



**Overview
Report**

Trends in Family Caring in Ireland in 2017:

**Review of Awareness, Self-Identification, Official Surveys
and Income Supports**

September 2017



1. Introduction

The purpose of this paper, as with most of our publications, is to stimulate debate and critical thinking within the family carer, disability and wider health and social care sectors. In this paper we explore the interrelationships between family carer identification, family carer prevalence statistics and supports for family carers.¹ We draw on recent quantitative data sources in an attempt to provide an objective analysis of family caring in Ireland in 2017.

To provide a context for the analysis, we provide a brief summary of the family carer movement, both in Ireland and internationally. We explore the meaning of the terms 'awareness' and 'identification' used by some leading not-for-profit family carer organisations. The combination of reliable statistics and personal carer stories in securing media and political interest and state supports is considered. Published Irish statistics and international data are reviewed, and some plausible reasons for the large discrepancy in family carer numbers reported in different studies are suggested. We review trends in state income supports, both absolute and relative, and the possible drivers of these changes. We also examine how policy changes in Ireland since 2000 may have impacted reported carer numbers.



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We conclude by discussing how family carer identification, family carer prevalence statistics and supports for family carers are closely interlinked. We ask if specific awareness campaigns can have population-level impacts, and raise other questions concerning public preferences in relation to income supports, prioritisation, the use of evidence-informed services and interventions, and, finally, what we call 'apparent demand' for care.

¹ The term 'family carer' is used to describe the work of family and friends who provide unpaid care to an individual. Several primary research reports have identified that between 85% and 98% of unpaid care is provided by family members, hence the use of the term 'family'. This definition does not include care associated with child rearing, although a percentage of parents whose children have long-term high care support needs may identify as family carers. The terms 'caregiver' and 'carer', as well as 'informal carer', are also used in some of the literature, and indeed internationally, but we believe it is important to differentiate paid care from unpaid care.

2. Awareness

2.1 A Brief History of the Family Carers Movement

A national family carers movement has been active in Ireland for over 30 years, and can be traced back to the meeting of a few concerned members of the public around a coffee table in the mid-1980s; the founders decided to establish an organisation (now called Family Carers Ireland) that would primarily focus on the needs of people providing care for a loved one. In the mid-1990s another carer-focused organisation, Care Alliance Ireland, was established, with the aim of encouraging existing disability and not-for-profit organisations to focus more on supporting family carers.



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In the UK, the family carers movement arguably started in 1963 when Reverend Mary Webster wrote a letter to the newspapers outlining the difficulty of working and caring for ageing parents. She subsequently went on to found what is now Carers UK.²

In the US, the Family Caregiver Alliance was established in the 1980s, operating initially in the San Francisco Area.³ The National Family Caregivers Association was founded in the US in 1993,⁴ followed by the National Alliance for Caregiving in 1996.⁵

Following initial work by Averil Fink and Clare Stevenson in the mid-1970s, Carers New South Wales (Australia) was established in 1980, followed by a national body in 1993 now known as Carers Australia.⁶

² <https://www.carersuk.org/about-us/who-we-are/our-history> Website accessed 3/8/17.

³ <https://www.caregiver.org/fca-history> Website accessed 3/8/17.

⁴ https://en.wikipedia.org/wiki/Carers_rights_movement Website accessed 3/8/17.

⁵ <http://www.caregiving.org/about/about-the-alliance/> Website accessed 3/8/17.

⁶ <http://www.carersaustralia.com.au/about-us/history/> Website accessed 3/8/17.



On the international level, the International Alliance of Carer Organisations (IACO) and Eurocarers provide a transnational focus. Both are now well-established with large membership bases. There are also regional and national carer organisations in many western countries, some embryonic, some well-established and some remaining within condition-specific organisations. The development of the disability movement, and more recently the independent living movement, is also significant.⁷ While the relationship between these movements is important, it is not within the scope of this paper.⁸

2.2 Awareness Raising

In the promotion of a cause in the not-for-profit sector, 'awareness raising' is often seen as key to success. In the case of family carers, individual self-identification is also considered important. Statements from not-for-profit family carer organisations across the world illustrate this (emphasis added in extracts below):

*One of CAN's main goals is to increase **awareness** of family caregiving issues in the general public, government, media circles and with family caregivers themselves. Getting the word out is critical to improving the quality of life for family caregivers and their care recipients. But this can be a challenge when so many people don't self-**identify** as a 'family caregiver' – even when they are handling caregiving responsibilities every day.*

Source: Caregiver Action Network, 2015 Annual Report (USA)⁹

*we've seen a greater **awareness** of carers' issues across all political parties. This **awareness** is due in part to our sustained success at getting carers' issues featured in the media . . . Over the coming year we will be looking to intensify our campaigning to turn greater **awareness** into concrete changes, like these, which make a difference to carers' lives.*

Source: Carers UK Annual Report 2016–2017¹⁰

⁷ Barnes, C. 2010. *A Brief History of Discrimination and Disabled People*.

⁸ Please see Care Alliance (2017) 'Disability and Family Carer Policy – Challenges and Responses' for a discussion of some of the interrelated issues. Downloadable at <http://www.carealliance.ie/userfiles/file/Discussion%20Paper%206%20Disability%20and%20Family%20Carer%20Policy.pdf>

⁹ <http://caregiveraction.org/sites/default/files/Caregiver%20Action%20Network%20FY15%20Annual%20Report.pdf> Website Accessed 3/8/17.

¹⁰ Carers UK Annual Report 2016–2017 <https://www.carersuk.org/about-us/what-we-do/our-annual-report> Website accessed 3/8/17.

*Achieve greater public **awareness** of and support for Family Carers and care issues
. . . Promote greater **self-identification** by Family Carers.*

Source: Family Carers Ireland Strategic Plan 2013–2020¹¹

*Each year we reach new heights in raising **awareness** of carers and their lives
across the community; in building a stronger profile for the organisation and
seeking to influence government . . . Significant **awareness-raising** achievements
included...*

Source: Carers Australia Annual Report 2014–2015¹²

Molyneaux and colleagues (2011: 425)¹³ have identified the taking on of the identity and label of ‘family carer’ as ‘the gateway through which supports are accessed’.

