



# Counting Carers: Carer prevalence in Ireland

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Working Paper 1



Family  
Carers  
Ireland

No one should have to care alone

# Counting Carers: Carer Prevalence in Ireland

## Working Paper 1<sup>1</sup>

### EXECUTIVE SUMMARY

In a policy-making system that increasingly looks to an 'evidence-base' for legitimisation, the existence of reliable and relevant data is of fundamental importance. Unfortunately, as this paper shows, the enumeration of family carers in Ireland is fraught with a number of practical challenges which typically contribute to inconsistencies and under-reporting in carer prevalence rates. As a consequence, policy in the area is inadequately informed, service planning is based on partial information and the effectiveness of interventions aimed at supporting carers cannot be properly assessed. Whilst having an accurate figure on carer prevalence is crucial, statistics must also show the circumstances in which carers live, the nature of the care they provide, the impact it has on their lives and the key factors influencing that impact. Regular, reliable and comprehensive survey data on carer prevalence and impact, together with research based on that data, has the potential to significantly improve our understanding of caring and the political and societal response needed. The purpose of this paper is to:

1. explain carer prevalence data, including the replacement value of care, used by *Family Carers Ireland* and the methodological and practical considerations that inform this approach;
2. identify the sources of data available with regard to the prevalence of family carers in Ireland and outline some of their weaknesses in terms of how care is conceptualised in survey/census questions.
3. examine the conceptualisation of care and how questions relating to what constitutes care, who cares and how much care they provide can impact carer self-identification and ultimately carer prevalence rates;
4. make recommendations on how data relating to caregiving in Ireland could be improved to give a more realistic and relevant insight into the prevalence of family caring.

### KEY FINDINGS

#### Anomalies in carer prevalence data

- The carer prevalence rate identified through the Census of Population has been consistently low and at variance with prevalence rates in other countries. For example, the Irish carer prevalence rate in Census 2002 was 4.8 per cent and decreased to 4.1 per cent in Census 2016 – this is compared to a carer prevalence rate of 12 per cent in Northern Ireland in 2011.
- The concern regarding this international disparity is heightened due to the significant difference between carer prevalence rates within Ireland identified by the Irish census (4.1%) and the Irish Health Survey (12.5%), both of which are undertaken by the CSO but differ in terms of the question asked and the methods of data collection.
- A review by the UK's Office for National Statistics on the unpaid care question included in the UK census found that family carers identified with the phrase 'look after' rather than 'help or support', particularly those caring for family members. Participants believed that 'look after' along with 'help or support' better encompassed all caring responsibilities and tasks

#### Problems with phrasing survey/census questions on unpaid care

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<sup>1</sup> [Census 2022 summary results published on 30<sup>th</sup> May 2023](#) show that over 299,000 people identify as unpaid carers, an increase of 53% on 2016. There was also an increase in the number of hours of care provided each week, with the largest increase among people providing care for 43 hours of more per week, up 111%. This paper will be updated after Census 2022 Profile 4 - Disability, Health and Carers is published on 28<sup>th</sup> September 2023.

- The phrasing of questions relating to caregiving and the understanding of what care activities that phrasing implies are critical to the validity of the measurement of care.
- Poor or ambiguous wording of survey questions can lead to under-reporting and may explain some of the discrepancies in carer prevalence data.
- The question relating to unpaid care in the Irish Census uses the terminology of 'personal help' which leaves the question open to interpretation and may cause some respondents who provide other types of 'non personal care' not to identify as a carer.
- Some people do not immediately identify with the term 'carer' but rather think of themselves in relational terms, such as a wife, father, son or daughter. This lack of self-identification with the term 'carer' can also lead to under-reporting of unpaid care.
- The Irish Health Survey uses the broad language of 'care or assistance' to measure the prevalence of carers in Ireland. However, a review by the UK's Office for National Statistics on the wording of the unpaid care question in their census found that the phrase 'look after' along with 'help or support' better encompassed all caring responsibilities.
- The low numbers of family carers enumerated through the census has led *Family Carers Ireland* and others in the sector, to rely predominantly on the CSO's Irish Health Survey as the most reliable source of data on carer prevalence because it uses a more broadly defined approach to care in its wording<sup>2</sup>. The prevalence rate of carers identified through the Irish Health Survey (12.5 per cent) is also in line with those identified in other European countries.

### **Problems with enumerating young carers**

- Young carers often do not identify as carers, instead seeing themselves as a daughter, son, sibling, grandchild. This is complicated further by societal norms around caring whereby adults are typically expected to provide care to other adults and children, whilst young people are not expected to be care-givers but rather care recipients. As a result, many young carers remain 'hidden'.
- This is compounded in surveys and censuses where the head of the household or adult is the respondent. For example, the Irish Census requires the parent or head of household to disclose their child's caring role. They may be reluctant to do this due to a fear of stigmatisation related to the aforementioned norms, concerns about privacy or the intervention of child protective services.
- This explains discrepancies between surveys completed by adults and those completed by young people themselves. Census 2016 identified 6,108 carers under 18, a total of 0.5 per cent of the child population. By comparison the Health Behaviour in School-aged Children Survey (HBSC) 2018, which is completed by the child, reported 13.3 per cent of 10-17 year olds surveyed (n= 15,557) said they provide regular, unpaid personal help for a family member with a long-term illness, health problem or disability.

### **Challenges in measuring the intensity of care**

- Measuring the intensity of care is based on family carers accurately reporting the number of hours of care they provide. The primary method for calculating time spent caring in national surveys is the 'recall' method. This has been studied extensively and it has been shown to be subject to bias, where overestimation and more often underestimation, is likely.
- An alternative method for capturing unpaid care is the diary method, where activities are recorded as they are conducted over a specified time period. However, implementation of this method is not feasible for large surveys or censuses because measuring hours in this way is too time-consuming for survey respondents and researchers.
- Irish national surveys recording average hours of weekly care use the recall method but take alternative approaches. The Census asks participants to write in how many hours of care they provide on a weekly basis. In its 2015 wave, the Irish Health Survey (IHS) similarly asked respondents to write in how many hours of care they provided. Respondents could state they

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<sup>2</sup> The Irish Health Survey (IHS) is the Irish version of the European Health Interview Survey (EHIS) which gathers data on health status, health care usage and health determinants and allows for health comparisons to be made across European Member States.

care for 168 hours per week, indicating the intense and full-time nature of their caring role. The two surveys were relatively consistent with an average of 38.7 hours (Census 2016) and 44.7 hours (IHS 2015) per week.

