipt of income support measures has increased dramatically in the recent years.

In 1998, a means-tested Respite Care Grant (now called the Carer Support Grant) was introduced. In 2005, the means test was removed so that all full-time family carers could receive this annual payment. The level of payment increased from €380 in 2000 to €1,700 in 2017. More than 100,000 full-time family carers now receive this annual payment.⁵²

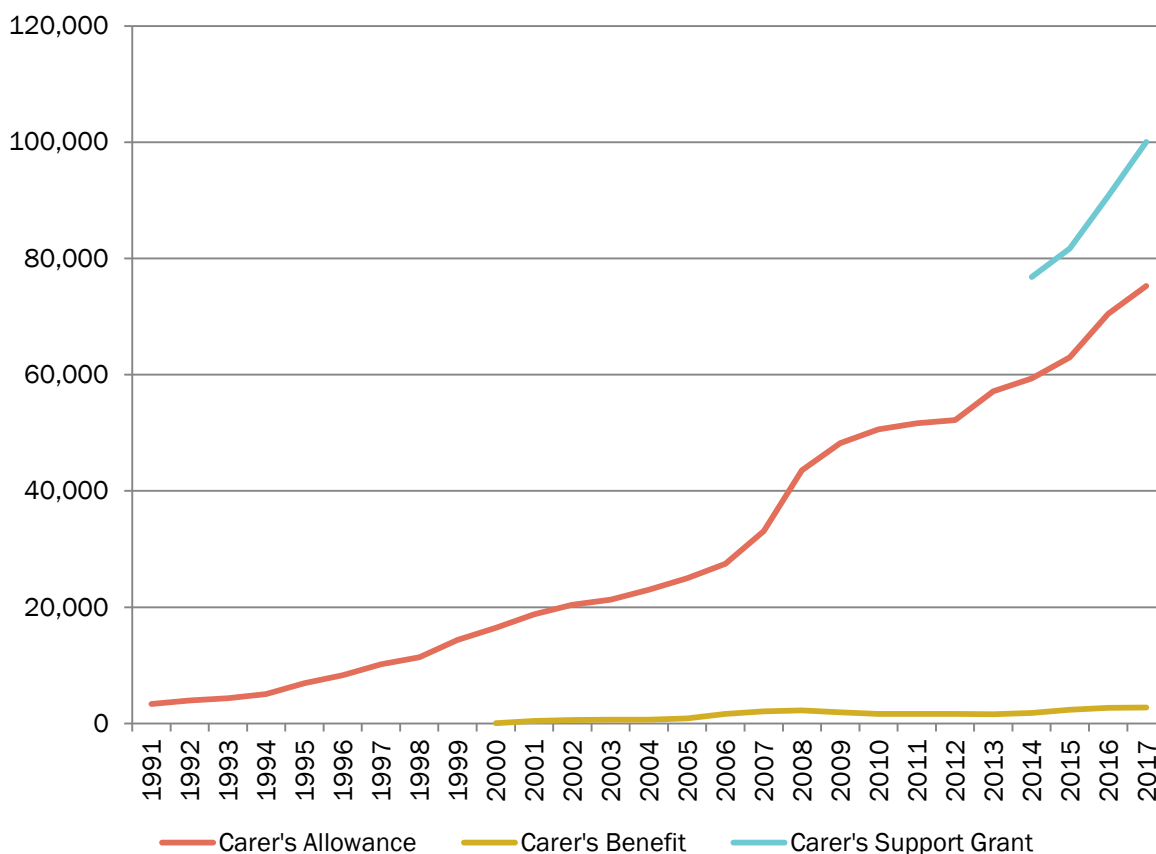
⁵⁰ http://www.citizensinformation.ie/en/employment/employment_rights_and_conditions/leave_and_holidays/carers_leave_from_employment.html

⁵¹ Citizensinformation.ie, "Carers," accessed February 5, 2019, http://www.citizensinformation.ie/en/social_welfare/social_welfare_payments/carers/.

⁵² Hughes, Zoey, "Trends in Family Caring in Ireland in 2017."

As the graph below demonstrates the numbers in receipt of Carer's Allowance has increased significantly. There were 16,478 people in receipt of Carer's Allowance in 2000 and 75,264 in receipt of the support in 2017, an increase of approximately 350%.

Figure 5: Recipients of income support measures



Source: L&RS graph sourced from information directly supplied to researcher by the Department of Employment Affairs and Social Protection. Data for the Carer Support Grant prior to 2013 is not displayed as payments prior to this were made from two computer systems and the data is incommensurable.

The dramatic rise in the number of people receiving Carer's Allowance is out of sync with the growth in the overall number of carers according to the censuses which has increased only modestly from 3.8% in 2002 to 4.1% in 2011, and remained at that level in the 2016 census.⁵³

Understanding the rise in Carer's Allowance recipients

Any metric of family carers increasing as dramatically as Carer's Allowance requires explanation. This is particularly the case when putting forward the possibility that the future supply of carers may not be adequate to meet future need.

It is likely that the dramatic growth in Carer Allowance recipients is due to a combination of changes to eligibility criteria, allowing more carers to avail of the support, and awareness raising initiatives, encouraging more people to see themselves as carers and to avail of income supports.

⁵³ Hughes, Zoey.

The introduction of half rate Carers Allowance by the Department of Social Welfare in 2007 allowed those receiving certain social welfare payments, who were caring full time, to keep their main social welfare payment and receive a half-rate Carer's Allowance as well.⁵⁴ By 2017, approximately 25,000 people were in receipt of this payment, with those aged 65+ and one-parent families the biggest beneficiaries. Heretofore, neither of these groups was eligible for the Carers Allowance.⁵⁵

Furthermore, the number of hours which a carer can work outside the home or engage in training or education and still be eligible for Carer's Allowance, Carer's Benefit or the Carers Support Grant was increased from 10 to 15 in June 2006.⁵⁶ The income disregard for Carer's Allowance has also been increased over time so that, a couple can have an income of €665 per week and still qualify for the payment as well as the associated household benefits and free travel.

There has long been a concern about the ability to reach isolated carers, to encourage them to self-identify so that they may avail of relevant supports. Not identifying oneself as a carer may serve as a barrier to accessing services and supports that they might need to support them in their caring role.⁵⁷ While unsubstantiated it is possible that the cuts to Respite Care Grant in Budget 2013 and the significant media attention which the cuts and carer's response and protest about said cuts garnered may have made more people aware of caring as a role and added to the numbers applying for supports like Carer's Allowance and the Respite Care Grant.

In advance of the 2011 and 2016 censuses, family carer organisations engaged with and received funding from the Central Statistics Office (CSO) to raise awareness and understanding of questions relating to caring.⁵⁸ The change in the proportion of people who identified as carers increased from 3.6% in 2006 to 4.1% in 2011 and remained at that level in 2016. The possibility has been suggested that the first campaign succeeded in raising carer identification and that the second simply maintained it at that level.⁵⁹ Another possibility is that these awareness raising campaigns had a positive knock-on effect in terms of raising awareness about carer supports prompting a greater proportion of carers to apply for carer support payments.

⁵⁴ "Minister's Speech at the Announcement of the Half Rate Carer's Allowance to Carers in Receipt of Other Social Welfare Payments," accessed January 7, 2019, http://www.welfare.ie/en/pressoffice/Pages/Ministers-Speech-At-the-announcement-of-the_-Half-rate-care.aspx.

⁵⁵ Hughes, Zoey, "Trends in Family Caring in Ireland in 2017."

⁵⁶ "Minister's Speech at the Announcement of the Half Rate Carer's Allowance to Carers in Receipt of Other Social Welfare Payments."

⁵⁷ Department of Health, "National Carers' Strategy."

⁵⁸ Submission to the Central Statistics Office on Questionnaire Content for Census 2021, Family Carers Ireland, <http://familycarers.ie/wp-content/uploads/2017/11/CSO-Census-2021.pdf>

⁵⁹ Hughes, Zoey, "Trends in Family Caring in Ireland in 2017."

Gap between supply and demand

Demand for care at home is likely to increase dramatically due to a rising ageing population, the shift away from institutional care for people with disabilities⁶⁰ and an increased emphasis on home-based care.

On the supply side the potential pool of available carers may be narrowing significantly because of demographic factors and labour force participation by women.

In this section we consider the data that points to a future gap between demand for and supply of family care in Ireland. We will see that:

- Ageing demographics clearly heighten the demand for family carers.
- The ESRI projects a rise in future demand for home care (and by proxy family care) of between 48% and 66%.⁶¹
- The future supply of family carers may be limited by demography including a decline of fertility rates, delayed average age of starting a family and increased labour force participation by women.
- Calculations of the value of family care to the State in fiscal terms return amounts ranging from €2.1 billion to €10 billion per annum.⁶² These high values underscore the dependency of the health system on family care and it's vulnerability to any future shortage in family carers.

Ageing demographics and demand for care

Ageing demographics heighten the demand for both formal and informal care services. Projected future demographics across Europe predict a pattern of population ageing that is likely to continue through to 2080.⁶³ While the total EU-28 population is projected to increase modestly during the period 2015 to 2080, the proportion of children is due to decrease slightly, the proportion of working age population is expected to decrease and the share of older people is projected to increase from 19.2% at the start of 2016 to 29.1% by 2080. The share of the very old – those aged 80 and over – is projected to increase from 5.4% in 2016 to 12.7% by 2080.⁶⁴

Across Europe while there were more than three persons of working-age for every elderly person in 2016, by 2080 this ratio is expected to be less than 2:1.