Reflecting on the language used by these leading family carer organisations, we believe it is reasonable to contend that there is a link between awareness raising at a societal or macro level, individual carer self-identification and access to services. A brief search of family carer and not-for-profit advocacy literature revealed a dearth of material specifically discussing these connections.

The relationship, however, is not simple, nor do all family carers accept a responsibility or need to identify as a family carer. A recent paper¹⁴ on the topic of ‘defining carers’ argues that ‘obliging [family] carers to identify as carers is not a helpful way to support them in contemporary Ireland’. Anecdotally, some carer support practitioners report that a key and almost cathartic event in their process of successful engagement with family carers is when such individuals identify as family carers.



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¹¹ The Carers Association (Ireland) Strategic Plan 2013–2020. (This organisation was renamed Family Carers Ireland after a merger with Caring for Carers Ireland in 2016.)

¹² Carers Australia Annual Report 2015 <http://www.carersaustralia.com.au/storage/annual-report-2015-16-final.pdf> Website accessed 3/8/17.

¹³ Molyneaux, V., Butchard, S., Simpson, J. and Murray, C. (2011) ‘Reconsidering the term “carer”’: a critique of the universal adoption of the term “carer”, *Ageing and Society*, 31(3): 422–37.

¹⁴ Hughes, Z. and O’Sullivan, L. (In press, 2017) ‘Defining and profiling family carers: reflections from Ireland’, *International Journal of Care and Caring*, 1(3).



Figure 1 below presents the inter-relationship between awareness raising, official family carer statistics and family carer supports and services.

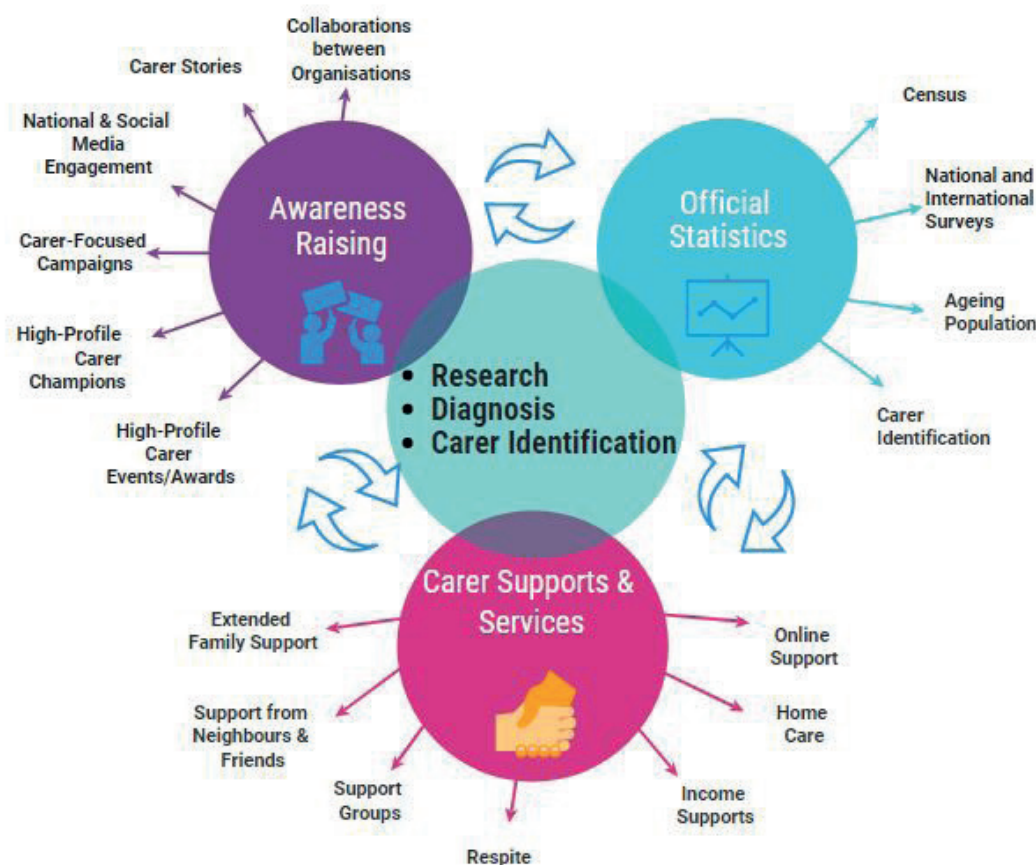


Figure 1 The relationship between awareness raising, official carer statistics and carer supports/services

2.3 Does Having Figures Matter?

Reliable quantitative data on family carer numbers is essential in advocating change. Many not-for-profit groups across the globe have successfully raised awareness of their cause through a combination of quantitative data, personal stories, recruitment of public champions and the benefit of a relatively free, liberal and uncritical media. This is particularly the case for organisations supporting groups who have experienced discrimination and isolation or who have been ignored or hidden from public discourse.

Robust data also provides evidence to support estimates of the quantum of need and unmet need. It also helps to prove the size of the sector represented. In the case of family carers, the data available in Ireland on the prevalence and intensity of caregiving also enables estimation of the contribution this caring makes to the national economy. The use of press releases, briefings reporting statistics and survey findings, together with personal family carer stories (often of struggles to access supports), appears to be an effective means of securing media interest. A cursory review of leading online and print media suggests regular coverage of family carer stories.



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While policy makers within government departments may review data presented with a critical eye, and indeed query the representativeness of individual carer stories, politicians may be more willing to accept data presented at face value, with less assessment of its robustness or overall merit.



3. Carer Prevalence and Self-Identification

3.1 The Origin of Carer Prevalence Statistics in Ireland

Few countries capture family carer prevalence on a population-wide basis. However, the family carers movement in Ireland successfully lobbied for the inclusion of a question on caring responsibilities in the 2002 national census, as well as the subsequent 2006, 2011 and 2016 censuses:

Question on caring in 2016 National Census of Population in Ireland¹⁵

Do you provide regular unpaid personal help for a friend or family member with a long-term illness, health problem or disability?

(Include problems which are due to old age. Personal help includes help with basic tasks such as feeding and dressing.)

If yes, for how many hours per week? Write in hours.