- The 2019 wave of the IHS changed its approach to measuring care hours, instead instructing respondents to record their average hours of weekly care in categories of less than 10 hours per week, between 10 and 19 hours per week and 20 hours per week or more. Almost one third of respondents stated they cared for 20 hours or more, which is a crude measurement that does not capture the full-time nature of caring.
- The Irish Census asks participants if they provide 'regular unpaid personal help' a term which is open to different interpretations. Is 'regular' every day, once a week, once a fortnight? There is scope for interpretation which undermines the validity of the instrument when 'regular' is used in the question without clarification on what counts as 'regular'.

### Replacement value estimates used by Family Carers Ireland

The replacement cost method measures the cost of 'buying' an equivalent amount of care from a private homecare provider, if the unpaid care provided by a family member or friend was not available. Using the replacement cost model to put an economic value on informal care results in the following annual replacement costs:

- Replacement cost based on average hours of care - €20bn per annum
- Replacement cost based on median hours of care - €7.8bn per annum
- Replacement cost based on Census 2016 carer prevalence 4.1 percent and mid-point hours – 8bn per annum

### Carer prevalence data officially used by *Family Carers Ireland*:

- **12.5 per cent** of the Irish population aged over 15 years provide care (Irish Health Survey 2019).
- Extrapolation to national population means Ireland has some **499,904 family carers**.
- Carers provide an average of **38.7 hours of care each week** (Census 2016).
- The median hours of care provided is **15 hours per week** (Census 2016).
- **Annual replacement cost of unpaid care ranges from €7.8bn to €20bn** depending on whether the average or median hours are used and based on an hourly replacement value of €20.
- HBSC study found 13.3 per cent of children aged 10-17 years provide care. Extrapolation to national population means there could be nearly **67,000 young carers** in this age cohort.

## Recommendations

### Address the disparity in CSO data in relation to unpaid care

In 2018 the CSO undertook a public consultation regarding Census 2022 with a range of stakeholders, including organisations representing family carers. While this engagement was welcome, a number of important changes recommended by sector representatives were not incorporated into the wording of the unpaid care question. Because of the disparities in carer prevalence data identified across CSO sources (census and IHS), it is important that the CSO investigates the reasons for this disparity and takes measure to address it.

### Review the phrasing of 'unpaid care' questions

Caring involves a wide range of tasks, not only activities of daily living (e.g. toilet hygiene, feeding) and instrumental activities of daily living (e.g. shopping, preparing meals), but also managing care and providing social support. When family caring is defined with such a broader focus in survey questions, carers who regularly provide emotional support, transport, cooking and cleaning and/or medication management are more likely to answer 'yes'. This can lead to a more accurate enumeration of unpaid carers in the population. As such, *Family Carers Ireland* encourages a broad understanding of care in the operationalisation of survey questions on unpaid caring.

### Guidance on the recording of care hours

Challenges exist with regard to the accurate measurement of the time spent providing care through carers' completion of census or survey questions. While there is no simple solution, the inclusion of questions relating to care hours is important for policy and service development. It is also the case that the identification of carers early in their caregiving journey, when they are providing a relatively small amount of care, can allow the supports they need to grow as the intensity of their caregiving increases. While the notes included as an appendix to the census questionnaire explain the unpaid care question, few people take the time to read this. Therefore an explanation of care hours and tasks should be included within the question itself.

### ***Combining censuses with more frequent national surveys***

Population censuses are major operations conducted at lengthy intervals, they are not meant to monitor change continuously. It is increasingly regarded as best practice to supplement census data with more regular national surveys. In an Irish context this can be achieved through the continued inclusion of a carer question in the Irish Health Survey while including for the first time a new question on workers with caring responsibilities in the national Labour Force Survey and the Personal Work Life Balance Survey as well as including a module on caring in the Quarterly National Household Survey.

### **Capturing the hours of care in the Irish Health Survey**

Given the under-reporting of carers in the census, carer advocates now rely on data from the Irish Health Survey. A question on unpaid care was included in the first Irish Health Survey in 2015 and again in the 2019 survey. In the 2015 survey, care hours were captured through an open-ended question however, in the 2019 survey the question was amended in line with the European Health Survey to record care hours in bands of 'less than 10 hours, between 10 and 20 hours or more than 20 hours per week'. *Family Carers Ireland* recommends that the CSO revert to the original open-ended question.

### **Campaign to raise awareness of young carers**

The extension of the census question to include young people with caring responsibilities in Census 2011 was an important development, however subsequently the disparity in young carer prevalence between census data and the HBSC survey (0.5% versus 13.3%) undermines the credibility of the census. *Family Carers Ireland* recommends that the CSO along with the caring sector undertake an awareness campaign targeted at young carers in advance of Census 2022 and that any review of census question wording will include a focus on achieving a more accurate enumeration of young carers.

### **Supporting carer identification**

How people conceptualise care and what they understand care activities to be, as well as how they define themselves in relational terms with the cared for person is a significant challenge towards a more accurate enumeration of family carers. Efforts to increase carer identification and ultimately improve their uptake of supports needs to be sensitive to both the carer and cared-for person's perceptions of their familial roles.

### **Inclusion of care specific questions in the Labour Force Survey:**

The inclusion of care-related questions in the Labour Force Survey is welcome, however the survey could be strengthened by a greater distinction between childcare and caring for a child or adult with additional needs as well as the inclusion of a question on the number of people in employment who juggle work with caring responsibilities. This would help inform the development of policies and practices designed to support working carers. Similar to the Quarterly National Household Survey, the Labour Force Survey will conduct modules on social topics, so the CSO could include a module to examine the prevalence, issues and experiences of working carers.

### **Creation of a Family Carer Register**

*Family Carers Ireland* recommends the establishment of a 'Family Carer Register', similar to the model used in the UK. Family carers could self-identify and ask to be placed on the register as well as being identified by healthcare professionals and others who provide support to them and their loved one.

This register would provide a local, regional and national register of family carers, regardless of what financial support they receive, that would assist in the planning and delivery of services.