Dependency ratios are used to give a useful indication of the age structure of a population with young (0-14) and old (65+) shown as a percentage of the population of working age (15-64). In Ireland, the male population aged over 85 increased by 24.8 per cent to 23,062 from the preceding

⁶⁰ The shift away from institutional care for people with disabilities is beyond the scope of this analysis

⁶¹ Wren et al., *Projections of Demand for Healthcare in Ireland, 2015-2030*.

⁶² Hanley, Paul and Sheerin, Corina, "Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary"; Family Carers Ireland, "Family Carers Ireland's Submission to the Health Committee."

⁶³ "People in the EU - Population Projections - Statistics Explained," accessed November 14, 2018, https://ec.europa.eu/eurostat/statistics-explained/index.php/People_in_the_EU_-_population_projections#An_ageing_society.

⁶⁴ "People in the EU - Population Projections - Statistics Explained."

2011 census while the female population increased by 11.4 per cent to 44,493. During the same period the total dependency ratio rose from 45.8% in 2006 to 49.3% in 2011 to 52.7% in 2016. Older dependency, stood at 20.4 per cent for the State in 2016, compared to 17.4 in 2011.⁶⁵

In Ireland the older dependency ratio (the population aged 65 years and over expressed as a percentage of the population aged 15 - 64 years) was 20.3% in 2016. This is projected to increase steadily from 2016 onwards, rising by 3 - 4 percentage points every five years. By 2051 this ratio is expected to have doubled, or nearly doubled, with values ranging from 40.3% to 47.6% under different prediction scenarios.⁶⁶

Due to the increasing ageing population the numbers of people with dementia is set to dramatically increase in the coming years and this will have consequent implications for care provision, care burden and public expenditure.⁶⁷ There is a growing need for family carers to help support older people in the community, particularly when that person has dementia.⁶⁸

Projected future demand for home care

According to the ESRI demand for home help hours is projected to increase from 2015 to 2030 by almost 38 per cent with demands for Home Care Packages to increase at the slightly higher rate of 44 per cent.⁶⁹ These figures rise to 48.4 per cent and 65.9 per cent respectively when existing unmet demand is incorporated into the modelling. The ESRI note that these projected increases are significant and the largest projected increases across the health system as a whole. The ESRI acknowledge that while family care is the largest source of home care, it was beyond the scope of their analysis, though they intend to incorporate it in future modelling.

In the next 15 years the Department of Health estimates that there will be up to a 70% increase in demand for home care, a 46% increase in demand for primary care and a 39% increase in the need for long term residential care.⁷⁰

It seems reasonable, in the absence currently of modelled projections, to use projected demand for home help hours and Home Care Packages as a proxy for future demand for family care. Given that these are expected to rise at a significantly high rate then future demand for family care may be at a similarly high level.

⁶⁵ "Average Age and Dependency - CSO - Central Statistics Office," accessed November 14, 2018, <https://www.cso.ie/en/releasesandpublications/ep/p-cp3oy/cp3/aad/>.

⁶⁶ Central Statistics Office, "Population and Labour Force Projections 2017 - 2051," accessed January 24, 2019, <https://www.cso.ie/en/releasesandpublications/ep/p-plfp/populationandlabourforceprojections2017-2051/populationprojectionsresults/>.

⁶⁷ Cahill S., O'Shea E. & Pierce M. (2012) Creating excellence in Dementia care: A research review for Ireland's National Dementia Strategy. DSID's Living with Dementia Research Programme, School of Social Work and Social Policy, Trinity College Dublin & the Irish Centre for Social Gerontology, NUI Galway, Dublin.

⁶⁸ Catherine Quinn et al., "Negotiating the Balance: The Triadic Relationship between Spousal Caregivers, People with Dementia and Admiral Nurses," *Dementia* 12, no. 5 (2013): 588-605.

⁶⁹ Wren et al., *Projections of Demand for Healthcare in Ireland, 2015-2030*.

⁷⁰ The Department of Health, "Health Service Capacity Review 2018," 2018, <https://health.gov.ie/wp-content/uploads/2018/01/Health-Service-Capacity-Review-2018-Executive-Report.pdf>.

Future supply of family carers

The potential pool of available carers may be narrowing significantly because of demographic factors relating to an ageing population, the decline in fertility rates, and labour force participation by women. In addition, the intensification of work means that people are struggling to find a work/life balance, particularly where they have children to care for.^{71,72}

As the educational attainment and labour force participation of women has increased, so too the average age of starting a family has extended. The average age of mothers giving birth increased from 30.3 years in 2001 to 32.8 years in 2018. In census 2016 65% of first time mothers were aged between 30 and 39. This has the effect of creating the “sandwich generation” where women are raising a family and performing an additional care role simultaneously.⁷³ Hanley and Sheerin’s assessment is that such a model is not sustainable.⁷⁴

Levine and Halper draw out some of the potential implications of changing family structure on the makeup of future populations of family carers:⁷⁵

- A reduction in family size may reduce the number of children available in the future to be family carers of older parents.
- An increase in the number of couples with no children at all will also impact the future family caring landscape as these households will have no available adult children to draw on.
- A decrease in fertility may also reduce the opportunity for certain roles such as sibling carer.
- Conversely, increased male longevity, getting closer to that of women, may increase the availability of spouses as carers.^{76,77}
- Increased longevity may increase the duration spent in certain caring roles, such as carer for an adult child with a disability.

⁷¹ Browne, “Responding to the Support & Care Needs of Our Older Population.”

⁷² Rodrigues, *The Indirect Costs of Long-Term Care*.

⁷³ McGarrigle, C. & Kenny, R. A., ‘Profile of the Sandwich Generation and Intergenerational Transfers in Ireland’, TILDA (2013)

⁷⁴ Hanley, Paul and Sheerin, Corina, “Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary.”

⁷⁵ Carol Levine et al., “Bridging Troubled Waters: Family Caregivers, Transitions, and Long-Term Care,” *Health Affairs* 29, no. 1 (2010): 116–124.

⁷⁶ Linda Pickard, “Informal Care for Older People Provided by Their Adult Children: Projections of Supply and Demand to 2041,” 2008.

⁷⁷ Increases in male mortality are evident in recent Irish Census data. In 2011 there were 767 men aged 70 and over for every 1,000 women in the same age band. In 2016 this has narrowed to 818 per 1,000.

Calculating the value of family care

Traditional measures of economic output emphasise the importance of paid work over unpaid work. Activities, including family care, lacking explicit valuations are less visible and so can lead to inefficient decision making.⁷⁸ A number of academics and commentators abroad and in Ireland have attempted to calculate family carers' contribution to the State in fiscal terms. Whilst different approaches produce quite different values for the contribution of family care to the State a common finding is that this contribution is extremely large and is relatively larger than other significant healthcare expenditure like the cost of all professional healthcare staff.

The number of carers providing family care is a multiple of those providing formal care in Ireland⁷⁹ and across Europe.⁸⁰ Given this when a monetary value is put on family carer work it tends to be very large and serves to underscore health system's dependency on unpaid care.

Using 2011 Irish census data and modelling to measure the economic contribution of family care in Ireland Hanley and Sheerin have underlined the considerable value of this care, their estimations range between €2.1 and €5.5 billion, depending on valuation approach.⁸¹ The application of the most prevalent model in the international literature to valuing family care yielded a value of €5.3 billion per annum. The authors describe this figure as conservative given that it does not include the hours of care of those carers who failed to state an informal care time estimate in the census.

The estimated value of informal care in Ireland (€5.3 billion: OCABC) far exceeded the expenditure by Government on home-based long-term care (€1.34 billion: 2013) or long-term residential facilities (€2.69 billion: 2013) in Ireland (CSO, 2015), and equated to 3.8 per cent of Irish GNP in 2011.⁸²

Using a more rudimentary approach Family Carers Ireland estimates that family carers provide an average of 16 million hours of unpaid care each week "saving the State some €10 billion each year in avoided health and social care costs".⁸³ This figure is based on the Irish Health Survey 2015 finding that 10 percent of the population over 16 years are carers providing an average of 45 hours of care each week. Family Carers Ireland extrapolates this figure to give a national population of carers equalling 355,000. They apply a replacement cost of €12 per hour to arrive at a figure of €10 billion per year.

It is clear that Irish healthcare structures, like those around the world, are built around unpaid care. The high valuations placed on family care in Ireland are replicated by estimations of the contribution of carers in other jurisdictions.

⁷⁸ Hanley, Paul and Sheerin, Corina, "Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary."

⁷⁹ Brenda Gannon and Bérengère Davin, "Use of Formal and Informal Care Services among Older People in Ireland and France," *The European Journal of Health Economics* 11, no. 5 (2010): 499–511.

⁸⁰ Judy Triantafyllou et al., "Informal Care in the Long-Term Care System European Overview Paper," 2010.

⁸¹ Hanley, Paul and Sheerin, Corina, "Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary."

⁸² Hanley, Paul and Sheerin, Corina.

⁸³ <http://familycarers.ie/wp-content/uploads/2017/10/Family-Carers-Ireland-Submission-to-the-Citizens-Assembly.pdf>

A 2015 report estimated the economic value of the contribution made by carers in the UK at £132 billion per year.⁸⁴ This figure is close to the total annual cost of health spending in the UK which was £134.1 billion in the year 2014-2015. The economic value of family care in the UK nearly doubled from its value in 2001 (£68 billion) to 2015 (£312 billion). This was due to two main reasons. Firstly care needs grew significantly during that period due to an increase in the number of people aged 85 and older and secondly there was a significant increase in the number of people living with a limiting life-long illness.