The baseline figure for the 2002 census of 148,754 family carers increased to a figure of 195,263 in the 2016 census.¹⁶ Allowing for population growth over this period, the overall percentage of the population reporting as providers of care increased from 3.8% in 2002 to 4.1% in 2011, and remained at that level in the 2016 census.¹⁷



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In the meantime, two other major surveys suggest much larger numbers of people are engaged in unpaid care.

¹⁵ http://census.ie/app/uploads/2016/02/65995-English-Household_2016-New-Version-Do-Not-Complete.pdf Website accessed 3/8/17.

¹⁶ http://www.cso.ie/en/media/csoie/newsevents/documents/census2016summaryresultspart2/Chapter_9_Health,_disability_and_caring.pdf Website accessed 15/8/17.

¹⁷ The population of Ireland was reported to be in 3,917,366 in 2002, 4,588,252 in 2011 and 4,757,976 in 2016. <http://www.cso.ie/en/media/csoie/census/documents/2002preliminary.pdf> and <http://www.cso.ie/en/releasesandpublications/ep/p-cpr/censusofpopulation2016-preliminaryresults/> Website accessed 18/8/17.

The Q3 2009 Quarterly National Household Survey (QNHS)¹⁸ asked the following question of 21,500 people:

Some people have extra responsibilities because they look after someone who has long-term physical or mental ill-health or disability, or problems related to old age.

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

The survey found that 8% of respondents aged 15 and over provided some level of unpaid care. On a national basis this would suggest that there were approximately 274,000 people aged 15 and over providing unpaid informal care in the state.



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In 2015 another question on caring was included, this time in the Irish Health Survey (IHS).

Question on caring in Irish Health Survey 2015:¹⁹

Are you providing care or assistance at least once a week to one or more people suffering from any chronic condition or infirmity due to old age (exclude professional activities)?

This survey concluded 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.'²⁰

¹⁸ Central Statistics Office (2010) Quarterly National Household Survey, Quarter 3 2009: Module on Caring. www.cso.ie/en/media/csoie/releasespublications/documents/labourmarket/2009/carersq32009.pdf (Please note: additional figures kindly provided to Care Alliance Ireland following request.)

¹⁹ http://www.cso.ie/en/media/csoie/qnhs/documents/qnhspecialmodules/IHS_questionnaire.pdf
Website accessed 3/8/17.

²⁰ <http://cso.ie/en/media/csoie/newsevents/documents/pressreleases/IHS2015.pdf>
Full report: <http://cso.ie/en/releasesandpublications/ep/p-ih/irishhealthsurvey2015/ct/> Website accessed 15/8/17.



In theory, based on the finding cited that 10% of the population aged 15+ were acting as carers in Ireland in 2015, this would suggest that there are approximately 360,000 carers in the state.



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Figure 2 below shows the significant disparity in reported levels of caregiving between the different Irish studies.

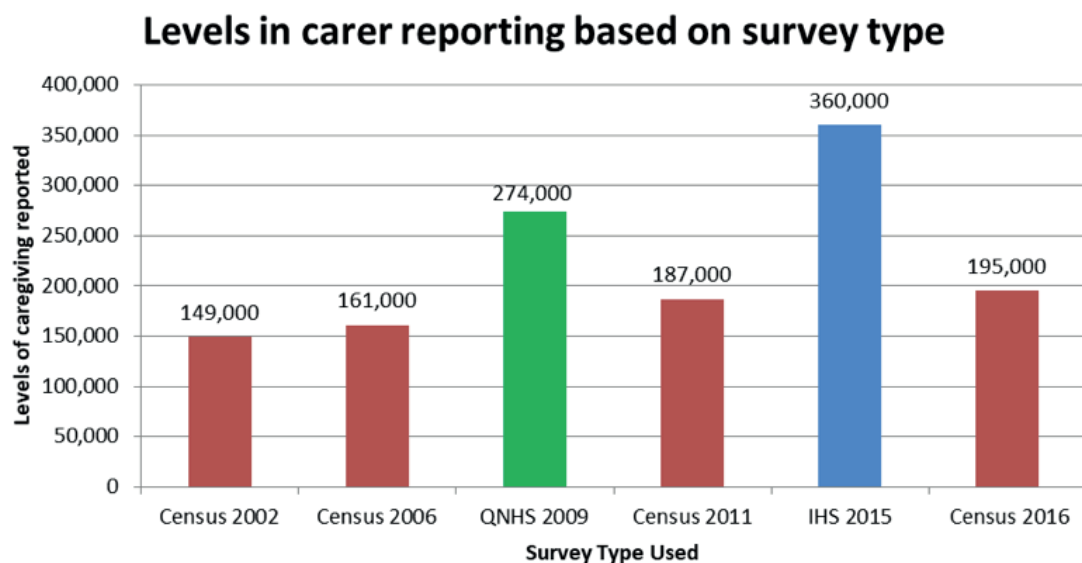


Figure 2 Levels of carer reporting based on survey type

3.2 Discussion of the Differences Between the Survey Results

The difference in reported numbers of family carers as between the various surveys and censuses is significant and warrants analysis. We now suggest three reasons for these differences.

1. The wording of the survey question

The authors of the 2009 QNHS point out:

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

The language used in the census – ‘personal help . . . including feeding or dressing’ – may well be a significant factor in the lower census prevalence figure. While many people with disabilities or health conditions may receive some level of support from family members, relatives or friends, the support may in many cases not extend to feeding or dressing. In that sense, people responding to the census question may have excluded themselves on reading the detailed wording of the question. Respondents may have interpreted the question as requiring a ‘no’ answer if they were not actually feeding or dressing someone. The wording of the 2015 health survey, which uses the term ‘help or assistance’, is arguably also wider than that used in the census.



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We suggest that those respondents replying in the affirmative to the census caring question are perhaps more likely than the respondents in the two surveys to be providing support for ‘Activities of Daily Living’ (ADLs) such as eating, bathing, dressing, toileting and transferring.

We also suggest that those who answered in the affirmative in the two other surveys were more likely to be primarily providing support with ‘Instrumental Activities of Daily Living’ (IADLs) including preparing meals, managing money, shopping for groceries or personal items, performing housework, doing laundry and using the telephone.



