

**Care Alliance Ireland submission to the Central Statistics Office**

**Census 2021**

Submitted: November 2017

Introduction

In Ireland it is not known definitively how many Family Carers support people with disability, mental ill-health, long-term conditions and complications arising from the ageing process. The latest credible statistics vary from 195,263 (Census 2016) to in the region of 360,000 (Irish Health Survey 2015). There is a lack of consistency in wording and methodology between studies, and subsequently there is a lack of clarity as to what the exact quantum of unpaid family caring is in Ireland. We in Care Alliance Ireland believe that due to the specific wording of Q.22 of the national census of population (which refers specifically to unpaid care in the home), census data regarding family caring in Ireland is significantly underreported. Indeed, the most recent "Men And Women in Ireland" publication<sup>1</sup> confuses matters even further by identifying 445,000 women who are "looking after home/family" versus 9000 men - clearly in conflict with the Census 2016 figures which indicate that 77,112 men are providing unpaid care in the home.

These contradictions only serve to confuse and conflate issues of disability and significant caring responsibilities with general child and family care. In turn, this makes it difficult for the comprehensive and truly evidence informed planning of services and supports.

This submission serves to highlight the current Irish national and international statistics on family caring, noting the large difference between Irish figures and intentional figures. In addition, we propose wording changes to the current question in the Census which addresses family care, with the changes proposed to address some of the key issues identified in this submission.

We appreciate the opportunity to make such a submission, and are available for further consultation as necessary.

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<sup>1</sup> CSO 2017

## Current Statistics in Ireland

There are a number of national studies which collect data on number of Family Carers across Ireland. These are;

1. The Census of Population
2. The National Quarterly Household Survey
3. The National Health Survey.

The Census of Population<sup>2</sup> has included a question on Family Caring for four iterations now; 2002, 2006, 2011 and 2016. This question is as follows;

*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. 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.

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

The Q3 2009 Quarterly National Household Survey (QNHS)<sup>3</sup> 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.)?*

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<sup>2</sup> Central Statistics Office, 'The Census Form- Each Question in Detail', 2011, <http://www.census.ie/the-census-form/each-question-in-detail.109.1.aspx>.

<sup>3</sup> Central Statistics Office, 'Quarterly National Household Survey-Carers (Quarter 3 2009)' (Central Statistics Office, 2010),

[http://www.cso.ie/en/media/csoie/releasespublications/documents/labourmarket/2009/care\\_rsq32009.pdf](http://www.cso.ie/en/media/csoie/releasespublications/documents/labourmarket/2009/care_rsq32009.pdf).

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.

In 2015 another question on caring was included, this time in the Irish Health Survey (IHS)<sup>4</sup>.

Question on caring in Irish Health Survey 2015:

*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.'

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, using estimates for 2015 population levels.

Figure 1 (below) shows the significant disparity in reported levels of caregiving between the different Irish studies.

The difference in reported numbers of family carers as between the various surveys and censuses is significant and warrants analysis. A full analysis of possible reasons for these discrepancies is included in a recent Care Alliance Ireland Overview Report titled *Trends in Family Caring in Ireland in 2017: Review of Awareness, Self-Identification, Official Surveys and Income Supports*<sup>5</sup>. However, that paper identified the wording of questions related to caring as one of the key reasons for such discrepancies.

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<sup>4</sup> Central Statistics Office, 'CSO Releases Irish Health Survey Results', 16 November 2016, <http://cso.ie/en/media/csoie/newsevents/documents/pressreleases/IHS2015.pdf>.

<sup>5</sup> Care Alliance Ireland, 'Trends in Family Caring in Ireland in 2017: Review of Awareness, Self-Identification, Official Surveys and Income Supports' (Care Alliance Ireland, 2017), [http://www.carealliance.ie/userfiles/file/Overview%20Report\(1\).pdf](http://www.carealliance.ie/userfiles/file/Overview%20Report(1).pdf).