An analysis conducted by Carers Australia and Deloitte Access Economics estimated the replacement cost of family care in Australia at \$60.3 billion. In 2015 Australian carers are estimated to have contributed 1.9 billion hours of care, equivalent to each carer providing 673 hours per year or 13 hours per week. The calculation took the position that if all hours of informal care provided in 2015 were replaced with services purchased from formal care providers, the replacement value of informal care would be \$60.3 billion (equivalent to 3.8% of Australian gross domestic product and 60% of the health and social work industry).⁸⁵

An approximation of the value of family care work in Spain in 2008 yielded an estimation of total hours of family care at 4,193 million and the monetary value ranged from €23,064 to €50,158 million depending on the method used. The value of informal care was estimated at figures equivalent to 1.73–4.90 % of the gross domestic product for that year.⁸⁶

In the United States the national economic value of family caring was estimated to be \$196 billion in 1997—higher than national spending for formal home health care (\$32 billion) and nursing home care (\$83 billion) combined.⁸⁷

Hanley and Sheerin on modelling the value of family care to the Irish health system concluded that *“regardless of approach, the estimated value of informal care is considerable, and given recent demographics trends, the demand for this resource is anticipated to increase further”*.⁸⁸

⁸⁴ Lisa Buckner and Sue Yeandle, “Valuing Carers 2015: The Rising Value of Carers’ Support,” *Carers UK*, 2015.

⁸⁵ Carers Australia and Deloitte Access Economics, “The Economic Value of Informal Care in Australia in 2015,” June 2015, <https://www.carersnsw.org.au/Assets/Files/Access%20Economics%20Report.pdf>.

⁸⁶ Juan Oliva-Moreno, Luz María Peña-Longobardo, and Cristina Vilaplana-Prieto, “An Estimation of the Value of Informal Care Provided to Dependent People in Spain,” *Applied Health Economics and Health Policy* 13, no. 2 (April 1, 2015): 223–31, <https://doi.org/10.1007/s40258-015-0161-x>.

⁸⁷ Peter S. Arno, Carol Levine, and Margaret M. Memmott, “The Economic Value Of Informal Caregiving: President Clinton’s Proposal to Provide Relief to Family Caregivers Opens a Long-Overdue Discussion of This ‘Invisible’ Health Care Sector.,” *Health Affairs* 18, no. 2 (March 1999): 182–88, <https://doi.org/10.1377/hlthaff.18.2.182>.

⁸⁸ Hanley, Paul and Sheerin, Corina, “Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary.”

Key policy considerations

There are a range of policy factors at play in relation to demand for and supply of family care in Ireland.

- The nature of care work is gendered, women may experience caring differently to men and caring has traditionally been considered 'women's work'.
- The aim of numerous Irish health policy documents is to shift a greater proportion of care delivery to the home and community which to succeed will require a larger proportion of the population to take on caring roles. National policy relating to supporting family carers (the National Carers Strategy) while ambitious has been constrained through lack of dedicated funding. The stated goals of all of these policies are challenged by gaps in home care and respite care provision which have negative consequences for the family care role.
- Disability policy too seems to be in tension with carer policy potentially to the detriment of implementing both.
- Most family carers combine a caring role with paid employment and this is likely to be increasingly a feature of our workplace. The challenges and benefits to juggling both roles are considered.

Gender and the care gap

It is factors affecting women that are most critical when considering the future supply of family carers. This is because most care in Ireland and worldwide is carried out by women^{89,90}. Women have traditionally been the principal carers in Ireland, and care was often stereotypically seen as part of a 'woman's role' whereas men demonstrated their care and concern by providing for the family financially.⁹¹ While women have suffered due an understanding of care as women's responsibility and work, this situation has also disadvantaged men in relation to participate in family life.⁹²

Gendered nature of care work

The evidence suggests that women tend to experience caring in a different way to men. Women report higher levels of subjective burden, are under greater societal pressure to give up paid work to care and are more reluctant to ask for an 'assessment of need' or support from services than their male counterparts.⁹³

Furthermore, women tend to provide more demanding and intensive forms of daily care, with a focus on personal care and assistance with medical care. Men's contribution, on the other hand, is much more likely to be concentrated in care management or household maintenance, shopping or

⁸⁹ Eurocarers, "The Gender Dimension of Informal Care.Pdf."

⁹⁰ Marika Morris, *Gender-Sensitive Home and Community Care and Caregiving Research: A Synthesis Paper* (Centres of Excellence for Women's Health, 2001).

⁹¹ The Women's Health Council, "Caregiving a Position Paper" (The Women's Health Council, December 2005).

⁹² The Women's Health Council.

⁹³ Alisoun Milne and Jennie Williams, *Women at the Crossroads: A Literature Review of the Mental Health Risks Facing Women in Mid-Life* (Mental Health Foundation, 2003).

transportation. This means that women are more likely to provide the care that is daily and inflexible, while men provide care that can be more easily planned and organised around paid work.⁹⁴

Women also often experience a “double burden” whereby in general they have increased their labour force participation without trading off household and caring duties bestowed by social norms.⁹⁵

Caring as ‘women’s work’

A consideration of the development of Irish social policy relating to caring is revealing. The introduction of a Prescribed Relative Allowance in 1968 marked the first recognition of informal caring in the Irish social security system. The structure of the scheme reflected the assumption that caring was a female role. The scheme was very restrictive in terms of the female relative who qualified (the care was to be provided by a ‘prescribed female relative’) as the allowance was paid not to the carer but as an increase in pension payments to pensioners who required full-time care in their homes. In addition, the carer was not allowed to participate in paid employment.⁹⁶

It has been argued that the inequitable division of caring responsibilities within the family is reflected within health policy where ‘care in the community’ it is suggested often stands for ‘care by the community’ which mostly refers to women.⁹⁷ The Women’s Health Council put forward the position that the means-tested nature of Carer’s Allowance entrenched gender roles as the nature of the support assumes that there will be a head of household whose income will be sufficient to support other family members.^{98,99}

Care and the constitution

Many commentators have observed that the Constitution enshrines a patriarchal vision of home and care work. [Article 41.2.1° of the Constitution of Ireland](#) states that

“In particular, the State recognises that by her life within the home, woman gives to the State a support without which the common good cannot be achieved.”

The Programme for a Partnership Government commits to holding a referendum on Article 41.2.1. There has been near consensus, amongst the various bodies and reports, that the Article should be amended, rather than repealed, so that it would play a symbolic role in valuing care work.

⁹⁴ Eurocarers, “The Gender Dimension of Informal Care.Pdf.”

⁹⁵ Hanley, Paul and Sheerin, Corina, “Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary.”

⁹⁶ Mairéad Considine and Fiona Dukelow, *Irish Social Policy: A Critical Introduction* (Dublin: Gill & Macmillan, 2009).

⁹⁷ The Women’s Health Council, “Caregiving a Position Paper.”

⁹⁸ The Women’s Health Council was established in 1997 primarily to advise the Minister for Health and Children on women’s health and well-being issues. In 2009 it was dissolved and subsumed into the Department of Health and Children.

⁹⁹ The Women’s Health Council, “Caregiving a Position Paper.”

The final chapter in this *Spotlight* looks at the consideration currently being given to repealing or amending Article 41.2.1 and considers the implications this may have for family carers.

Home care policy pressure on carers

The stated aim of Irish Government health care policy is to prioritise care in the home or in the community to as large an extent as possible.¹⁰⁰ The 2012 Department of Health's Primary Care Strategy underlined a shift away from hospital to community-based care.¹⁰¹ Successive strategies have further emphasised this shift (e.g. *National Carers Strategy*; *Future Health: A Strategic Framework for Reform of the Health Service 2012-2015*, *National Positive Ageing Strategy* and *National Dementia Strategy*). More recently SláinteCare is the first Irish health and social care government policy to receive cross-party commitment guaranteeing a 10 year implementation plan. The report orientates the health system towards universal access and points to the development of a new model of coordinated health and social care shifting the focus of service delivery from acute to community.

In line with this the Department of Health is undertaking a consultation on the Government's proposal that home care be placed on a statutory footing. This is considered in greater detail in the final chapter.

The proposed benefits of a shift towards home and community care have included cost reducing ones such as minimising the cost of more expensive alternative care (acute and residential) as well as according with care recipients wishes generally to receive care at home and in their community for as long as possible.¹⁰²

The overall state funding allocated for home care in 2018 was €408m (an increase from €376 in 2017). In comparison the Nursing Home Support Scheme budget for 2017 was €962 (€22m more than 2017).¹⁰³ Academics Virpi Timonen and Martha Doyle argue that funding policy decisions have delivered a mixed message outwardly encouraging home-based care while simultaneously undermining its value from a funding perspective.¹⁰⁴ A recent analysis of home care funding by Care Alliance Ireland echoes this assessment.¹⁰⁵ Despite the challenges of an absence of robust publically available data, Care Alliance Ireland claim, through information obtained through FOI requests, that there has been a reduction in the intensity of home care per client and an overall marked decrease in the absolute level of home care provision over the past 15 years. Where

¹⁰⁰ Hanley, Paul and Sheerin, Corina, "Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary."

¹⁰¹ Department of Health, "Future Health – A Strategic Framework for Reform of the Health Service 2012 – 2015," Strategy, October 6, 2002, <https://health.gov.ie/blog/publications/future-health-a-strategic-framework-for-reform-of-the-health-service-2012-2015/>.