2. Different response rates

An exploration of the response rates may also be relevant. It would appear that of the 26,000 individuals originally selected in the 2015 Irish Health Survey, only 10,323 responded, giving a response rate of just under 40%.²¹ Given this relatively low response rate, it could be argued that those who did complete the survey may not be fully representative of the population. The National Census of Population, by its mandatory nature, tends to secure close to a 100% response rate.²² We have been unable to establish the response rate of the 2009 QNHS.

3. How the surveys are completed and by whom

It may be of significance that while the census must be completed by the householder or any adult member of the household, as is the Irish Health Survey, the QNHS is different. It is completed by an enumerator in conversation with the respondents.

The census is completed by an adult member of the household, and as such, there may be some reluctance to report on caregiving. This may be due to concerns about privacy or perceived stigma. There is some evidence of this type of reluctance with respect to reporting on the prevalence of young carers. A school-administered survey indicated that 11.4% of 10- to 17-year-olds identify as carers,²³ which would equate to approximately 60,000 young carers nationally. However, according to the most recent census figures (2016) there are only 3,800 children aged less than 15 years reported as providing care. In an earlier paper on the topic of stigma and caregiving we postulate that 'due to the stigma particularly surrounding a family that relies on young children to provide intimate and personal care to other members of the household, many of these young carers remain unacknowledged.'²⁴



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²¹ <http://cso.ie/en/releasesandpublications/ep/p-ihs/irishhealthsurvey2015/bgn/> Website accessed 15/8/17.

²² Personal communication with Declan Smyth, Statistician, Central Statistics Office, 17/8/17, when he confirmed that the response rate for census 2016 was estimated to be over 99%.

²³ Callaghan, M., Keane, E. & Molcho, M. (2016, February). 'Short Report – HBSC Ireland: Young Carers in the 2014 HBSC study'.

²⁴ 'We Need to Talk About It – Stigma and Family Care'. Dec 2016. Discussion Paper 5.

[http://www.carealliance.ie/userfiles/file/Discussion%20Paper%205%20\(Stigma\)%20FA%20Web.pdf](http://www.carealliance.ie/userfiles/file/Discussion%20Paper%205%20(Stigma)%20FA%20Web.pdf)

3.3 Triangulation of Survey Data for Hours of Caring

Looking at the census and IHS figures for the average number of hours of care provided weekly, the data suggests a small but significant difference in reported intensity of care provision. As referenced earlier in this report, the IHS suggested an average of 44.6 hours of care provided each week. An analysis of the 2016 census data, using mid-point estimates for the census bands (e.g. 2–6 hours), results in a figure of 40 hours of care per week.²⁵ It may be that some of those providing personal care tend to have different but less around-the-clock care responsibilities. For example, someone caring for a spouse with incontinence and frailty issues may get some respite from caring, whereas someone caring for a loved one with dementia may have a 24/7-type caring role but fewer personal care support demands, at least in the early and middle stages of dementia.



An analysis of the 2016 census data, using mid-point estimates for the census bands (e.g. 2–6 hours), results in a figure of 40 hours of care per week

3.4 International Comparisons

We now look at some international data on family caring.

In the UK, a question on caring appeared in both the 2001 and 2011 censuses.

The 2011 census showed that approximately 10% of the population of England and Wales provided some form of unpaid or informal care, i.e. 'look[ed] after, or [gave] any help or support to family members, friends, neighbours or others because of either: long-term physical or mental ill-health/disability/problems related to old age'.²⁶

Question on Caring in UK Censuses 2001 and 2011:²⁷

Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

²⁵ http://www.cso.ie/en/media/csoie/newsevents/documents/census2016summaryresultspart2/Chapter_9_Health,_disability_and_caring.pdf Page 70, Table 9.1. Full calculations are available on request.

²⁶ '2011 Census analysis: Unpaid care in England and Wales, 2011 and comparison with 2001' (2013) http://webarchive.nationalarchives.gov.uk/20160109213406/http://www.ons.gov.uk/ons/dcp171766_300039.pdf Website accessed 3/8/17.

²⁷ <https://www.ons.gov.uk/census/2001censusandearlier/aboutcensus2001/census2001forms>



Long-term physical or mental ill-health/disability?

Problems related to old age?

Do not count anything you do as part of your paid employment

Even allowing for the older age profile of the UK population (age 65+: 18% in the UK versus 13% in Ireland),²⁸ the difference in self-reported caring between the censuses of the two countries is significant. However, we suggest that the wording of the UK census may be interpreted by respondents to mean a wider definition of caring than the more 'personal' care that the Irish census seems to imply.

A comparison of data between Northern Ireland, part of the UK but arguably culturally closer to the population of the Republic of Ireland, is useful. Northern Ireland established a self-reported carer prevalence rate of 12%, somewhat higher than the figure for the UK as a whole.²⁹ This potentially undermines any argument that self-reported prevalence is strongly a function of culture or indeed a function of the type of state welfare model. Indeed, Northern Ireland has a younger population profile than the rest of the UK, so a lower prevalence rate³⁰ might have been expected.



A comparison of data between Northern Ireland, part of the UK but arguably culturally closer to the population of the Republic of Ireland, is useful. Northern Ireland established a self-reported carer prevalence rate of 12%, somewhat higher than the figure for the UK as a whole

In Australia, 11.6% of the population report as family carers.³¹ The explanation of the survey method is very detailed, and seems to include both ADLs and IADLs

²⁸ <http://www.indexmundi.com/factbook/compare/united-kingdom.ireland/demographics>

²⁹ <http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2017-2022/2017/health/2517.pdf>
Website accessed 18/8/17.

³⁰ <http://www.assemblyresearchmatters.org/2016/04/29/a-demographic-profile-of-northern-ireland-in-2016/>
Website accessed 18/8/17.

³¹ <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Appendix302015?opendocument&tabname=Notes&prodno=4430.0&issue=2015&num=&view>
Website accessed 3/8/17.

in the definition of caregiving, also giving detailed directions and support to the enumerator in identifying family carers within a household.³²

Question used in the 2015 Survey of Disability, Ageing and Carers (SDAC):

A carer is defined as a person who provides any informal assistance, in terms of help or supervision, to people with disability or older people (aged 65 years and over). Assistance must be ongoing, or likely to be ongoing, for at least six months.