### Next steps

This working paper is the first in a series of papers which will examine carer prevalence, the intensity of care provision, the valuation of care and the mutuality of caregiving using various data sources. These papers will be published periodically and will be available at [www.familycarers.ie](http://www.familycarers.ie)

## Counting Carers: Carer Prevalence in Ireland

### Working Paper 1

In a policy-making system that increasingly looks to an ‘evidence-base’ for legitimisation, the existence of reliable and relevant data is of fundamental importance. Unfortunately, as this paper shows, the enumeration of family carers in Ireland, as in other countries, is fraught with a number of practical challenges which typically contribute to inconsistencies and under-reporting in carer prevalence rates. This means that only a partial picture of the prevalence and impact of caring in Ireland is available. As a consequence, policy in the area is inadequately informed, service planning is based on partial information and the effectiveness of interventions aimed at supporting carers cannot be properly assessed. This is especially important given the adverse impacts that caring can have on a person’s health, wellbeing, employment and quality of life. Whilst having an accurate figure for the number of carers in the general population is crucial, statistics must also aim to show the circumstances in which carers live, the nature of the care they provide, the impact it has on their lives and the key factors influencing that impact. Obtaining a clearer picture of the prevalence and impact of caring while addressing inconsistencies in current data sources is needed to reduce unmet needs and inequalities experienced by carers. Regular, reliable and comprehensive survey data on carer prevalence and impact, together with research based on that data, has the potential to significantly improve our understanding of caring and the political and societal response needed.

### Why Carers Count

Informal care, also known as unpaid or family care, is of significant and increasing importance in the context of an ageing population, increasing life expectancy, improved survival rates for chronic conditions and policies to shift the delivery of care towards care in the home. Family carers are the main source of care provision for those in need of care due to a long-term illness, disability or frailty and are estimated to provide between 70 to 95 per cent of all care in the community<sup>3</sup> with an economic value equivalent to 50 to 90 per cent of the overall cost of long-term care across the EU.<sup>4</sup> The European Social Survey on Informal Carers found that on average one in three adults between 25 and 75 years provide informal care across Europe and about one in 13 are considered intensive caregivers<sup>5</sup>. Indeed, the European Union has taken an important step in recognising the crucial role of family carers in long-term care provision through its Social Protection Committee/European Commission (DG EMPL) Report on Long-term Care, which provides a comprehensive overview of the common long-term care challenges faced by Member States<sup>6</sup>. The short and long-term costs of caring as well as the economic

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<sup>3</sup> Zigante, Valentina. 2018. ‘Informal Care in Europe: Exploring Formalisation, Availability and Quality.’ Brussels: LSE Consulting for the European Commission, 2018.

<sup>4</sup> Social Protection Committee and the European Commission. Adequate protection for long-term care needs in an ageing society [Internet]. Luxembourg: Publication Office of the European Commission; 2014 [cited 2020 May 24] Available from: <https://opeco.europa.eu/en/publication-detail/-/publication/71532344-ddf1-4d34-a7aa-f65c701a22a2>

<sup>5</sup> *European Journal of Public Health*, Volume 27, February 2017, Pages 90-95, <https://doi.org/10.1093/eurpub/ckw229>

<sup>6</sup> Social Protection Committee/European Commission (DG EMPL) (2021) ‘Joint Report on Long-term Care: Trends, challenges, and opportunities in an ageing society’, <https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8396>



value of informal care are mapped out in the report, highlighting why supporting carers is a fundamental social policy issue across Europe

Caring for a loved one is associated with a number of benefits, such as emotional rewards, personal growth and a sense of accomplishment<sup>7</sup>. However, caring can also have adverse impacts on carers when they are not adequately supported. There is mounting evidence that unpaid caring should be considered a social determinant of health with caregiving frequently having an impact on the physical and mental health of family carers. Compared to the general population, carers who responded to Family Carers Ireland’s State of Caring survey in 2020 were more likely to have poorer health and a longstanding disability, illness or health condition than the non-caring population<sup>8</sup>. Specific adverse effects on physical health include higher rates of back injuries and high blood pressure<sup>9</sup>. Carers are less likely than others to prioritise their own needs which can lead to harmful behaviours such as poor diet or sleep habits and a failure to take preventative health measures. Many carers also find it difficult to balance paid work with caring responsibilities, which can impact on labour force participation. The pressure of combining paid work and care can lead carers (many of whom are working-age women) to give up work or reduce their hours, which can result in financial difficulties and pension disadvantage in later life. In addition, there are potentially considerable indirect or non-financial costs of caring, costs such as social exclusion, erosion of personal relationships and psychological wellbeing.

Given the reliance on family carers juxtaposed with the significant financial and personal costs they bear, it is imperative that every effort is made to provide more accurate estimates of the numbers of family carers in Ireland and the intensity of care they provide. This is an important first step to ensure appropriate funding and resources are made available to support the gamut of practical, social, health, financial and wellbeing needs of family carers.

#### **National Carers’ Strategy commitments to capture carer prevalence**

- 1.1: Strengthen awareness and recognition of the role and contribution of carers at national, regional and local level.
- 1.1.3: Build on the work begun in Census 2011 to establish a comprehensive statistical profile of Family Caring in Ireland.
- 2.2.4: Investigate and analyse the situation of children and young people undertaking caring roles.

#### **Structure of the paper**

This working document is the first of a series of papers examining carer prevalence and impact using different data sources. This paper is presented in four parts:

**Section 1** sets out *Family Carers Ireland’s* current estimates in regard to carer prevalence in Ireland and the underlying rationale. It also examines the economic cost and value of family caring in Ireland.

**Section 2** provides a summary of the sources of data with regard to the prevalence of family carers and outlines some of their weaknesses in terms of how care is conceptualised in survey/census questions or where proxy sources are used.

**Section 3** examines the conceptualisation of care and how our understanding of what does or does not constitute ‘care’ impacts on what is measured through survey or census questions with regard to caregiving. This section also considers the hidden nature of care and the fact that many carers fail to

<sup>7</sup> Pysklywec, A., Plante, M., Auger, C., Mortenson, W., & Eales, J. (2020) ‘The positive effects of caring for family carers of older adults: a scoping review’, *International Journal of Care and Caring*, 4(3) pp.349-375.

<sup>8</sup> Family Carers Ireland (2020) *The State of Caring 2020*, Dublin: Family Carers Ireland, <https://familycarers.ie/media/2022/family-carers-ireland-state-of-caring-2020.pdf>

<sup>9</sup> Family Carers Ireland, the Irish College of Psychiatrists and UCD School of Nursing, Midwifery and Health Systems (2019) *Paying the Price – The Hidden Impacts of Caring*, Dublin: Family Carers Ireland, <https://familycarers.ie/media/1422/paying-the-price-the-hidden-impacts-of-caring.pdf>

identify as a family carer, instead recognising their role in relational terms such as wife, father, daughter; and the challenge of accurately capturing the intensity or hours of care provided. Understanding these factors and their impact on the reporting of caregiving are critical precursors to our interpretation of recorded carer prevalence rates.