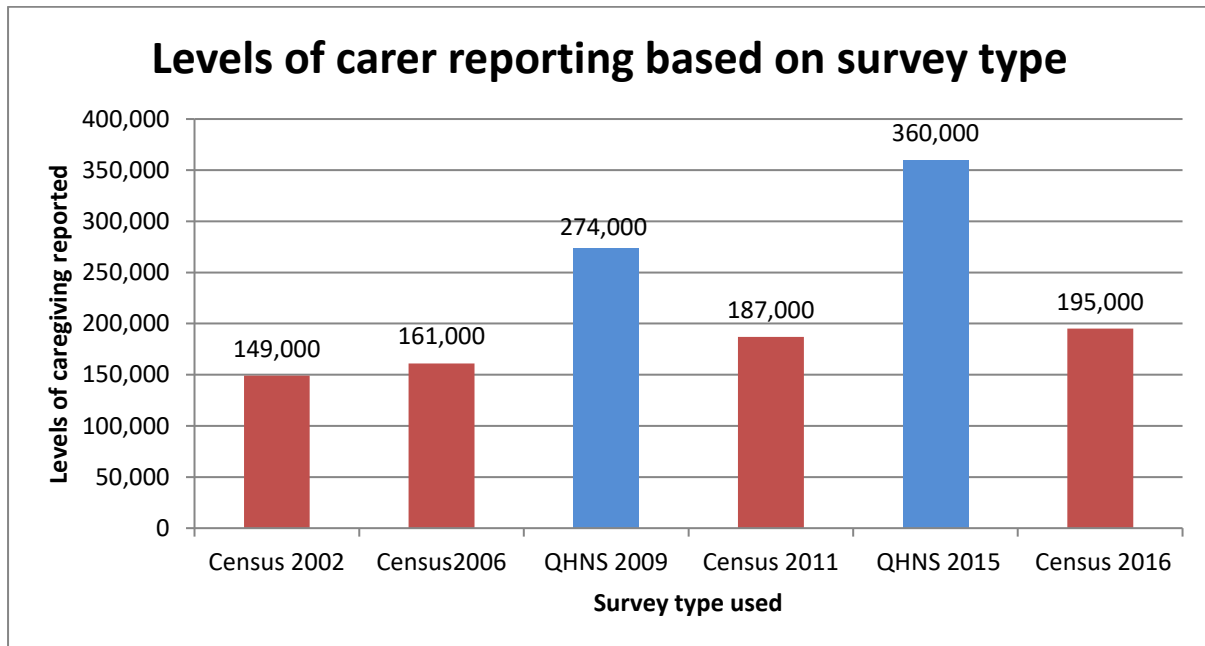


Figure 1. Levels of carer reporting based on survey type

As 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.

We suggest that those respondents replying in the affirmative to the census caring question are perhaps more likely than the respondents in the two other surveys (QNHS/IHS) 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.

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. 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 needs, at least in the early and middle stages of dementia.

### International examples & statistics

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'<sup>6</sup>.

Question on Caring in UK Censuses 2001 and 2011:

*Do you look after, or give 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?*

*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)<sup>7</sup>, the difference in self-reported caring between the censuses

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<sup>6</sup> Carers UK, 'Facts About Carers' (Carers UK, 2015),  
[https://www.carersuk.org/images/Facts\\_about\\_Carers\\_2015.pdf](https://www.carersuk.org/images/Facts_about_Carers_2015.pdf).

<sup>7</sup> <http://www.indexmundi.com/factbook/compare/united-kingdom.ireland/demographics>

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 current 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<sup>8</sup>. 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<sup>9</sup>, so a lower prevalence rate might have been expected.

In Australia, 11.6% of the population report as family carers<sup>10</sup>. The explanation of the survey method is very detailed, and seems to include both ADLs and IADLs in the definition of caregiving, also giving detailed directions and support to the enumerator in identifying family carers within a household.

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.

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

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

<sup>9</sup> <http://www.assemblyresearchmatters.org/2016/04/29/a-demographic-profile-of-northern-ireland-in-2016/>

<sup>10</sup> <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>

(16.2%, unofficial, Italy)<sup>11</sup>. No carer prevalence data, either official or unofficial, could be found for 11 of the 29 countries.

In the US, a 2015 survey question (presented below) provides the latest figures for caregiving<sup>12</sup>.

*At any time in the last 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.*

*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, behavioral, or other condition or 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 behavioral problems, or developmental problems.*

Estimated caregiver prevalence lies at 18.2% of the adult population or approximately 43.5 million. 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.

It is clear from the details above that Ireland's current estimated Family carer prevalence of approximately 4.1% is far below comparable rates in the US, UK, Australia and much of Europe. Indeed, other CSO backed studies (such as the Irish Health Survey 2015) suggest numbers of Family Carers across Ireland which are far more in keeping with expected rates (c. 10%). In order to ensure that the national Census data is robust enough to withstand critique, we are now suggesting a rewording of the relevant question for Census 2021. This suggestion for rewording is outlined later.

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<sup>11</sup> Eurocarers, 'Overview of Carers' Needs and Existing Support Measures across Europe – 2017.' (Eurocarers, 2017),

<http://eurocarers.org/userfiles/files/factsheets/Eurocarers%20Situation%20of%20carers%20in%20EU.pdf>.

<sup>12</sup> AARP Public Policy Institute and National Alliance for Caregiving, 'Caregiving in the U.S.' (National Alliance on Caregiving, 2015).

## Why changes are needed

### Current & future need planning

Robust data provides evidence to support estimates of the quantum of need when used in parallel with official data on state support provision 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.

### Advocacy work

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.