Again, this definition is perhaps interpreted by respondents as encompassing a wider concept of caring than is the definition in the Irish census.

Both the UK and Australian census prevalence data (10% and 11.6% respectively) are close to the Irish Health Survey figure of 10%, especially when allowing for the older population age profiles in both countries.³³

At European level, there has been some attempt to capture levels of reported family caring across various EU countries. A 2017 review by Eurocarers of 29 European countries identified a massive range in both official and unofficial reported family caring prevalence amongst national populations. These ranged through 0.4% (official, Denmark), 6.3% (unofficial, Finland), 21.3% (official, Netherlands) and (16.2%, unofficial, Italy). This wide range makes the delivery of a coherent and credible message based on the prevalence of caregiving a more difficult task at EU level.³⁴ No carer prevalence data, either official or unofficial, could be found for 11 of the 29 countries. A figure of 100 million carers across Europe is currently used by Eurocarers, but figures of between 19 million and 125 million have been articulated in other publications.³⁵ The robust and well-regarded 2007 Quality of Life Survey across 31 European countries found that 6.5% of adults reported providing daily care to an elderly or disabled relative. This would equate to approximately 35 million people across Europe.³⁶

³² <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Appendix302015?opendocument&tabname=Notes&prodno=4430.0&issue=2015&num=&view=Website> accessed 3/8/17.

³³ <http://www.indexmundi.com/factbook/compare/united-kingdom.ireland/demographics>

³⁴ Eurocarers Annual Report 2016-2017 <http://eurocarers.org/userfiles/files/Annual%20Report%202016-2017%20-%20Revised%20version.pdf>

³⁵ The 100m estimate is based on a fairly broad definition derived from the European Quality of Life Survey which does not specify any minimum number of hours per week or duration of caregiving episode and is therefore likely to include many people with only very light care commitments. Stokes, A. (2009) 'Carers in Europe: Factsheet'. Brussels: Eurocarers.

<https://www.eurocarers.org/userfiles/files/factsheets/Carers%20in%20Europe%20-%202009.pdf>
Website accessed 15/8/17.

³⁶ Anderson, R., Mikulić, B., Vermeulen, G., Lyly-Yrjanainen, M. & Zigante, V. (2009). 'Second European quality of life survey—overview'.



In the US, a 2015 survey question (presented below) provides the latest figures for caregiving. Estimated caregiver prevalence lies at 18.2% of the adult population or approximately 43.5 million.³⁷ This figure is amongst the highest of any country which gathers national family carer data. Interestingly, while the narrower 'personal needs' term is used, other tasks are also included, as is the possibility for inclusion of caregivers who do not live with the person receiving care. Indeed, only 34% of those reported as providing care actually lived with the care recipient.

Question on Caregiving in the US 2015 Survey:

This report is based primarily on quantitative online interviews with 1,248 caregivers age 18 or older. Caregivers of adults are defined as those who provide unpaid care, as described in the following questions:

At any time in the least 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you.

Additionally, to estimate the national prevalence of caregiving for someone of any age, the study asked respondents if they had provided care to a child with special needs in the past year, as described in the following question:

In the last 12 months, has anyone in your household provided unpaid care to any child under the age of 18 because of a medical, behavioural, or other condition of disability? This kind of unpaid care is more than the normal care required for a child of that age. This could include care for an ongoing medical condition, a serious short-term condition, emotional or behavioural problems, or developmental problems.

In light of this discussion of prevalence rates nationally and internationally, what can be understood about the supports available to family carers and how they have developed over time?

³⁷ 'Caregiving in the US 2105 Report'. AARP and NAC.
http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf
Website accessed 15/8/17.

4. Income Supports for Family Carers

4.1 Trends in Income Supports Since 2000

Not-for-profit advocacy organisations consistently claim that ‘awareness raising’ is a tool through which better supports can be delivered for the people they are seeking to represent.

Formal state income support for family carers is one aspect of support that can be readily measured. A separate 2016 paper on the evolution of publicly funded formal home care provision in Ireland is available to read on our website.³⁸ That paper highlights that the reach of formal home care support has increased since 2000 but arguably at the expense of service intensity.



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Weekly rates of income support payments, specifically the Carers Allowance, for full-time family carers also increased significantly from €102 in 2000 to €209 in 2017. This equates to an increase of 103% in nominal terms (53% in real terms, allowing for inflation). Increases in other social welfare payments were also significant in both nominal and real terms over this period. For example, unemployment assistance payments increased by 99% and the state contributory pension increased by 95%.³⁹ During the period in question average weekly wages went from €436 in 2000 to €703 in 2016, an increase before tax of 61%.⁴⁰ Inflation over the same period was approximately 34%.⁴¹

The number of full-time Irish family carers in receipt of income support measures of some sort – whether weekly (Carers Allowance, Carers Benefit) monthly (Domiciliary Care Allowance) or annually (Carer Support Grant) – appears to

³⁸ <http://www.carealliance.ie/userfiles/file/Briefing%20Paper%201%20%3B%20An%20Analysis%20of%20Home%20Care%20Supports%20Funded%20by%20the%20HSE%202008–2016%20June%202016.pdf> Website accessed 15/8/17.

³⁹ https://www.welfare.ie/en/downloads/Rates_of_Payment_2000.pdf and <https://www.welfare.ie/en/Pages/bud17s1.aspx> Website accessed 18/8/17.

⁴⁰ <http://www.cso.ie/en/statistics/earnings/> Website accessed 15/8/17.

⁴¹ <http://www.hargaden.com/enda/inflation/calculator.html>



have increased by approximately 200% from an estimated 35,000 in 2000 to an estimated 100,000 in 2017.⁴² To put this in context, the national population increased over the same period only by approximately 25%⁴³ and those in paid employment increased by a similar amount.⁴⁴ Of particular interest to the family carers movement is the percentage of the population aged 65+, which has increased by approximately 60%, while the population of those aged 85+ has increased by an estimated 66%, the latter group being at high risk of requiring intensive care support.⁴⁵ In contrast with personal health and social care services, which tend to have specific annual budgets, state income support measures in Ireland are described as ‘demand led’. There is some evidence in many countries with developed welfare states of an ongoing and annual increase in the cost of income support measures, even without changes to formal eligibility criteria.