**Section 4** concludes with a number of preliminary recommendations on how data relating to caregiving in Ireland could be improved and sets out the next steps in terms of obtaining a more realistic and relevant insight into the prevalence and impact of family caring in Ireland.



## Section 1: Explaining the carer prevalence and replacement value estimates used by *Family Carers Ireland*

### Carer prevalence data used by *Family Carers Ireland*:

- **12.5 per cent** of the Irish population aged over 15 years provide care (Irish Health Survey 2019).
- Extrapolation to national population means Ireland has some **499,904 family carers**.
- Carers provides an average of **38.7 hours of care each week** (Census 2016).
- **Annual replacement cost of unpaid care ranges from €7.8bn to €20bn** depending on whether the average or median hours are used and is based on an hourly replacement cost of €20.
- 13.3 per cent of children aged 10-17 years provide care. Extrapolation to national population means there could be **almost 67,000 young carers** in this age cohort (HBSC survey 2018).

Ireland is one of a number of countries who are fortunate to have a question on caring included in the Census of Population. First included in the Irish Census 2002, the question relating to caring has undergone some minor modifications over the years, including the addition of the hours of care provided and the inclusion of young carers in 2011. Unfortunately, however, the carer prevalence rate identified through the census has been relatively low and at variance with prevalence rates in other countries. For example, the Irish carer prevalence rate in Census 2002 was 4.8 per cent and decreased to 4.1 per cent in Census 2016 – this is compared to a carer prevalence rate of 12 per cent in Northern Ireland in 2011. *Family Carers Ireland* believes that the census question has a number of weaknesses in how it captures information relating to carers which has led to significant underreporting (see section 2).

The low numbers of family carers identified through the census has led *Family Carers Ireland* and others in the sector, to rely predominantly on the CSO's Irish Health Survey as the most reliable source of data on carer prevalence because it uses a more broadly defined concept of care in its wording<sup>10</sup>. The prevalence rate of carers identified through the Irish Health Survey (12.5 per cent) is also in line with those identified in other European countries. The wording of the question is not without its problems, however (see Section 3).

While the carer question in the Irish Health Survey 2015 captured the actual number of hours of care provided by individuals, Eurostat<sup>11</sup> amended the wording in the 2019 survey to capture care hours in bands i.e. less than 10 hours, between 10-20 hours, more than 20 hours. This change meant *Family Carers Ireland* could no longer calculate the hourly replacement value of care using Irish Health Survey data and so relies on the average hours of care enumerated in Census 2016 (ave. 38.7 hours per week).

With regard to the prevalence of young carers, *Family Carers Ireland* notes the significant disparity between census data on young carers and the findings of the Health Behaviour in School Aged Children survey (HBSC).<sup>12</sup> Census 2016 identified 3,800 young carers under the age of 15 (a decrease from 4,228 in 2011) and a total of 6,108 carers between 0 and 17 years old<sup>13</sup>. By comparison the HBSC survey 2018 found that 13.3 per cent of 10-17 year olds surveyed (n= 15,557) said they provide regular, unpaid personal help for a family member with a long-term illness, health problem or disability. Extrapolation to the national population would suggest that almost 67,000 young people in the 10-17 year age-group potentially provide regular unpaid care. This is more in line with prevalence rates of young carers in other European states, which suggests between 5-12 per cent of children and adolescents under 18

<sup>10</sup> The Irish Health Survey (IHS) is the Irish version of the European Health Interview Survey (EHIS) which gathers data on health status, health care usage and health determinants and allows for health comparisons to be made across European member states.susu

<sup>11</sup> Eurostat oversee the European Health Interview Survey.

<sup>12</sup> The HBSC survey is a WHO collaborative cross-national study that monitors the health behaviours, health outcomes and social environments of school-aged children.

<sup>13</sup> See State of the Nation's Children 2022 <https://assets.gov.ie/217089/c81cc2ed-a2c9-48d9-baa3-6c6a93488a80.pdf>  
Accessed 28/03/22

years have caring roles; and in the age group 18-25 year olds the figure is higher<sup>14</sup>. Although the two surveys are not directly comparable (the Census results relate to children under 15 whilst the HBSC results relate to 10-17 year olds), there are nonetheless significant differences in the results that are worth investigating further.

### **Replacement value of informal care**

Financial sustainability is one of the main challenges facing long-term care systems across Europe, with some estimates suggesting public spending on long-term care may double or even triple in the decades ahead. Alongside public expenditure, it is broadly accepted that up to 70 to 95 per cent of care across Europe is provided on an unpaid basis by family members and friends. Given this, any consideration of the sustainability of long-term care systems must reflect the economic value of informal care, which cannot be assumed to be a free resource.

Three elements are typically used in the economic valuation of informal care (i) replacement cost (ii) opportunity cost and (iii) contingent valuation (willingness to pay and willingness to accept). Larger studies are required to determine opportunity costs and contingency valuations and as such this analysis focuses only on the replacement cost of informal care. The replacement cost method measures the cost of ‘buying’ an equivalent amount of care from a private homecare provider, if the unpaid care provided by a family member or friend was not available.

Table 1: Replacement cost of family carers

<b>Method</b>	<b>Calculation</b>	<b>Annual Replacement Cost</b>
Replacement cost based on average hours of care	<ul style="list-style-type: none"> <li>- Family carers provide average of <b>38.7 hours of care per week</b> (Census 2016).</li> <li>- 12.5 percent of people aged over 15 years (<b>499,904 people</b>) provide care (Irish Health Survey 2019).</li> <li>- Estimated therefore that <b>1bn hours of unpaid care is provided each year</b>.</li> <li>- <b>Hourly replacement rate of €20</b> based on sector analysis<sup>15</sup>.</li> </ul>	<b>€20bn</b>
Replacement cost based on median hours of care	<ul style="list-style-type: none"> <li>- Median hours of care provided by family carers is <b>15 hours per week (Census 2016)</b>.</li> <li>- 12.5 percent of people aged over 15 years (<b>499,904 people</b>) provide care (Irish Health Survey 2019).</li> <li>- Estimated therefore <b>390m hours of unpaid care</b> is provided by family and friends each year.</li> <li>- <b>Hourly replacement rate of €20</b> based on sector analysis.</li> </ul>	<b>€7.8bn</b>
Replacement cost based on Census 2016 carer prevalence 4.1 percent and mid-point hours. (See appendix 1).	<ul style="list-style-type: none"> <li>- <b>195,263</b> family carers enumerated (Census 2016)</li> <li>- <b>Mid-point hours for each band of care hours provided in Census 2016</b>.</li> <li>- <b>Hourly replacement rate of €20</b> Method uses an average hourly care provision of <b>38.7hrs for the 24,327 carers who did not specify how many hours</b> of care they provide in the census form.</li> </ul>	<b>€8bn</b>

<sup>14</sup> Leu, A., Frech, M., Wepf, H., Sempik, J., Joseph, S., Helbling, L., Moser, U., Becker, S. and Jung, C. (2019). Counting young carers in Switzerland—a study of prevalence. *Children & Society*, 33(1), pp.53-67.