¹⁰² Hanley, Paul and Sheerin, Corina, "Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary."

¹⁰³ The Department of Health, "Health Service Capacity Review 2018."

¹⁰⁴ Timonen, Virpi and Doyle, Martha, "From the Workhouse to the Home: Evolution of Care Policy for Older People in Ireland," *International Journal of Sociology and Social Policy* 28 (April 25, 2008): 76–89, <https://doi.org/10.1108/01443330810862151>.

¹⁰⁵ Care Alliance Ireland, "Public Provision of Home Care in Ireland - Update," October 2018, <http://www.carealliance.ie/userfiles/file/Briefing%20Paper%202%20Web.pdf>.

constrained public finances limit expenditure on formal home care it places greater pressure on family carers.¹⁰⁶

Extract from the Report on the Forum on Long-Term Care for Older People¹⁰⁷

Policy continues to be based on the premise that the family has a responsibility to provide for the care needs of their older relatives. However, the ability of families to provide the levels of care required is undermined by the fact that services for people being cared for in the community (older people and people with disabilities) – continue to be characterised by:

- Fragmentation
- Low levels of provision
- Inadequate needs assessment
- Entitlement which is frequently arbitrary
- Geographical inconsistencies
- Poor availability of good-quality community respite care services
- Prioritisation of funding for nursing home care under the NHSS. There is a scarcity of imaginative, diversified, dependency-graded respite care (residential and day care). Clearly some family carers of older persons have needs over and above the normal needs of carers which need to be identified specifically and addressed.
- Carers who are older themselves
- Carers living in more isolated rural areas
- Carers of people with dementia
- People who find themselves in the caring role ‘overnight’ as a result of stroke or the sudden onset of illness

Authors of a 2016 report on meeting older people’s preference for care argue that there is a tension between the goal of providing as much care at home as possible with the heavy reliance on the Nursing Home Support Scheme.¹⁰⁸

The Nursing Homes Support Scheme, also known as the “Fair Deal”, provides financial support to people who need long-term nursing home care. The scheme is operated by the Health Service Executive (HSE). Under this scheme, the older person makes a contribution towards the cost of their care and the State pays the balance. The scheme covers approved private nursing homes, voluntary nursing homes and public nursing homes.

The Nursing Home Support Scheme is available on a statutory basis but there is no statutory entitlement to home care.¹⁰⁹ The Department of Health’s current consultation on statutory entitlement to home care is also a recognition of this as a vital issue.¹¹⁰

¹⁰⁶ Hanley, Paul and Sheerin, Corina, “Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary.”

¹⁰⁷ Browne, “Responding to the Support & Care Needs of Our Older Population.”

¹⁰⁸ Donnelly, Sarah et al., “I’d Prefer to Stay at Home but I Don’t Have a Choice” (University College Dublin, March 6, 2016), https://researchrepository.ucd.ie/bitstream/10197/7670/1/IASW.AGE_ACTION.ASI.UCD_Research_Report_on_Care_of_Older_People_2016.pdf.

¹⁰⁹ Browne, “Responding to the Support & Care Needs of Our Older Population.”

Dedicated family carer policy

The National Carers Strategy marked a significant milestone in the recognition of the contribution made by family carers in Ireland.¹¹¹ However, the Strategy's ambition was limited by the constraints on public spending at the time. Minister Kathleen Lynch in her forward to the Strategy acknowledged that new services could not be delivered in the short term and that most of the actions were selected on the grounds of being 'cost neutral'.¹¹²

Government departments produce annual reports on the implementation of strategy objectives and each year family carer organisations give their assessment of this progress. The most recent Family Carer Scorecard reviewing 2017 gives an insight into the highs and lows relating to the strategy as perceived by carers.

Carers' assessment of the implementation of the National Carers Strategy in 2017¹¹³

Highs

- Allocation of €500,000 Dormant Accounts funding for information and training supports for carers.
- Commitment to establish a statutory home care scheme and the launch of a public consultation on home care services.
- Announcement of an additional €10m in funding towards the enhancement of respite supports for people with disabilities, €5m of which will go towards an additional respite houses in each CHO¹¹⁴; €3m for additional respite houses in the greater Dublin areas; and €2m for alternative models of respite.
- Carers in receipt of Carer's Allowance and Carer's Benefit to receive a GP Visit Card.
- Medical Card for all children in receipt of Domiciliary Care Allowance.
- Allocation of funding towards the implementation of a waste collection allowance for households where incontinence care is provided.
- Completion of Ireland's first Carer Needs Assessment developed in collaboration with the HSE, InterRAI, Family Carers Ireland, Care Alliance Ireland and the Carer Reference Group.
- Establishment of the Office of the Decision Support Service and the appointment of a Director of Decision Support to oversee the implementation of the [Assisted Decision Making \(Capacity\) Act 2015](#).
- Extension in the payment of Carer's Allowance from 6 to 12 weeks when the caring role ends due to admission to long term care.
- Publication of Census 2016 Profile 9 on Health, Disability and Carers.

¹¹⁰ The Institute of Public Health in Ireland, "Improving Home Care Services in Ireland: An Overview of the Findings of the Department of Health's Public Consultation" (Dublin: The Institute of Public Health in Ireland, 2018), <https://health.gov.ie/wp-content/uploads/2018/06/Homecare-Consultation-Report.pdf>.

¹¹¹ Family Carers Ireland, "Submission to Citizens Assembly on How We Best Respond to the Challenges and Opportunities of an Ageing Population."

¹¹² Department of Health, "National Carers' Strategy."

¹¹³ Family Carers Ireland, "National Carers' Strategy Scorecard 2017" (Family Carers Ireland, December 2018).

¹¹⁴ HSE services are divided into 9 Community Healthcare Organisations (CHOs). They include the broad range of services that are provided outside of the acute hospital system and includes Primary Care, Social Care, Mental Health and Health & Wellbeing Services.

Lows

- Access to respite remains problematic and is often dependent on the nature of the person's condition and where in the country they live, rather than on need. While respite is consistently identified as a key intervention to support the health and well-being of carers and is critical to the sustainability of caregiving efforts, funding cuts, staff shortages, bed closures and the transfer of respite beds to transitional care beds or long stay beds have combined to reduce respite availability.
- Continued underfunding of home care and the postcode-lottery experienced by families trying to access supports.
- Reliance by carer organisations on short-term funding and annual grants such as Dormant Accounts funding which prevents long-term planning and causes uncertainty in service delivery.
- Practice of reducing home care supports where a family member is in receipt of Carer's Allowance.
- Findings from the National Patient Experiences Survey undertaken in May 2017 showed ongoing issues with hospital discharges, including poor discharge planning and inadequate consultation with family members.
- The 'trolley crisis' continued and the total number of public hospital patients on some form of a waiting list surpassed the 600,000 barrier.
- Failure to replace the Mobility Allowance and the Motorised Transport Grant withdrawn in 2013 with the long awaited 'Transport Support Scheme'.
- An increasing number of carers and people with disabilities on the social housing waiting list and at risk of homelessness due to a shortage of accessible houses.

While recent action, like the legislation to allocate a General Practice Visit Card to all carers in receipt of Carer's Allowance and Carer's Benefit speaks to an understanding of the need to support carers in their own right other more controversial practice relating to carer resource allocation is at odds with this. Carers' organisations state that the practice of rationing home care services is 'common practice' where a family member is in receipt of Carer's Allowance.

*"The practice of rationing home care hours when a family member receives Carer's Allowance is common practice. In fact, the question of whether someone in the family receives Carer's Allowance is prominent on most home care assessment forms and PHNs [Public Health Nurses] from across the country admit that the presence of a family carer is a significant factor in deciding whether someone is considered a priority for home care or how many hours they should be allocated."*¹¹⁵

Similarly, a study exploring Irish social workers experiences also found that "where family are available, people are less likely to get a service".¹¹⁶

Carers' organisations, while lamenting the rationing of home care services where a relative is receiving Carer's Allowance, suggest that such practice may serve to nudge people to shun Carer's Allowance in favour of Jobseeker's Allowance. The trade-off of €16 per week in the

¹¹⁵ Family Carers Ireland, "Submission to Home Care Consultation," accessed February 5, 2019, <https://familycarers.ie/wp-content/uploads/2017/10/Family-Carers-Ireland-Submission-to-the-DoH-on-Homecare.docx-FINAL.pdf>.

¹¹⁶ Donnelly et al, 'I'd prefer to stay at home but I don't have a choice': Meeting Older People's Preference for Care: Policy, but what about practice? University College Dublin. School of Social Policy, Social Work and Social Justice, page 21.

difference between the two supports being trumped by the fear of being denied much-needed home care support. In addition to undermining an understanding that Carer's Allowance is an income support rather than a payment for services, this practice seems to indicate a view in certain segments of the health service of carer's needs as marginal.

Disability and carer policy

Another challenge for policy relating to family carers is the tension between it and disability policy. The term 'carer' itself can be problematic in the sphere of disability policy. It is seen as paternalistic, not reflective of the interdependent relationship between carer and care recipient and not in keeping with the dominant social model of disability.¹¹⁷ A stark difference in the representation and recognition of caring roles has been observed through one exercise in comparing language use in Irish national policy relating to carers and people with disabilities.¹¹⁸

"Whilst the National Carers Strategy (Department of Health, 2012) is explicit in seeing a role for family carers as partners in care involved in the process of support to the greatest extent possible, the National Disability Strategy Implementation Plan (National Disability Strategy Implementation Group, 2013) does not use the words 'family', 'carer', or 'caregiver' at all. In contrast, the word 'support' or its derivatives (supports and supporter) are used 74 times".