In contrast with personal health and social care services, which tend to have specific annual budgets, state income support measures in Ireland are described as ‘demand led’

The family carer prevalence surveys in Ireland suggest a modest increase over the period 2001–2016 but analysis is complicated by the different wording used in the three data sources. As alluded to earlier in this paper, allowing for population growth over the past 17 years, the overall percentage of the population reporting as providers of care (according to the censuses) has increased only modestly from 3.8% in 2002 to 4.1% in 2011, and remained at that level in the 2016 census. Since both of the other surveys from which prevalence data was extracted (QNHS 2009 and IHS 2015) were undertaken on a single occasion only, we cannot obtain any clear trends from them regarding the prevalence of carers in the population.

⁴² <http://www.welfare.ie/en/pressoffice/Pages/pa010617.aspx> Website accessed 18/8/17.

⁴³ https://www.google.ie/publicdata/explore?ds=d5bncppjof8f9_&met_y=sp_pop_totl&idim=country:IRL:NZL&hl=en&dl=en World bank. Website accessed 15/8/17.

⁴⁴ <https://tradingeconomics.com/ireland/unemployment-rate> and https://www.ictu.ie/download/pdf/celtic_tiger.pdf Website accessed 15/8/17.

⁴⁵ <http://www.cso.ie/px/pxeirestat/Statire/SelectVarVal/saveselections.asp> and http://www.cso.ie/en/media/csoie/releasespublications/documents/population/2017/Chapter_3_Age_and_sex_composition.pdf Website accessed 15/8/17. Data from the 2002 and 2016 Censuses and using estimates of annual increases of between 2% and 3.25% for the population aged 65 and over for the years 2000, 2001 and 2017 and 4% for those aged 85 and over for the same years.

4.2 Policy Changes

Over this period there have been four important policy changes pertaining to income supports for family carers:

In 2001, the **Carers Leave Act** was introduced. This granted people in paid employment the right to take leave of absence from their work for a period of up to two years to care for someone. Since its introduction, those in receipt of Carers Benefit (the benefit introduced following the Carers Leave legislation) increased from 425 in 2001 to an estimated 2,710 in 2017.⁴⁶

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.

In 2007, the family carers movement successfully lobbied for the introduction of a **half-rate Carers Allowance** for those already in receipt of income support. 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.

Throughout much of the 2000s the weekly **income eligibility limits**⁴⁷ for the means-tested Carers Allowance has been increased, rising from €90 in 2000 to €335 in 2017. The numbers in receipt of Carers Allowance has gone from 18,785 in 2001 to an estimated 75,000 in 2017.⁴⁸



The numbers in receipt of Carers Allowance has gone from 18,785 in 2001 to an estimated 75,000 in 2017

⁴⁶ <http://www.welfare.ie/en/downloads/2002stats.pdf> and <http://www.welfare.ie/en/downloads/Ministers-Brief-2017.pdf> Website accessed 15/8/17.

⁴⁷ Many of Ireland's state income supports have income eligibility limits. That is to say, if a person's family income exceeds a certain amount, then the person becomes ineligible for that support.

⁴⁸ <http://www.welfare.ie/en/downloads/2002stats.pdf> and <http://www.welfare.ie/en/downloads/Ministers-Brief-2017.pdf> Website accessed 15/8/17. Includes those in receipt of the half-rate Carers Allowance.



4.3 Other Changes

Other changes, not led by new income support schemes per se, are also significant. In 2000 there were 10,570 family carers, mostly parents of young children, in receipt of a Domiciliary Care Allowance. This had increased to almost 32,000 at the end of 2016.⁴⁹ Similar to the Carers Allowance, the rate of payment has increased materially over the period from approximately €150 per month in 2000 to €309 in 2017. A detailed analysis of the changes in eligibility for this payment since its inception in 1975 is available.⁵⁰

Other indirect financial supports that have evolved since 2001 include the increase in personal tax relief on employing a carer, from approximately €10,000 in 2000 to €75,000 in 2017. Although this measure appears to be used, at least formally through the tax system, only by a very small number of families (1,880), it nonetheless represents a support of €4,360/year per family on average to augment the care they are often providing to family members themselves.⁵¹

4.4 Cumulative Changes to Income Supports

In summary, direct income supports by the state to family carers (including Carers Benefit, Carers Allowance, Domiciliary Care Allowance and Carers Support Grant) increased from an estimated €115m in 2000 to €752 million in 2010 and to an estimated €1,046 million in 2017.⁵² By all accounts, even allowing for inflation and wage growth over the period, this represents a massive increase in both the coverage and level of income support payments. Nominally it represents a ninefold increase in resourcing; allowing for inflation of approximately 34% over that period, the increase is still approaching sixfold.⁵³

If we look at the percentage of the social welfare cake that now goes to full-time family carers, our analysis suggests that this has increased from 1.8% to 5.3% over the period 2000 to 2017.⁵⁴ The increase has not been driven by changes in the rates of all social welfare payments, as these have universally increased by generally similar amounts over the period.

⁴⁹ <https://www.welfare.ie/en/downloads/DCARReviewReportFinal.pdf> and <http://www.welfare.ie/en/downloads/Ministers-Brief-2017.pdf> Website accessed 15/8/17.

⁵⁰ <https://www.welfare.ie/en/downloads/DCARReviewReportFinal.pdf>

⁵¹ <http://www.revenue.ie/en/corporate/documents/statistics/tax-expenditures/costs-tax-expenditures.pdf>

⁵² Based on an estimate of €15m cost in 2000 of the Domiciliary Care Allowance scheme that operated under the Dept of Health until 2009. Also <http://www.welfare.ie/en/downloads/Ministers-Brief-2017.pdf>

⁵³ <http://www.hargaden.com/enda/inflation/calculator.html> Over the 17-year period in question there may have been moderate numbers of family carers transferring from one income support payment (possibly unemployment assistance type payments) to what has become in recent years a relatively more financially attractive Carers Allowance. This may inflate somewhat the actual increase in extra income supports for carers.