<sup>15</sup> An analysis of hourly homecare rates in the Dublin region ranged from €25 per hour on weekdays to €29 at weekends. Average hourly rates for HSE funded homecare across all their provisions was €25.26 in 2020.

## Section 2: Sources of data on family carer prevalence

A number of Irish data sources on the prevalence of unpaid care exist, and while welcome, the variation in prevalence rates between Census data and other national surveys can cause confusion and risk undermining the credibility of the various data sources. The low rate of carer prevalence identified by successive censuses is at odds with prevalence rates in other countries and also at odds with the Irish Health Survey conducted also by the CSO. For example, in Northern Ireland 12 per cent of the population provide care, in Denmark 13 per cent are carers; in Belgium 9 per cent are carers; and in Sweden 18 per cent are carers - while in Ireland, Census 2016 suggests only 4.1 per cent provide care. Concern regarding this international disparity is heightened when one considers the significant difference between carer prevalence rates within Ireland identified by the Irish census (4.1%) and the Irish Health Survey (12.6%), both of which are undertaken by the CSO but differ in terms of the question asked and the methods of data collection. With the Irish Government confirming that Census 2022 will be a 'no change census' the disparity in prevalence rates, both internationally and within Ireland will persist well into this decade.

### Sources of carer prevalence data

The following table provides a summary of the sources through which carer prevalence in Ireland is estimated, the questions used to gather the information, the prevalence rate identified and any anomalies or considerations relating to that source.

Table 2: Sources of carer prevalence data

Source	Question	Prevalence	Points for Consideration
CSO: Census of Population 2016 <sup>16</sup>	Q.22. Do you provide regular, unpaid personal help for a friend or family member with a long-term illness, disability or health problem? <i>(Include problem which are due to old age. Personal help includes help with basic tasks such as feeding and dressing).</i>  Yes / No  If yes, for how many hours each week. <i>Write in hours.</i> _____ hrs.	Based on entire population  - 4.1% - <b>195,263 carers</b> - 38.7hrs average weekly care - 6,108 <18 yrs	<ul style="list-style-type: none"> <li>• <b>4.1% doesn't align</b> with international data where carer prevalence typically exceeds 10%.</li> <li>• <b>Low enumeration of young carer</b> - reduction between 2011 and 2016 and does not align with the HBSC study, which is completed by the young person themselves.</li> <li>• Considered underestimation due to <b>question wording</b>: <ul style="list-style-type: none"> <li>- Term '<b>unpaid</b>' discourages response from recipients of Carers Allowance, Carers Benefit or Carer Support Grant;</li> <li>- Term '<b>personal help</b>' implies assistance with personal care. Carers providing other forms of care may not respond.</li> <li>- Examples '<i>long-term illness, health problem or disability</i>' and prompt to include care associated with old age, not sufficiently broad. <b>Deters carers of children with autism or carers of people with a mental health difficulty</b> from responding.</li> <li>- Unrealistic expectation carers will accurately calculate weekly hours of care.</li> </ul> </li> </ul> <p><b>High incidence of 'spoiled' questions</b> in previous Census due to carers writing 24/7 rather than 168 hours each week.</p>

<sup>16</sup> A dedicated question on the provision of unpaid care has been included in the Census of Population since 2002.

Source	Question	Prevalence	Points for Consideration
CSO: Irish Health Survey (IHS) 2019 <sup>17</sup>	<p>Q50: 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 (<i>exclude professional activities</i>)? Yes / No</p> <p>Q51: If yes: Are the person or persons concerned family members? Yes / No</p> <p>Q52: If yes: How many hours a week do you give the care or assistance? &lt; 10hrs /10– 120 hrs/&gt;20 hrs</p>	<p>N=7,600 aged &gt;15 years</p> <ul style="list-style-type: none"> <li>- 12.58% carers</li> <li>- <b>499,904 carers</b><sup>18</sup></li> <li>- 86% care for family member</li> <li>- 44.7hrs average weekly care<sup>19</sup></li> </ul>	<ul style="list-style-type: none"> <li>- Accepted within the caring sector as the <b>most reliable source of data</b> on carer prevalence</li> <li>- IHS is <b>Irish version of European Health Interview Survey (EHIS)</b>. Fulfils need for public health policies to obtain reliable data on health status, health usage and health determinants and allows comparisons across Europe.</li> <li>- Prevalence rate <b>closely aligned with international data</b> including UK.</li> <li>- <b>Interviewer administered</b> survey.</li> <li>- Issue with regard to IHS 2019 change in the <b>collection of weekly care hours</b> from absolute hours to banded hours.</li> <li>- Survey includes <b>people aged over 15 years</b> and so includes only young carers aged 15 – 18 yrs.</li> <li>- Phrasing of the question may be biased towards those caring for older people. Explicitly reference to ‘infirmity due to old age’ is not sufficiently broad. Like the Census, this <b>deters carers of people under 65 or carers of people with a mental health difficulty</b> from responding.</li> </ul>
WHO / NUIG Health Behaviour in School-aged Children (HBSC) 2018	<p>Do you provide regular unpaid personal help for a family member with long-term illness, health problem or disability? (<i>Include problems which are due to old age. Personal help includes help with basic tasks such as feeding or dressing</i>) Yes / No</p>	<p>N=15,557 aged 10-17yrs</p> <ul style="list-style-type: none"> <li>- 13.3% report a caring role.</li> <li>- <b>66,956 young carers</b> aged 10-17 yrs<sup>20</sup></li> </ul>	<ul style="list-style-type: none"> <li>- HBSC internationally recognised and supported by <b>WHO and used in 50 countries/regions</b> across Europe and N. America.</li> <li>- Conducted in <b>255 Irish primary and post-primary schools</b></li> <li>- Prevalence <b>aligns with UK studies</b> on young carers.</li> <li>- Young carers more likely to miss school so results may slightly underestimate the prevalence of caring in young people given <b>school-based administration</b> of the survey.</li> <li>- No suggestion that all young people identified carry inappropriate or burdensome caring responsibilities but rather lie along a <b>continuum of care</b>.</li> <li>- Like the Census and the Irish Health Survey, this question also references ‘old age’ so may deter young people looking after parents with mental health difficulties, drug use or alcohol dependencies.</li> </ul>

<sup>17</sup> Question relating to unpaid care has been included in the Irish Health Survey since 2015.