Hughes explains this lack of articulation of the family and caring roles as a 'casualty' of a welcome move away from a medical model of disability towards social model which emphasises people with disabilities' capabilities and potential for contribution to society.¹¹⁹ However, she asserts that the presentation of caring roles within the National Disability Strategy Implementation Plan (NDSIP) does not take into account people with disabilities who require significant support from family members and trained medical staff on a daily basis.

"This overreliance on the social model of disability, without acknowledgement of the high medical and support needs that some individuals have, risks people with these higher support needs and their families being increasingly left out of the dominant narrative around self advocacy and independent living".

The National Carers Strategy advocates greater involvement by families in the care and support of their loved ones whereas the actions in the NDSIP ostensibly push in the opposite direction.¹²⁰

On the other hand, Hughes calls for carers and carer support organisations to become more comfortable with and supportive of the rights of people with disabilities to make decisions without recourse to family members.

¹¹⁷ Hughes, Zoey, "Disability and Family Carer Policy - Challenges and Responses," Discussion Paper, Discussion Paper 6 (Care Alliance Ireland, January 4, 2017), <https://www.carealliance.ie/userfiles/file/Discussion%20Paper%206%20Disability%20and%20Family%20Carer%20Policy.pdf>.

¹¹⁸ Hughes, Zoey.

¹¹⁹ Hughes, Zoey.

¹²⁰ Hughes, Zoey.

This chimes with the results of a review of relevant research in the UK which has noted calls by scholars for the expectations and aspirations of carer-related policy and legislation to be seen in the wider context of social care reform and the introduction of the personalisation agenda, with themes of choice, control and empowerment frequently referenced.¹²¹ Both the UK and Australian government have been criticised for conflating the needs and opinions of carers and the people they support into a single (implicitly harmonious) unit.^{122,123} Australian scholars argue there are at times ‘conflicting agendas’, and that nursing staff experience particular conflict when trying to balance the desire of carers to be fully involved and given appropriate information, with the preferences of the person needing care “to whom they owe a primary duty of care.”¹²⁴

“the tendency of Australian Government policy to present consumers and carers as a collective with an apparent assumption that these needs can be met by similar initiatives” (P.136)

A 2017 scoping review of carer-related research concludes that the tensions and contradictions between the interests of carers and those they support, and between the respective carers’ and disability political movements, remain unresolved.¹²⁵

On a positive note the future implementation of the [Assisted Decision Making \(Capacity\) Act 2015](#) and the introduction of Carer Needs Assessments considered in the chapter Catalysts for Change may provide a useful framework for a more harmonious resolution of some of these issues.

Carers and employment

The majority of Irish carers combine a care role with paid employment. In census 2016, 54.6% (n=98,491) of carers over the age of 15 were participating in the labour force.¹²⁶ This rate declines with increasing hours of care provided. For example carers reporting 1 to 14 hours of unpaid care per week had a 71 per cent labour force participation rate compared to 44.6% for those reporting 43-84 hours of unpaid care per week. An influencing factor here may be the structure of social welfare supports which preclude those working 15 hours or more per week from availing of Carer’s Allowance or Carer’s Benefit.

Combining work and care is likely to increasingly common. It is especially likely that older workers, as mandatory retirement ages rise or full retirement is put off for financial reasons, will end up having to balance work with caring obligations.¹²⁷

¹²¹ Larkin, Henwood, and Milne, “Carer-Related Research and Knowledge.”

¹²² Val Goodwin and Brenda Happell, “Conflicting Agendas between Consumers and Carers: The Perspectives of Carers and Nurses,” *International Journal of Mental Health Nursing* 15, no. 2 (2006): 135–143.

¹²³ Hilary Arksey and Caroline Glendinning, “Choice in the Context of Informal Care-Giving,” *Health & Social Care in the Community* 15, no. 2 (2007): 165–175.

¹²⁴ Goodwin and Happell, “Conflicting Agendas between Consumers and Carers.”

¹²⁵ Larkin, Henwood, and Milne, “Carer-Related Research and Knowledge.”

¹²⁶ Central Statistics Office, “Census of Population 2016 – Profile 9 Health, Disability and Carers.”

¹²⁷ Jean-Marie Jungblut, “Working and Caring: Reconciliation Measures in Times of Demographic Change” (Eurofound, October 22, 2015), <https://www.eurofound.europa.eu/publications/report/2015/working-conditions-social-policies/working-and-caring-reconciliation-measures-in-times-of-demographic-change>.

Here we consider state policies related to employment and care. First we consider mechanisms that allow carers to take leave from paid employment to perform a caring role and then we consider the situation of carers who are trying to combine a caring role and employment.

Leaving employment to care

Ireland has legislation aimed at supporting carers who leave the work place to take up a caring role. Carer's Benefit is a short-term payment paid for up to 24 months to people who give up employment to care on a full-time basis for someone who requires full-time care and attention. As of 29 March 2019 the maximum weekly rate for Carer's Benefit is €215.00. After one year's service, employees may take unpaid Carer's Leave for between 13 and 104 weeks to provide full-time care for someone who needs it.

Carer's Leave and Carer's Benefit when compared with supports in other European jurisdictions are relatively progressive in their intent and generous in their provisions.¹²⁸ However, take-up of the leave appears quite moderate, even low – although this would be in line with European trends.¹²⁹

Some 2,762 carers received Carer's Benefit in 2017; this represents 2.8% of the total number of family carers in employment which was 98,491 according to census 2016. Even when considering that not every caring situation would require a carer to leave paid employment entirely for a period of time this take up rate seems low.

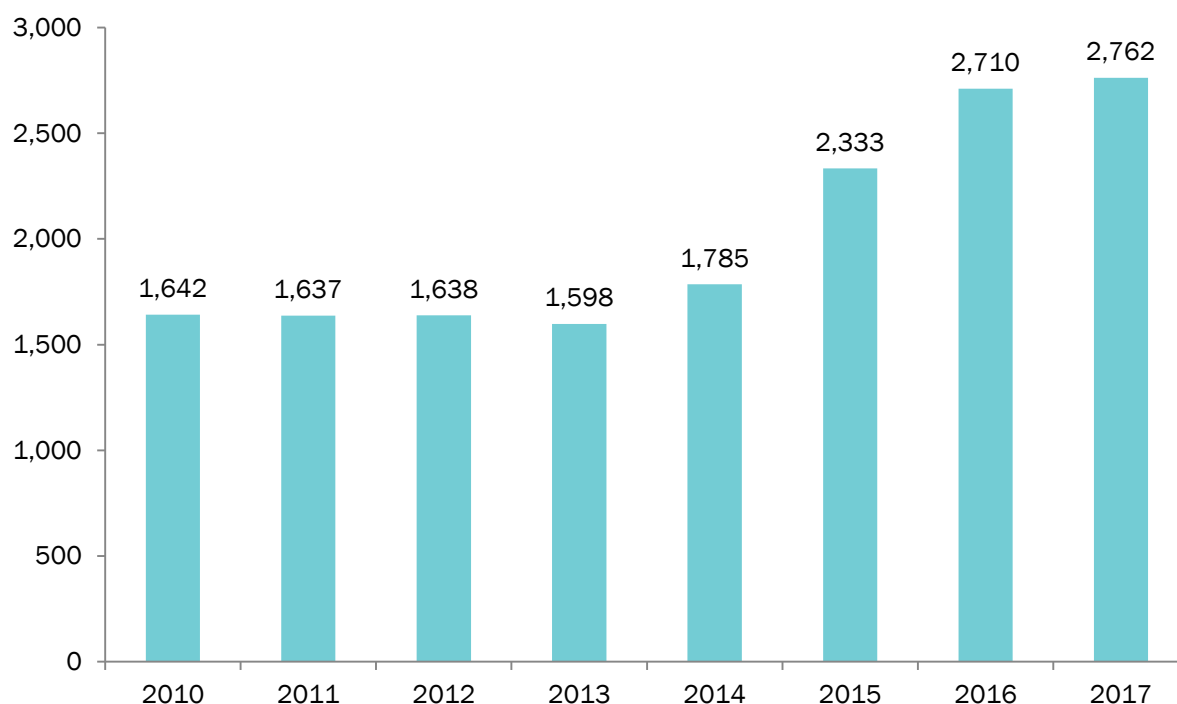
There is a knowledge and research gap relating to the low take up of Carer's Leave. In the absence of a firm evidence base carer's organisations have put forward the following explanations for the low take up of Carer's Leave¹³⁰:

- The structure of the scheme may not fit with requirements of people's caring role (the shortest time-block facilitated by the scheme is 13 weeks).
- There may be a fear of negative career consequences to taking up Carer's Leave.
- The economic, psychological and social costs of taking up Carer's Leave may be too high.
- There may be low awareness about entitlement to Carer's Leave among employers and employees.

¹²⁸ Paul O'Mahoney, "Balancing Work and Care: International Challenges and Irish Perspectives," Briefing Paper (Family Carers Ireland, November 2017), <http://familycarers.ie/wp-content/uploads/2017/11/Working-Carers-Briefing-Paper-corrected.pdf>.

¹²⁹ Bouget et al. 2016: 28, cited in O'Mahoney.