⁵⁴ <http://www.welfare.ie/en/downloads/Ministers-Brief-2017.pdf> p16 Website accessed 15/8/17.



the percentage of the social welfare cake that now goes to full-time family carers, our analysis suggests that this has increased from 1.8% to 5.3% over the period 2000 to 2017

4.5 What Is Driving the Increase in Income Supports?

The increase in financial supports has been driven largely by the changes in eligibility criteria for the existing schemes. Most significant has been the move away from restrictive means-testing towards universal entitlement (though an element of means-testing still remains). Also of significance is the removal for family carers of the historical rule against receiving more than one state income support at a time. Clearly our ageing population is also a driver of demand for family care. Better infant survival rates and increased rates of diagnosis of those on the autism spectrum and those with dementia are also possible factors. Securing a diagnosis can act as a gateway not only to accessing health and social care services for the client but also income supports for the family carer.




The increase in financial supports has been driven largely by the changes in eligibility criteria for the existing schemes

Any analysis of those in receipt of family carer income supports must also take account of the general move away from institutionalisation of young people with higher care support needs, our older population and those with mental health conditions. While these developments have been widely welcomed, they do place greater pressures on the families of those affected. Although this paper does not provide hard evidence to support this supposition, families of such individuals, in particular those with children with special needs, appear to be receiving more home-based state support than was available in the past. It may be that care is now more likely to comprise a sharing of care between support agencies and families rather than the 'either-or' option of full-time care within an institution



or full-time care at home by the family. This approach demands much greater cooperation and communication between stakeholders than in the past, and reflects the aspiration of the National Carers Strategy to work with families as ‘partners in care’.



It may be that care is now more likely to comprise a sharing of care between support agencies and families rather than the ‘either-or’ option of full-time care within an institution or full-time care at home by the family

It is interesting to note that there is some evidence that rates of admission to nursing homes have also reduced in recent years,⁵⁵ while home care support for older people is now increasing again after several successive years of reductions in state provision and access.

Total welfare expenditure peaked at nearly €21bn in 2012 at the height of the economic downturn and has been on a downward trajectory since then, only recently stabilising. However, income supports for family carers have continued to rise since then.

Table 1 Social Welfare Budget 2000–2017

Year	Total Social Welfare Budget	Carer Income Supports	% of Total Welfare Budget
2000	€6.8bn	€115m	1.8%
2008	€17.8bn	€657m	3.7%
2012	€20.8bn	€772m	3.7%
2017	€19.9bn	€ 1048m	5.3%

By any standard this sectoral shift in income support measures towards full-time family carers is significant. Any analysis must consider the increase in average wages over the period and the associated increased cost of the loss of opportunity associated with being a full-time family carer. The change in average weekly income over this period (2000–2017) for someone reliant on the Carers Allowance (€102 to €209) remains low when compared to the increase in the average pre-tax industrial wage (€436 to €703).

⁵⁵ Data on overall admissions are difficult to come by, but the state-funded Fair Deal Scheme appears to indicate a levelling off in absolute terms of admissions, which means a reduction in relative terms. The numbers were 22,705 in June 2013 and 22,840 in March 2017, equating to less than a 0.5% increase over four years, compared to a probable increase in excess of 10% in the 65+ population during the same period. <http://www.hse.ie/eng/services/publications/performance-reports/January-March-2017-Quarterly-Report.pdf> and <http://www.hse.ie/eng/services/publications/performance-reports/june13pr.pdf>

4.6 Other Drivers of Apparent Demand for Care

Another factor which may impact the 'apparent demand' for family care might be higher expectations of what family care means today. Increasing societal and state emphasis on health and safety and specifically a more prevalent 'avoidance of risks' attitude might indeed be translating into a greater 'apparent need/demand' for care. In the past those with care support needs may have received limited supports and were perhaps less closely supervised but now there may be an element of providing too much 'care' for some individuals at the risk of inhibiting their autonomy.



a more prevalent 'avoidance of risks' attitude might indeed be translating into a greater 'apparent need/demand' for care

A separate paper might usefully undertake a more detailed analysis of such drivers of both demand for, and supply of, family care.



5. Policy and Self-Reported Carer Prevalence

5.1 Does Policy Influence Self-Reported Carer Prevalence?

There is strong evidence that the introduction of the half-rate Carers Allowance in 2007 is associated with a very large increase in those aged 65 and over reported as providing care.



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The 36% increase in such self-reported older carers⁵⁶ (i.e. 65 and over) between the 2006 and 2011 censuses compares with a much more modest increase of 14% in the overall population of those aged 65 and over.⁵⁷ This increase has continued in recent years, albeit at slower rate, as Table 2 below indicates (18.5%, 2011–2016).⁵⁸

Carers 2011 to 2016 (Number) by Regular Unpaid Help, Sex, Age Group and Census Year

	2011	2016
All carers		
Both sexes		
65 - 69 years	9,587	11,037
70 - 74 years	6,483	7,813
75 - 79 years	4,770	5,375
80 - 84 years	2,588	3,310
85 years and over	1,318	1,776

Table 2 Trends in family carers aged 65 and over between 2011 and 2016 censuses

It may be that the impact of the introduction of the half-rate Carers Allowance has begun to reduce over time as more of this age cohort are already identifying as family carers and securing income support in recognition of that role.

⁵⁶ Our Bill of Health, Census 2011 data.

http://www.cso.ie/en/media/csoie/census/documents/census2011profile8/Profile_8_Full_document.pdf
Website accessed 20/8/17.

⁵⁷ http://www.cso.ie/en/media/csoie/census/documents/census2011profile2/Profile2_Older_and_Younger_Entire_Document.pdf Website accessed 20/8/17.

⁵⁸ <http://www.cso.ie/px/pxeirestat/Statire/SelectVarVal/Define.asp?maintable=EZ044&PLanguage=0>

Anecdotally, we have heard that spouses have sometimes been reluctant to identify as family carers, in particular if that signals an end to a previous relationship.⁵⁹ It may be that many people aged 65 and over who provided care to an ageing spouse or an adult child with a lifelong disability simply registered as family carers in the 2011 Census after the introduction of this half-rate payment in 2007; the introduction by the state of the payment may have made it more acceptable to identify as a family carer.