<sup>18</sup> CSO estimated population April 2020 was 4,977,400 persons. Deducting the younger age groups gives an estimate for the population aged 15 years and older of 3,973,800 persons. Extrapolation of the Irish Health Survey estimate of 12.58% to this figure of 3.973m, estimates the number of carers aged 15 years and older at 499,904 persons.

<sup>19</sup> Weekly hours of care derived from Irish Health Survey 2015, where absolute hours were captured. Wording of the question was amended in 2019 and allowed only categorisation of hours of care into bands which meant it is not possible to provide average weekly hours as previously allowed for.

<sup>20</sup> 66,956 young carers is based on an extrapolation of 13.3% to the national population aged 10-17 years old.

Source	Question	Prevalence	Points for Consideration
Behaviour & Attitudes Survey 2020	<p>Q1a. Are you a family carer?</p> <p>Q.1b. Which, if any, of the following types of support do you provide to a family member or friend who is either living with you or currently lives independently but who requires support?</p> <p>Q.1c. On average how many hours per week do you personally provide in order to help that family member/friend?</p>	<p>N=1,044</p> <ul style="list-style-type: none"> <li>- 12% identify as family carer</li> <li>- <b>470,000 carers</b></li> <li>- Increases to 38% when care tasks are considered/ approx. <b>1.4m people.</b></li> <li>- Full-time carers average <b>56hrs per week</b></li> <li>- Ave for all carers is 11.5hrs.</li> </ul>	<ul style="list-style-type: none"> <li>- <b>Small sample of carers</b> approx. 125.</li> <li>- Online data collection due to COVID</li> <li>- Asks respondents about support with the Instrumental Activities of Daily Life (IADL) as well as personal care so relies on a broad concept of care.</li> <li>- High prevalence of people undertaking care tasks at <b>38% is likely due to supporting cocooning relatives</b> during COVID.</li> <li>- <b>12% prevalence aligns to IHS</b></li> </ul>
Data from Government Schemes	<p>Limited data regarding family carers could be gleaned through various Government schemes e.g. claimants of:</p> <ul style="list-style-type: none"> <li>- Carer's Allowance/ Carer's Benefit</li> <li>- Carer's Support Grant</li> <li>- Care related tax credits/reliefs<sup>21</sup></li> <li>- Homemakers Scheme</li> <li>- Housing Adaptation Grant scheme</li> <li>- Disabled Drivers and Passengers Scheme.</li> </ul>	<p>Carers Allowance - <b>91,000</b></p> <p>Carers Benefit - <b>3,600</b></p> <p>Carers Support Grant - <b>118,813</b></p>	<ul style="list-style-type: none"> <li>- Does not provide an accurate reflection of the prevalence of caregiving as <b>only a proportion of carers captured.</b></li> <li>- Do not capture the <b>extent of care</b> being provided.</li> <li>- Risk of <b>double counting</b> as the same carer is likely to be included across different sources.</li> <li>- <b>Data protection</b> legislation is likely to mean these sources of information cannot be used for any purpose.</li> </ul>

### **Annual Carer's Support Grant**

One of the most commonly used sources of information regarding 'full-time' family carers is the number of carers who receive the Carer's Support Grant. The Carer's Support Grant is an annual, non-means tested grant of €1,850 paid to family carers who (i) provide in excess of 35 hours of care each week (ii) to someone medically assessed as in need of full-time care and (iii) who doesn't work or study for more than 18.5 hours a week. In 2021, 118,813 family carers received the grant, an average of 2.5 per cent of the total adult population<sup>22</sup>. The inference that can be drawn from these data is that of the 13% of the Irish population who identify themselves as a family carer (Irish Health Survey 2019), a minimum estimate suggests that 2.5 per cent provide high level, full-time care for a person medically assessed as in need of full-time care.

<sup>21</sup> Home Carer Tax Credit; Dependent Relative Tax Credit; Incapacitated Child Tax Credit; Tax Relief on Employing Home Carer.

<sup>22</sup> Ireland's population in 2020 is estimated at 4,937,786 according to UN data.

### Section 3: The conceptualisation of care – what is care, who cares and how often?

#### **What is care?**

Interest in family care has grown in recent years due to our ageing population, the growing incidence of age-related conditions and the shift away from institutional care for people with disabilities and towards home-based care. Against this backdrop, community care has become a priority in most EU Member States with the shift towards home-based care regarded as a practical measure to contain the costs of services while also supporting widespread preferences among (older) people.

This changing context has led to a greater attempt to gather statistical data on caring activities taking place in the home. One of the challenges in measuring family care is ensuring there is a clear definition of what activities constitute care i.e. what we are trying to measure. At its simplest, family care is the provision of help and support to others without contractual obligation. However, this definition becomes ambiguous in the home setting where it is difficult to distinguish between caring tasks and the many activities that form routine parts of family life e.g. preparing a hot meal or driving someone to a medical appointment. Understanding caring activities that address a need or dependency of the recipient is one way to distinguish between routine and caring activities<sup>23</sup>. Van den Berg and Spauwen<sup>24</sup> go further and distinguish between support with Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADLs) and housework activities. ADLs include support with personal care such as bathing, dressing, feeding or using the bathroom. On the other hand, IADLs include shopping, cleaning, transport or managing medications. The OECD opts for this broader approach, as increasingly does the EU. However, Van den Berg and Spauwen also recognise the difficulties in separating out ‘normal housework’ from caring activities. Other studies also refer to emotional or psychosocial support as an active caring activity<sup>25</sup>.