¹³⁰ O'Mahoney.

Figure 6: Numbers in receipt of Carer's Benefit over time

L&RS graph. Source census 2016.

Reconciling employment and care

National and international policy

The importance of supporting people to combine employment and family care roles is well recognised in national and international policy:

The World Health Organisation recognises the importance of introducing “measures aimed at reconciling the conflicting pressures of paid work and care for carers, enabling them to engage with or retain paid employment”.¹³¹

The European Commission has identified the need to “modernise current EU legal and policy framework and adapt it to today’s labour market to allow for parents with children or workers with dependent relatives to better balance caring”.¹³²

Goal 4.2.3. in Ireland’s National Carers Strategy commits to “encourage work-life balance provisions that are needed to ensure that working arrangements are carer friendly”.¹³³

¹³¹ Rosanna Tarricone and Agis D Tsouros, “The Solid Facts: Home Care in Europe” (World Health Organisation, 2008).

¹³² European Commission, “New Start to Address the Challenges of Work-Life Balance Faced by Working Families,” August 2015, http://ec.europa.eu/smart-regulation/roadmaps/docs/2015_just_012_new_initiative_replacing_maternity_leave_directive_en.pdf.

¹³³ Department of Health, “National Carers’ Strategy.”

Combining employment and care roles

There are mixed findings on the impact on carers of combining employment with a caring role. Some studies suggest that reconciling work with care results in poor health, depression, diabetes, hypertension, or pulmonary disease in carers,¹³⁴ while others suggest that carers are happier, financially secure, and less socially excluded.¹³⁵

Literature on work and care suggests that carers who retain a working identity often respond better to the demands of caring, and are not as exposed to some of the risks associated with the caring role, such as social exclusion or isolation, or negative impacts on psychological and physical wellbeing as well as on financial circumstances.^{136,137}

Caring can have a significant negative impact on carers' careers. Carers are sometimes forced to reduce their hours, change to less demanding roles, exit the workforce entirely or take early retirement.¹³⁸ An English study, using data from the English Longitudinal Study on Ageing (conducted in 'waves' two years apart), shows that just ten hours of care provision by people aged between fifty and retirement age (the State Pension age in the UK was 65 for men and 60 for women at the time of the research) significantly increased the chances of an individual's having left employment by the next wave.¹³⁹

Whether carers receive support to balance their caring and employment roles has an impact on the positive or negative outcomes listed above. Carers who are supported are less likely to exit the workforce allowing employers to retain talented employees in roles for which they are suited.¹⁴⁰ The move toward a supportive work environment for informal carers has benefits for families, businesses and the overall economy.¹⁴¹

A 2012 UK initiative between the Department of Health and Employers for Carers reflects this positive view of the potential impact of supporting people to combine employment.¹⁴² The report from this initiative set out the position that supporting carers in this way is "not only a problem, but also an economic opportunity". It described potential social and economic gains to be made from supporting carers to juggle their work and family lives across several fronts:

¹³⁴ Larkin, Henwood, and Milne, "Carer-Related Research and Knowledge."

¹³⁵ Jungblut, "Working and Caring."

¹³⁶ Sue Yeandle, "Caring for Sick and Disabled Children: Policies, Services and Support in the UK" (University of Leeds, 2011).

¹³⁷ Rob Anderson (2016) cited in O'Mahoney, "Balancing Work and Care: International Challenges and Irish Perspectives."

¹³⁸ Caroline Glendinning et al., *Care Provision within Families and Its Socio-Economic Impact on Care Providers* (Social Policy Research Unit, University of York Heslington, York, 2009).

¹³⁹ Derek King and Linda Pickard, "When Is a Carer's Employment at Risk? Longitudinal Analysis of Unpaid Care and Employment in Midlife in England," *Health & Social Care in the Community* 21, no. 3 (2013): 303–314.

¹⁴⁰ Bittman et al. 2007; Glendinning et al. 2009; Carers UK 2015 cited in O'Mahoney, "Balancing Work and Care: International Challenges and Irish Perspectives."

¹⁴¹ Employers for Carers 2017; Carers UK/Employers for Carers 2013; Grayson 2017: 53–66 cited in O'Mahoney.

¹⁴² Employers for Carers is an employers membership forum committed to ensuring that employers have the support to retain and manage employees with caring responsibilities. It is an initiative of CarersUK. <https://www.employersforcarers.org>

- Individuals and families will not face the financial, health and social disadvantage of being outside the labour market;
- Employers will realise quantifiable benefits, including retention of skills and experience, increased employee resilience in terms of health, productivity and engagement, and better results through improved performance;
- The economy will benefit from improved output at lower cost, higher public revenues and a reduced benefits bill;
- There will be a new and previously unrealised opportunity to turn the need for public investment in care services on its head and grow a vibrant, technology-enabled care sector that supports individuals and families, employers and business, while delivering benefits for the whole economy.

One academic analysis viewed the commitments above as compelling but asserted that the challenge of translating these aspirations into reality has some way to go.¹⁴³ A government-funded Carers in Employment (CiE) project which operated from 2015 to 2017 in nine local authorities in England offers a concrete example of pragmatic supports to working carers.¹⁴⁴ This project aimed to examine 'what works' in supporting carers to remain in or return to employment. Activities provided for carers and/or employers included information, advice and guidance to carers; advice on assistive technology, and employer measures such as raising awareness of the opportunities for, and the challenges of, support employed carers. An independent evaluation offered insights on this initiative.¹⁴⁵ On employer practice, the report suggest that more supportive workplace cultures and reduced conflict between staff over work adjustments for carers were reported thanks to the CiE project. Interaction with the project had, for some, particularly smaller, employers, enabled the introduction of carer-friendly HR policies and practices, such as considering requests for flexible working. There were also key findings in areas such as the challenges facing larger or regionally dispersed employers; carer assessments; and the identification of 'hidden' carers.

Irish State support for reconciling work and care

As referenced earlier goal 4.2.3. in the National Carers Strategy commits to “Encourage work-life balance provisions that are needed to ensure that working arrangements are carer friendly”.¹⁴⁶

This *Spotlight* has described how carers who work less than 15 hours a week and fulfil other criteria can avail of state income supports. Beyond this, however, there are very few other mechanisms to support those juggling employment and care roles.¹⁴⁷

¹⁴³ Employers for Carers/Department of Health Task & Finish Group, 2013 cited in Larkin, Henwood, and Milne, “Carer-Related Research and Knowledge.”

¹⁴⁴ “Supporting Carers to Stay in Paid Employment,” GOV.UK, accessed March 29, 2019, <https://www.gov.uk/government/news/supporting-carers-to-stay-in-paid-employment>.

¹⁴⁵ Institute for Employment Studies (IES), “Evaluation of the Carers in Employment (CiE) Project,” accessed March 29, 2019, <http://www.employment-studies.co.uk/resource/evaluation-carers-employment-cie-project-final-report>.

¹⁴⁶ Department of Health, “National Carers’ Strategy.”

¹⁴⁷ Ursula Barry and Ciara Conlon, “Elderly Care in Ireland-Provisions and Providers,” 2010.

Government's annual reports on the implementation of the National Carers Strategy include very little on this goal aside from implementing and promoting the benefits of the [Carer's Leave Act 2001](#) and family friendly policies within state bodies and Government departments.

In their annual assessment of the implementation of the strategy carers' groups have consistently assigned poor scores to this goal.¹⁴⁸ The most recent assessment states that they observe 'no evidence' of progress in relation to encouraging work-life balance to carers. They point to a future where greater numbers of people will have to juggle caring obligations and full-time work and call for a new carers' strategy with more robust actions relating to this area and suggest

"that the Carer's Leave Act 2001 be reviewed to include the right to request flexible work. This is in line with the recent EU Directive on Work-Life Balance and the EU Pillar on Social Rights which would give the right to request flexible working arrangements (reduced working hours, flexible working hours and flexibility in place of work) to all working parents of children up to 12 and carers with dependent relatives".¹⁴⁹

Employment and Care Developments

In the final section 'Catalysts for Change' we consider a number of initiatives that may improve the situation of carers trying to combine employment and caring. These include three initiatives aimed at supporting work-life-balance; one is a proposed EU-Directive, another is a considerable academic research project and the third is a practical initiative between carers' organisations and employers.

¹⁴⁸ Family Carers Ireland, "National Carers' Strategy Scorecard 2017."

¹⁴⁹ Council of the European Communities, "Council Directive 80/987/EEC on the Approximation of the Laws of the Member States Relating to the Protection of Employees in the Event of the Insolvency of Their Employer," Pub. L. No. 80/987/EEC (1980), <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:31980L0987:EN:HTML>.

Catalysts for change

In the final section we examine a number of factors that directly relate to the predicted family care gap. They may positively or negatively impact the future demand for family carers or the future supply of carers. The following factors are considered.