5.2 Do Specific Campaigns on Carer Awareness Have Population-level Impacts?

In advance of both the 2011 and 2016 Censuses, family carer NGOs engaged with the official state statistics agency in a campaign to explain the question on caring.⁶⁰ The success of the campaign is difficult to assess. While the change in reported level of caring increased between 2006 and 2011 from 3.6% to 4.1% of the population, there was no increase in reported prevalence between 2011 and 2016. It is possible that the first campaign was successful in raising the level of carer identification, and that the second simply maintained it at that level. Alternatively, the introduction of the half-rate Carers Allowance may have been the most significant driver of this change in the period 2006 to 2011.



It is possible that the first campaign was successful in raising the level of carer identification, and that the second simply maintained it at that level

A small-scale study undertaken at the time of the 2016 Census involving a local leaflet drop and geographically targeted paid social media posts in three separate communities found that these interventions increased self-identification by between 40% and 60%, using the 2011 Census data as the baseline. This suggests that there is an opportunity for specific awareness campaigns to significantly increase individual carer identification at population level.⁶¹

⁵⁹ Discussion Paper 1, 'Defining carers'. October 2015

<http://www.carealliance.ie/userfiles/file/CAI%20Discussion%20Paper%201-%20Defining%20Carers.pdf>

⁶⁰ <http://census.ie/and-communities/census-for-carers/> Website accessed 20/8/17.

⁶¹ 'Do leaflet drops and targeted social media ads increase carer identification?' Liam O'Sullivan, Care Alliance Ireland. Poster presentation at 7th International Carers Conference, Adelaide October 2017 (upcoming).



6. Discussion and Conclusion

The disparity in family carer numbers reported in different studies both in Ireland and internationally does suggest that the wording of the survey question can be significant. We believe that cultural, demographic or welfare model variations are unlikely to be key determinants of self-reported family carer prevalence rates. Based on a review of the data from larger western countries we believe that the use in surveys of terms such as 'personal care' is likely to reduce reported prevalence rates, whereas the use of more general terms such as 'support' or 'help out' are likely to result in higher reported family carer prevalence rates.



We believe that cultural, demographic or welfare model variations are unlikely to be key determinants of self-reported family carer prevalence rates

Securing internationally comparable robust data is difficult. As such, there may be limited value in attempting to agree a standardised definition of family caregiving, at least if the sole purpose is the comparison of prevalence rates across countries.

In Ireland, family carer surveys report significantly different prevalence rates. The censuses report a significant increase in absolute numbers of family carers over the past 15 years, but only modest increases in prevalence rates. There is some evidence that this initial increase may have been driven by the introduction of a new half-rate Carers Allowance, and may also have been supported by specific census awareness campaigns.

Such moderate increases contrast with a welcome significant increase in both the rates and coverage of income supports for full-time family carers over the past 15 years.

There does however appear to be a disconnect between the census data as reported and the increase in the rate of applications for Carers Allowance and the Domiciliary Care Allowance. Although not within the remit of this paper, issues such as improved awareness of income supports amongst new parents of children with development delays, and amongst older carer spouses; amended eligibility guidelines; strong peer and NGO agency advocacy for individuals; and increased diagnosis rates are likely to help explain this phenomenon.

The very low base that income supports were at in 2000 reflected the state's low priority on and poor recognition of family carers at that time. Indeed the €1bn in income supports that is currently provided still represents only approximately 10% of the estimated economic contribution made by such families.⁶² Many in the family carers movement have in the past advocated for the rate of Carers Allowance to be at least equivalent to the minimum wage, in part because the Carers Allowance remains the only welfare payment which requires full-time work to claim it. Some family carers themselves would feel that they should be paid a wage, equivalent to that paid to health care workers such as social care workers.



represents only approximately 10% of the estimated economic contribution made by such families

While it is not possible to exclusively attribute the increase in income supports to the efforts of the family carer movement, it would be naive to discount the movement's impact. In all likelihood, this sectoral increase in income supports is indeed testament to the positive impact of the family carers movement, through its ceaseless advocacy, lobbying, smart and creative use of the media and social media, innovative awards and promotion of awareness-raising events. It also perhaps reflects the general goodwill and willingness shown by both state officials and most politicians to support, advocate for and prioritise enhanced income supports for family carers.



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⁶² Assumptions are: 360,000 family carers providing an average of 45 hours of care per week at €12 per hour.



6.1 Some Unanswered Questions

Inevitably a paper like this can raise more questions than it can answer. This is of course one of its purposes.

Ireland is a wealthy western democracy with an ageing population but good access to the most advanced life-extending medical treatments. These interventions continue to drive down infant mortality rates and extend life expectancy. In light of this, what proportion of our national resources can we collectively agree to direct towards care supports – specifically family carer supports – and within that which groups or sub-groups do we prioritise? Full-time family carers? Income-poor family carers? Dementia family carers? At a wider level, do we respond first to those who shout the loudest or to those who vote in greater numbers? Are the types of supports and interventions provided based on the strongest evidence for impact or spread widely to please as many groups as possible?



do we respond first to those who shout the loudest or to those who vote in greater numbers?

Within society at large, within individual families and within the health and social care professions, how has the way we define, conceptualise and measure unmet needs changed in recent decades? What implications, if any, does this have on the apparent ‘demand’ for services and supports?

This paper has begun to tease out the complex relationship between awareness of the role of family carers, official prevalence surveys and income supports. The relationships are not linear, nor can the trends be strongly attributed to specific causes.

This paper has also attempted to assess the level of income supports provided to Ireland’s family carers. It has not, however, attempted to assess the change over time in the level of other supports available for example, home care provision, carer support groups, educative interventions, residential respite care, extended

familial support or online peer support. An individual's experience of providing care will be influenced by the totality of these supports, together with other more individual traits such as resilience and perspective and the degree to which they have other responsibilities.



An individual's experience of providing care will be influenced by the totality of these supports, together with other more individual traits such as resilience and perspective and the degree to which they have other responsibilities

Caring exists on a continuum but is also often a private and sometimes stigmatised experience. What matters more than surveys and prevalence rates is how as a society and a state we seek to acknowledge, support, share with, and at times celebrate family caring in all its forms.



Guiding support for family carers

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