The phrasing of questions relating to caregiving and what care activities that phrasing implies are critical to the validity of the measurement of care. The consensus from the academic literature is that informal care metrics should be broad enough to capture a diverse range of activities, they should demonstrate that caring is ‘additional’ to regular household tasks and they should measure the intensity of the activity, at least through capturing the number of hours spent caring<sup>26</sup>. In practice, however, survey questions on family caring are typically relatively simple, operationalised by asking a yes or no question about whether an individual has provided care for others rather than asking questions about the activity. The UK’s Office for National Statistics (ONS) undertook a review of the unpaid care question in advance of Census 2021, in consultation with family carers and other stakeholders. The review found that family carers identified with the phrase ‘look after’ rather than ‘help or support’, particularly those caring for family members. Participants thought ‘look after’ along with ‘help or support’ encompassed all caring responsibilities and tasks. In contrast, the unpaid caring question in the Irish Census uses the terminology of ‘personal help’ which leaves the question open to interpretation by the respondent – what sort of activities constitute care in this question? Respondents may have interpreted the question as requiring a ‘no’ because they do not dress or feed someone yet they regularly provide emotional support and transport, cook and clean and/or take responsibility for medications. The wording of the survey questions can therefore lead to significant under-reporting of unpaid care and helps explain some of the differences in results outlined below. The Irish Health Survey, for example, uses the broad language of ‘care or assistance’ to measure the prevalence of carers in Ireland but given the ONS review, the language of ‘look after’ may be more appropriate. The

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<sup>23</sup> Arber, S., & Ginn, J. (1990). The meaning of informal care: gender and the contribution of elderly people. *Ageing & Society*, 10(4), 429-454.

<sup>24</sup> Van den Berg, B., & Spauwen, P. (2006). Measurement of informal care: an empirical study into the valid measurement of time spent on informal caregiving. *Health economics*, 15(5), 447-460.

<sup>25</sup> Hielscher, E., Diminic, S., Kealton, J., Harris, M., Lee, Y. Y., & Whiteford, H. (2019). Hours of care and caring tasks performed by Australian carers of adults with mental illness: results from an online survey. *Community mental health journal*, 55(2), 279-295.

<sup>26</sup> Rutherford, A. C., & Bu, F. (2018). Issues with the measurement of informal care in social surveys: Evidence from the English Longitudinal Study of Ageing. *Ageing & Society*, 38(12), 2541-2559.



choice of what question and terminology to use in operationalising unpaid care is therefore critical to the validity of measurements.

### **Who cares?**

A further issue is that surveys of family carers rely on self-reported data collected by carers themselves or by asking people with care needs if they have a family carer. Despite initiatives to identify carers (e.g. *Family Carers Ireland's 'Carers Count'* campaign which encouraged family carers to complete the Census 2011 caring question accurately), a significant number of family carers remain unidentified. A widespread finding in carer research is that people do not immediately identify with the term 'carer' but rather think of themselves in relational terms, such as a wife, father, son or daughter<sup>27 28</sup>. This is especially the case when the care needs increase gradually over time for older spousal carers, and when caring for children, who generally require considerable care, even in the absence of illness or disability. However, self-identification for carers is not merely about a lack of awareness. The label of 'carer' may be actively resisted for many reasons, such as the complex emotions involved when acknowledgment of the caring role means recognition of the care needs or dependency of another<sup>29</sup>; they may experience feelings of guilt and question the legitimacy of their need's vis a vis the needs of the cared for person<sup>30</sup>. Those who don't identify with the term 'carer' or 'care' may respond 'yes' to a carefully worded survey question that is inclusive of a broad range of caring activities.

A further area of concern relates to the hidden nature of caring, particularly among young people. Often young carers aren't identified until a crisis. However, the sooner a person is identified as a young carer, the more support can be put in place to help keep them safe, well and able to enjoy normal childhood experiences. It is also critical to understand that the impacts of caring are not always negative, but rather there is a continuum of caring in terms of the tasks a young carer performs and the impact this has on their lives<sup>31</sup>. It is important to differentiate between a level of caring that has largely positive consequences and a level of physical or emotional caring that impairs the child's health, development or welfare. These two points are also relevant to adult carers.

The lack of self-identification amongst young carers is complicated further by societal norms around caring<sup>32</sup>. Adults are typically expected to provide care to other adults and children, whilst young people are not expected to be care-givers but rather care recipients<sup>33</sup>. As a result, many young carers remain 'hidden'. This is further compounded in surveys and censuses where the head of the household or adult is the respondent. For example, the Irish Census requires the parent or head of household to disclose their child's caring role. They may be reluctant to do this due to a fear of stigmatisation related to the aforementioned norms, concerns about privacy or the intervention of child protective services. This is another factor leading to the under-reporting of care and explains discrepancies between surveys completed by adults and those completed by young people themselves. For example, according to the Census 2016, which was completed by the head of the household, there were 6,108 young carers in Ireland under 18, whereas the Health Behaviours in School-Aged Children (HBSC) 2018 study, completed by young people themselves, suggests there are approximately 67,000 young carers between 10 and 17 years old in Ireland. These disparities have important implications for research and

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<sup>27</sup> Hughes, N., Locoock, L., & Ziebland, S. (2013). Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis. *Social science & medicine*, 96, 78-85.

<sup>28</sup> Carduff, E., Finucane, A., Kendall, M., Jarvis, A., Harrison, N., Greenacre, J., & Murray, S. A. (2014). Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. *BMC Family Practice*, 15(1), 1-10.

<sup>29</sup> Larkin, M., Henwood, M., & Milne, A. (2019). Carer-related research and knowledge: findings from a scoping review. *Health & social care in the community*, 27(1), 55-67.

<sup>30</sup> Soothill, K., Morris, S. M., Harman, J. C., Francis, B., Thomas, C., & McIlmurray, M. B. (2001). Informal carers of cancer patients: what are their unmet psychosocial needs?. *Health & social care in the community*, 9(6), 464-475.

<sup>31</sup> Frank, J. (2002) Making it Work. Good Practice with Young Carers and their Families. London: The Children's Society and The Princess Royal Trust for Carers.

<sup>32</sup> Smyth, C., Blaxland, M., & Cass, B. (2011). 'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers. *Journal of Youth Studies*, 14(2), 145-160.

<sup>33</sup> Becker, S. (2007). Global perspectives on children's unpaid caregiving in the family: Research and policy on 'young carers' in the UK, Australia, the USA and Sub-Saharan Africa. *Global social policy*, 7(1), 23-50.



practice. Policy-makers and stakeholders need to know how many young people have caring responsibilities and the impacts of caring on them so they can develop appropriate and effective support on a national scale.