- Will increasing funding to home care increase the numbers of family carers in the future? Surprisingly the literature is not clear on this. One interpretation indicates that it may lead to a more sustainable caring population. More generous home and long term care provision may reduce the number of carers with intensive caring roles but may lead to 'many carers doing a little each'.
- A Carers Needs Assessment has been developed in addendum to a tool to assess older people's care needs. If adopted, mainstreamed and broadened to include all full-time carers this may have the potential to dramatically alter how carers are supported in Ireland.
- [The Assisted Decision-Making \(Capacity\) Act](#) has the potential to dramatically change caring relationships. Those with a difficulty making decisions about their finances, healthcare, living arrangements etc. will be assisted, where possible, to make these decisions for themselves. Currently many family carers are making decisions on behalf of these people in a legal vacuum, this legislation, if implemented successfully will remove this vacuum and may help to clarify some of the tensions referenced earlier in relation to disability policy and carer policy
- There is currently an opportunity to amend the constitution, Article 41.2.1, to recognise the value of caring work in gender neutral terms. It taken this would speak to calls for the need for care work to be valued and for the encouragement of a greater distribution of care work between genders.
- There are a number emerging initiatives that may improve the situation of carers trying to combine employment and caring. These include three initiatives aimed at supporting work-life-balance; one is a proposed EU-Directive, another is a considerable academic research project and the third is a practical initiative between carers' organisations and employers.

Increase home care, increase caring?

Earlier in this document (section: home care policy pressures on carers) the policy shift towards providing as much care in the home and community as possible is explored. The implications this has on the State in terms of a greater reliance on family carers is noted as is the fact that, despite significant investment, shortfalls in the implementation of this vision, as evidenced through factors such as insufficient home care and respite services, are increasing pressure on family carers.

This is a live issue. In the first wave of the Government's recent consultation process most respondents agreed with the Government's proposal that home care should be placed on a statutory basis. The consultation process highlighted the need for greater investment in home care

and for the development of a long-term approach to how it is financed, for example between the State and service-users, or through tax-relief and social insurance.¹⁵⁰

For more on this issue a Library & Research *Spotlight*¹⁵¹ explores the current context of home care provision and payment for services and sets out the high level policy questions facing policy makers seeking to determine strategy in this area.

Further Reading - Library & Research Service: Home Care for Older People

This report examines seven policy challenges facing policy makers in relation to home care for older people; determining access; selecting a funding model; finding the right mix of service provision; introducing effective regulation; sustaining informal care; securing a care workforce; and developing other alternatives to nursing home care.

The analysis above indicates broad consensus that greater emphasis and investment is needed in long term care and in home care in particular. However, there is surprisingly little consensus in the literature as to whether increased investment will encourage more or fewer people to take on a family care role in the future.

There is contradictory evidence on whether home care substitutes or complements informal care. Some studies suggest that state support makes informal care less likely, that welfare generosity 'crowds out' public effort.¹⁵² In these scenarios more informal care is to be expected when state support becomes less generous. Other studies suggest that formal long-term care and informal care are complementary, instead of substitutes. In these scenarios more formal long-term care provisions relieve family members from heavy caregiving tasks, which facilitate and encourage them to provide care on a voluntary basis. This crowding-in view sees care provision as a mixed responsibility of state and family.¹⁵³

Findings from a recent study (June 2018) offer one explanation of this phenomenon whereby both crowding in and crowding out may be happening simultaneously in a population but may be impacting those performing lower or higher intensive family care in different ways.^{154,155} Analysing data from the European Social Survey Round 7 (n = 32,894 respondents in n = 19 countries) showed that generous formal long-term care provisions led to less intensive caregiving by family

¹⁵⁰ The Institute of Public Health in Ireland, "Improving Home Care Services in Ireland."

¹⁵¹ Anne Timoney, "Spotlight: Home Care for Older People - Seven Policy Challenges," Spotlight (Oireachtas Library & Research Service, December 1, 2018), https://data.oireachtas.ie/ie/oireachtas/caighdeanOifigiul/2011/2011-12-16_spotlight-home-care-for-older-people-seven-policy-challenges_en.pdf.

¹⁵² Bianca Suanet, Marjolein Broese van Groenou, and Theo Van Tilburg, "Informal and Formal Home-Care Use among Older Adults in Europe: Can Cross-National Differences Be Explained by Societal Context and Composition?," *Ageing & Society* 32, no. 3 (2012): 491–515.

¹⁵³ Ellen Verbakel, "How to Understand Informal Caregiving Patterns in Europe? The Role of Formal Long-Term Care Provisions and Family Care Norms," *Scandinavian Journal of Public Health*, 2018, 1403494817726197.

¹⁵⁴ Verbakel.

¹⁵⁵ In this study intensive care is defined as those who perform informal care for at least 11 hours a week.

carers (crowding out) but also encouraged more people to provide some level of family care (crowding in).

The authors of this study suggest that more generous formal long-term care systems which lead to 'many caregivers doing a little each' may be more sustainable in the long term for family carers and the health system given the negative impact of high intensive caring on family carers health and the risk that overtaxed family carers "may provide lower-quality care, may drop-out as caregivers, and may even become in need of care themselves".¹⁵⁶

Carers Needs Assessment

Carers Needs Assessments have the potential to dramatically alter how carers are supported in Ireland.

Identifying the needs of family carers is increasingly being viewed as a key intervention in the development of fully integrated health and social care.¹⁵⁷ The positive impact of such assessments on carers is wide and varied, particularly in reducing their burden of stress and depressive symptoms.¹⁵⁸

The Carer Needs Assessment, developed in partnership with the HSE, InterRAI¹⁵⁹ and carer representatives was completed in December 2017. It was developed as an addendum to the Single Assessment Tool which is being used to assess the health and social care needs of mostly older people who may be looking for home care support or to apply for the Nursing Home Support Scheme. These developments speak to action point 2.1.3. in the National Carers Strategy which commits to: "Develop and roll out a single assessment tool for older people and ensure that the views of carers as well as the people they care for are taken into consideration".¹⁶⁰

The Single Assessment Tool for Older People is being rolled out across designated hospitals and CHOs. In July 2018 Minister Harris announced the allocation of €180,000 to pilot the Carers Needs Assessment tool in one HSE area over two years. This initiative is described as assisting in identifying and meeting the needs of carers across all care groups and will track health and wellbeing outcomes for carers over time.¹⁶¹

Carers' groups have welcomed the development of the Carer's Needs Assessment and called for it to be adopted by the HSE and made available to all full-time carers, not just those caring for older

¹⁵⁶ Verbakel, "How to Understand Informal Caregiving Patterns in Europe?"

¹⁵⁷ Guberman et al, 2007 cited in Liam O'sullivan et al., "Carer Needs Assessment Development-A Republic of Ireland Led International Joint Working Project to Support Delivery of Integrated Health and Social Care," *International Journal of Integrated Care* 17, no. 5 (2017).

¹⁵⁸ Guberman et al, 2003; Becker et al, 2005; Kwak et al, 2011 cited in O'sullivan et al.

¹⁵⁹ interRAI is an international collaborative to improve the quality of life of vulnerable persons through a seamless comprehensive assessment system <http://www.interrai.org/>

¹⁶⁰ Department of Health, "National Carers' Strategy."

¹⁶¹ The Department of Health, "Health Ministers Welcome the Approval of the 2018 Dormant Accounts Action Plan," accessed March 27, 2019, <https://health.gov.ie/blog/press-release/health-ministers-welcome-the-approval-of-the-2018-dormant-accounts-action-plan-e6-466m-for-health-related-projects/>.

people.¹⁶² Furthermore, there have been calls for family carers to be given an entitlement to a Carers Needs Assessment, similar to the entitlement that has existed in the UK for over 20 years where they are significantly embedded in assessment processes.¹⁶³

The Assisted Decision Making (Capacity) Act (2015)

[The Assisted Decision-Making \(Capacity\) Act 2015](#)¹⁶⁴ was signed into law on the 30th December 2015. The Office of the Decision Support Service has been established and a Director of Decision Support has been appointed but the Act has not yet been commenced.

This legislation has the potential to dramatically change caring relationships. The national association for people with an intellectual disability, Inclusion Ireland, have described it as demonstrating a “seismic cultural shift away from a paternalistic and ‘best interests’ approach towards persons with intellectual disabilities to a right-based approach of choice, control and consent”.¹⁶⁵

The Act is a reforming piece of legislation which will abolish the Wards of Court system and repeal that [Lunacy Regulation \(Ireland\) Act, 1871](#). Those with cognitive impairment which challenges their capacity to make decisions about their finances, healthcare, living arrangements etc. will be encouraged to put in place supports to assist their decision making. Where this is not possible, a representative will be appointed by the Circuit Court to act as a co-decision making representative. This person can be, but is not necessarily, a family carer.

On the one hand family carers’ organisations have welcomed this legislation pointing out that currently family members and carers are making day to day decisions, including decisions on the spending of money, on behalf of people who do not have capacity. They state that there is no legal right to make such decisions for adults or any protection for the person making the decision. In particular, they assert that there is a legal vacuum in respect of routine decision-making on behalf of people over the age of 18 who have intellectual disabilities and lack capacity.¹⁶⁶

The new *Assisted Decision-Making (Capacity) Act 2015* will provide a legal framework and process so that the person whose capacity to make a decision is in question can appoint a person to assist, co-decide or have somebody appointed to represent them for the purpose of making a decision. Whether the person appointed is a family carer or not it should remove this current legal vacuum. This legislation may also help to ease the tension between family carer and disability policy

¹⁶² Family Carers Ireland, “National Carers’ Strategy Scorecard 2017.”

¹⁶³ O’sullivan et al., “Carer Needs Assessment Development-A Republic of Ireland Led International Joint Working Project to Support Delivery of Integrated Health and Social Care”; Family Carers Ireland, “National Carers’ Strategy Scorecard 2017.”

¹⁶⁴ “Assisted Decision-Making (Capacity) Act,” Pub. L. No. 64 of 2015, accessed February 13, 2019, <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>.