### Encourage identification & access to services

Currently, for many, taking on the identity and label of 'family carer' is 'the gateway through which supports are accessed'<sup>13</sup>. A reluctance to assume this identity can affect the support they themselves receive or are open to receiving in their role as carer, a role which has of course been acknowledged to have many challenges for individuals in terms of physical and mental health<sup>14</sup>, social isolation<sup>15</sup>, finance<sup>16</sup> and employment. Many Family Carers in Ireland don't identify themselves as "Family Carers." For some, they prefer to think of themselves purely as family members helping out, and view their significant contribution in this manner as simply "what families' do". There are many issues which can have an impact on this willingness to

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<sup>13</sup> Victoria Molyneux et al., 'Reconsidering the Term "Carer": a Critique of the Universal Adoption of the Term "Carer"', *Ageing and Society* 31, no. 3 (2011): 422–37.

<sup>14</sup> Liam O'Sullivan, 'Health and Well-Being of Family Carers in Ireland: Results of a Survey of Recipients of the Carer's Allowance' (Combat Poverty Agency, 2008); Ann Stokes, 'The Caring Reality of Family Carers: An Exploration of the Health Status of Family Carers of People with Parkinson's Disease.', 2010, <http://www.carealliance.ie/userfiles/file/FullReportFinal.pdf>; The Carers Association of Ireland and Royal College of Psychiatrists, 'The Health of the Carer in Ireland' (The Carers Association, 2009).

<sup>15</sup> O'Sullivan, 'Health and Well-Being of Family Carers in Ireland: Results of a Survey of Recipients of the Carer's Allowance'.

<sup>16</sup> OECD, 'The Impact of Caring on Family Carers', in *Help Wanted? Providing and Paying for Long-Term Care* (OECD, 2011); E O'Shea, 'The Costs of Caring for People with Dementia and Related Cognitive Impairments' (National Council on Ageing and Older People, 2000).



self-identify, but it is possible that clear definitions, via national surveys such as the Census of Population may introduce them to the identity of "Family Carer", and consequently to the supports which can assist them in their role.

### Recommended Wording

In light of the issues highlighted above, and consistent with the language used in the UK Census and the Irish Health Survey, Care Alliance Ireland join with our colleagues in Family Carers Ireland in recommending the wording of question 22 to be changed to:

Q22. Do you look after, or give any help or support to family members, friends, neighbours or others (adults or children) because of either a:

- long-term illness, physical or intellectual disability or mental ill-health
- problems related to old age

Do not include anything you do as part of your paid employment.

- Yes
- No

If Yes, for approximately how many hours of care do you provide each week. (Please note care provided on a 24 hour basis, 7 days a week equates to 168 hours).

\_\_\_\_\_ hours per week

### Addendum

As an addendum, we would like to offer for consideration a recommendation that more information be sought regarding who Ireland's Family Carers are caring for. This would include a sub-question with two parts as follows;

**To whom to you give this support? (You may choose more than one)**

Child  
Parent  
Sibling  
Partner

Other relative  
Neighbour/friend

**Why does this person require this support? (You may choose more than one)**

Physical disability  
Intellectual disability/autism  
Other cognitive impairment (E.g. dementia)  
Mental ill health  
Long-term illness  
Problems related to old-age

This additional information would be useful to build upon the basic information regarding the supports needed for Family Carers, to ensure that the correct supports are in place. Whilst the broad needs of Family Carers are similar regardless of the person they provide care to, those caring for a spouse will encounter some significantly different support needs than a parent caring for a child with a disability, or a parent with a cognitive impairment. Having robust data regarding these issues, and in particular the specific quantum of need, will allow government departments, health and social care services and not-for-profit groups to plan and deliver their supports and commitments under national policy such as the National Carers Strategy<sup>17</sup>.

Conclusion

It is clear that there is a need to reword Q22 of the Irish census of population, regarding the quantum of family caring in Ireland. This submission has outlined why this is necessary, with reference to current Irish national statistics, and to comparable statistics internationally. A new wording of Q22 is suggested, along with a possible addendum to further expand the level of data collected to bolster the practical application of this data.

<sup>17</sup> Department of Health, 'The National Carers' Strategy' (Department of Health, 2012).

## Background Information on Care Alliance Ireland

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. Our vision is that the role of Family Carers is fully recognised and valued by society in Ireland.

We exist to enhance the quality of life for Family Carers. We achieve this by supporting our member organisations in their direct work with Family Carers through the provision of information, developing research and policy, sharing resources, and instigating opportunities for collaboration.

There are in the region of 360,000 Family Carers in the Republic of Ireland. Family Carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions. We work with our 85 member organisations and other agencies to support them in their work with Family Carers.

Our legitimacy derives in part from our membership base which includes a wide range of organisations currently providing services to Ireland's Family Carers. Our membership is comprised of both large and small, regional and national organisations. We provide them with opportunities to collaborate on initiatives including National Carers Week, a multi-agency and multi-disciplinary Family Carer Research Group, and joint policy submissions. We actively encourage collaboration in all our projects. We provide cohesion to those organisations working to support family carers. We commission relevant research that supports quality interventions in the lives of family carers.

By focusing on these functions we enable more of our member's resources to go directly to coal face services.

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