¹⁶⁵ Inclusion Ireland, “Assisted Decision-Making (Capacity),” accessed March 12, 2019, <http://www.inclusionireland.ie/capacity>.

¹⁶⁶ Family Carers Ireland, “Assisted Decision-Making (Capacity) Bill 2013,” Briefing Paper, n.d., <http://familycarers.ie/wp-content/uploads/2016/01/Briefing-Paper-on-Assisted-Decision-Making-Capacity-Bill1.pdf>.

referenced earlier as it is underpinned by the individual's right of autonomy and self-determination.¹⁶⁷

On the other hand carers' organisations "remain sceptical about the practical application of the legislation and the need for provision to be made by the Department to ensure the needs of decision-makers, most likely to be family carers, are also addressed".¹⁶⁸

Care Alliance Ireland have expressed concern about the very limited references to family carers and their role in the guidance literature for health and social care professionals about the Act.

"Information for professionals who may need to support the family as a whole through this process- which is potentially a challenging scenario and one which has the possibility to negatively impact on family relationships- is missing from these guidelines. It is almost as if there is an assumption that families and Family Carers will be excluded from the entire process".¹⁶⁹

Care Alliance also contend that the Act may contradict some of the core principles of the National Carers Strategy (2012).¹⁷⁰ Contrasting section 2.6.2. of the Act "the 2015 Act requires that certain people must be consulted when an intervention is being made, unless it is not appropriate and or practicable to do so" with strategic goal one of the National Carers Strategy "Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for".¹⁷¹

Notwithstanding these observations Care Alliance Ireland anticipate that the *Assisted Decision Making (Capacity) Act (2015)* will have a positive impact on both people with disabilities and their families. They expect that the legislation will allow families to have a role in supporting their loved ones to make decisions in matter that affect them.¹⁷²

Further Reading:

Library & Research Service *Note*: [Assisted Decision-Making \(Capacity\) Act 2015: how will it work?](#) This *Note* looks at what is contained in the Act and how the legislation will work in a health and social care context as well as more broadly.

¹⁶⁷ Hughes, Zoey, "Disability and Family Carer Policy."

¹⁶⁸ Family Carers Ireland, "National Carers' Strategy Scorecard 2017."

¹⁶⁹ Care Alliance Ireland, "Assisted Decision-Making (Capacity) Act 2015 Guide for Health and Social Care Professionals Consultation," April 2017, <https://www.carealliance.ie/userfiles/file/CAI%20ADM%20Guidance%20for%20Professionals%20Consultation%202017%20final.pdf>.

¹⁷⁰ Department of Health, "National Carers' Strategy."

¹⁷¹ Care Alliance Ireland, "Assisted Decision-Making (Capacity) Act 2015 Guide for Health and Social Care Professionals Consultation."

¹⁷² Hughes, Zoey, "Disability and Family Carer Policy."

Care and the Constitution

In previous chapters we considered the relationship between gender and the predicted care gap. It was observed that the Constitution enshrines a patriarchal vision of home and care work and that there is currently the possibility that the relevant article may be removed or used to recognise the value of caring roles to Irish society. [Article 41.2.1° of the Constitution of Ireland](#) states that

“In particular, the State recognises that by her life within the home, woman gives to the State a support without which the common good cannot be achieved.”

The Programme for a Partnership Government commits to holding a referendum on Article 41.2.1. There has been near consensus, amongst the various bodies and reports, that the Article should be amended, rather than repealed, so that it would play a symbolic role in valuing care work.

In December 2018 the Joint Committee on Justice and Equality produced a report following hearings in September. The Committee proposed two potential courses of action for the Irish Government.

One option was to replace Article 41.2 with "more appropriate, gender-neutral language" along the lines of previous recommendations by a Department of Justice and Equality task force in 2016 and the Constitution Review Group in 1996.

The second option is to postpone any referendum on the matter until the government formally consult the public, potentially following the model it employed ahead of the Irish abortion referendum.

If Article 41.2.1. is amended to reflect caring work it may go some way to meet calls for the revalorisation of the role of care in Irish society.^{173,174}

Further Reading:

[An L&RS Note on Article 41.2 of the Constitution: Women in the Home](#) explores the issue in detail in the context of

- Gender equality in Ireland today
- History of Article 41.2
- Practical affect of 41.2
- Proposals for reform
- Referenda and the role of the Referendum Commission

¹⁷³ The Women's Health Council, "Caregiving a Position Paper."

¹⁷⁴ <https://familycarers.ie/constitution-should-recognise-and-support-family-carers/>

Supporting employment and care

As outlined in the Carers and Employment section above the majority of Irish carers combine a care role with paid employment and this is likely to increasingly be a feature of our workplace.¹⁷⁵ The importance of supporting people to combine these dual roles is well recognised in national and international policy.¹⁷⁶ Here we consider a number of initiatives that may improve the situation of carers trying to combine employment and caring.

This section on developments in Ireland relating to employment and care draws heavily from a Family Carers Ireland Briefing Paper *Balancing Work and Care*.¹⁷⁷ It should be noted that the views of Irish employers have not yet been captured about the proposals outlined below relating to work life balance and caring roles. Responses from IBEC to recent proposals to extend parental leave offer an insight into how employers might possibly see these issues. IBEC have stated that flexibility in relation to leave can be difficult and expensive for employers, particularly those with small businesses and that policy makers had to be cognisant of the costs of recruiting and replacing people in this regard.¹⁷⁸

Proposed EU Directive on work-life balance

A noteworthy development at EU level is the recent proposal of a Directive on work-life balance.¹⁷⁹ The aim of the proposal is to improve the access for working parents and carers to work-life balance arrangements, such as leave and flexible working arrangements.¹⁸⁰ The new directive will encourage men and women to take an equal share in family-related responsibilities. Two elements of the proposed Directive are

- a new concept at EU level – carer’s leave for workers caring for relatives in need of care or support due to serious medical reasons. Carers will be able to take 5 working days per year. Member states may use a different reference period, allocate leave on a case-by-case basis, and may introduce additional conditions for the exercise of this right;
- an extension of the right to request flexible working arrangements to working carers in addition to this right for all parents.

This proposal has been described as the first indication that the interests of family carers are central to Commission thinking.¹⁸¹

¹⁷⁵ Central Statistics Office, “Census of Population 2016 – Profile 9 Health, Disability and Carers.”

¹⁷⁶ Tarricone and Tsouros, “The Solid Facts: Home Care in Europe”; European Commission, “New Start to Address the Challenges of Work-Life Balance Faced by Working Families”; Department of Health, “National Carers’ Strategy.”

¹⁷⁷ This section draws heavily from O’Mahoney, “Balancing Work and Care: International Challenges and Irish Perspectives.”

¹⁷⁸ “Motion to Extend Parental Leave Sent to Committee,” *RTE.ie*, February 8, 2018, <https://www.rte.ie/news/ireland/2018/0208/939167-parental-leave/>.

¹⁷⁹ European Commission, “New Start to Address the Challenges of Work-Life Balance Faced by Working Families.”

¹⁸⁰ If approved by member states this proposal, as it is a directive, will be binding, the Commission can take legal action against a state which fails to accomplish the directed result, or whose legislation is incompatible with it – but directives do not prescribe how Member States should achieve the result.

¹⁸¹ <http://www.marianharkin.com/news/latest-news/single-article/article/eu-paid-leave-proposal-for-family-carers-warmly-welcomed/>

Project on work-life balance and supporting working carers

The Health Research Board recently awarded €800,000 to a research project entitled '*Development of a workplace-based programme to promote health and self-care behaviours among working family carers*'.¹⁸² This will involve a major, four-year study focusing on self-care behaviours of working carers. It will investigate how better to support carers in maintaining their health and wellbeing, creating a programme to help working family carers to improve their physical and mental health. If the new programme is successful, it may be applicable on a larger scale in different work settings throughout the country.

Family Carers Ireland project on work-life balance

Family Carers Ireland are using funds secured from Pobal to encourage employers to support employees with caring responsibilities. This project is at an early stage, in February 2019 Family Carers Ireland held a breakfast briefing with employers billed as 'future-proofing your workforce' with the message that greater support for employees with caring roles would help them to retain top talent.¹⁸³

¹⁸² O'Mahoney.

¹⁸³ Family Carers Ireland, "Caring Employers," Family Carers Ireland, January 31, 2019, <https://familycarers.ie/caring-employers/>.

Conclusion

Family carers are the main source of care provision for those in need of care due to a long-term illness, disability or frailty living in the community. National policy dedicated to supporting family carers while ambitious has been constrained through lack of dedicated funding. This ambition as well as the ambition to shift a greater proportion of care delivery to the home and community, central to Irish health policy, is challenged by gaps in home care and respite care provision.

Demand for care at home is likely to increase dramatically due to a rising ageing population, the shift away from institutional care for people with disabilities and an increased emphasis on home-based care. The future supply of family carers may be limited by demographic factors including a decline of fertility rates, delayed average age of starting a family and increased labour force participation by women.

Greater investment in home care may lead to a more sustainable form of family caring where there are less people carrying out high-intensity family care roles and more carers 'doing a little each'. However, the literature is unclear on this.

For policymakers seeking to track and influence the future of family care in Ireland there are a number of current developments that will have a dramatic impact on carers lives. These include; the development of a Carers Needs Assessment, the implementation of the *Assisted Decision-Making (Capacity) Act 2015*, the opportunity to amend Article 41.2.1 of the Constitution to recognise the value of caring work in gender neutral terms, and a range of initiatives to support those trying to combine employment and care roles.



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