### ***Intensity of care***

Generally, measuring the intensity of care relies on family carers to accurately report the number of hours of care they provide. In practice, this is very difficult and subject to significant error. The primary method for calculating time spent caring in national surveys is the 'recall' method. This has been studied extensively and it has been shown to be subject to bias, where overestimation and more often underestimation, is likely<sup>34</sup>. This was reported to be particularly true for older and female caregivers<sup>35</sup>. Underestimation occurs because carers don't account for 'joint production' (i.e. activities that can serve multiple purposes when the carer and the person they support are doing things together, for example shopping) and they often find it difficult to distinguish between caring and non-caring tasks, especially when living in a shared household<sup>36</sup>. Over-estimation can occur when tasks completed simultaneously are reported several times. An alternative method for capturing unpaid care is the diary method, where activities are recorded as they are conducted over a specified time period. However, implementation of this method is not feasible for large surveys or censuses because measuring hours in this way is too time-consuming for survey respondents and researchers, and too expensive for the surveys.

Irish national surveys recording average hours of weekly care use the recall method but take different approaches. The Census asks participants to write in how many hours of care they provide on a weekly basis. In its 2015 wave, the Irish Health Survey (IHS) similarly also asked respondents to record how many hours of care they provided. Respondents could state they cared for up to 168 hours per week, indicating the intense and full-time nature of their caring role. The two surveys were fairly consistent with an average of 38.7 (Census 2016) and 44.7 hours (IHS 2015) per week. However, the 2019 wave of the IHS changed its approach to measuring care hours, instead instructing respondents to record their average hours of weekly care in categories of less than 10 hours per week, between 10 and 19 hours per week and 20 hours per week or more. Almost one third of respondents stated they cared for 20 hours or more, which is a crude measurement that underestimates the full-time nature of caring. This all contributes to making it difficult to put a valuation on unpaid care since it is not possible to calculate average or median hours of care per week.

The idea of caring 'full-time' also needs unpacking. In Ireland, one of the criteria a carer must meet to qualify for Carer's Allowance is to provide more than 35 hours of care per week. Yet studies have shown that full-time care often means attending to the person's care needs 24-hours a day. Whilst the allowance is not thought of as a salary but as a social assistance payment, the maximum amount, €219 in 2021, is far below the minimum wage. Thus, the family carer is recognised as a carer but not as a worker. Although out of the scope of this paper, a discussion is needed about the reasonable limits that can be expected from carers and what might constitute a 'caring day'.

In a similar vein, the use of the term 'regular' in questions about care is not a neutral or clear concept. The Irish Census asks participants if they provide care 'regularly' which may take on different meanings for different people. Is 'regular' every day, once a week, once a fortnight? Does 'regular' care not take into account the out-of-the-ordinary or crisis care that may take place in the event of a fall or deterioration of a condition? There is scope for interpretation here which again calls into question the validity of the instrument. Given these and the issues outlined above, it is critical that users of care-related statistics are aware of the understanding of family care implicit in the data they are using, the issue of self-identification and problems with recording hours of care using the recall method.

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<sup>34</sup> Van den Berg, B., & Spauwen, P. (2006). Measurement of informal care: an empirical study into the valid measurement of time spent on informal caregiving. *Health economics*, 15(5), 447-460.

<sup>35</sup> Flyckt, L., Lothman, A., Jorgensen, L., Rylander, A., & Koernig, T. (2013). Burden of informal care giving to patients with psychoses: A descriptive and methodological study. *International Journal of Social Psychiatry*, 59(2), 137-146.

<sup>36</sup> Van den Berg & Spauwen, *ibid*.

## Section 4: Recommendations

Improvements in existing data collection are needed to build a more robust and accurate enumeration of carer prevalence in Ireland. Recommendations on how some of these data collection issues could be improved are outlined below.

### 1. Understand and address the disparity between Census and Irish Health Survey data on care

In 2018 the CSO undertook a public consultation regarding Census 2022 with a range of stakeholders, including organisations representing family carers. While this engagement was welcome, a number of important changes recommended by sector representatives were not incorporated into the wording of question 22 (which we understand will become question 23 in Census 2022). By comparison in 2018 the UK's Office for National Statistics reviewed the health and unpaid care questions' guidance, formats and wording to improve data quality and reduce the burden placed on respondents. This involved a comprehensive programme of research and wide stakeholder consultation to address problems with the 2011 Census unpaid care question, which many felt was too long, overly complicated with inadequate ranges for time spent caring. The review resulted in changes to the question design, changing the wording of the question and breaking down time ranges into more response options. Because of the disparities in carer prevalence data identified across CSO sources, it is important that the CSO investigate further the reasons for this disparity and take measures to address it.

### 2. Review the phrasing of 'unpaid care' questions

Caring involves a wide range of tasks, not only activities of daily living (e.g. toilet hygiene, feeding) and instrumental activities of daily living (e.g. shopping, preparing meals), but also managing care and providing social support. When family caring is defined with such a broader focus in survey questions, carers who regularly provide emotional support and transport, cooking and cleaning and/or medication management are more likely to answer 'yes'. This can lead to a more accurate enumeration of unpaid carers in the population. Family Carers Ireland encourages a broad understanding of care in the operationalisation of survey questions on unpaid caring.

### 3. Guidance on the recording of care hours

Challenges exist with regard to the accurate measurement of the time spent providing care through carers' completion of census or survey questions. While there is no simple solution, the inclusion of questions or sub-questions relating to care hours is important for policy and service development. It is also the case that the identification of carers early in their caregiving journey, when they are providing a relatively small amount of care, could allow the supports they need to grow as the intensity of their caregiving increases. While the explanatory notes included as an appendix to the census questionnaire explain the unpaid care question, few people take the time to read this and as such efforts to explain care hours and tasks should be included within the question itself.

### 4. Combining censuses with more frequent national surveys

Population censuses are major operations conducted at lengthy intervals. Censuses typically start by updating the cartography of a country's inhabited areas and so provide a means of georeferencing data on the location of people and households. However, censuses are not meant to monitor change continuously. National surveys and other innovative approaches to gather census-type data at shorter intervals are increasingly relied on. For example, the Netherlands conducts a virtual census by integrating data from registers and multipurpose surveys, while the USA has used the annual American Community Survey to update the results of its 2010 census. France has been conducting a "rolling census" since 2005, consisting of repeated surveys that, over time, cover the whole population. It is therefore increasingly regarded as best practice to supplement census data with more regular national surveys. In an Irish context this can be achieved through the continued inclusion of a carer question in the Irish Health Survey while including for the first time a new question on workers with caring responsibilities in the national Labour Force Survey and the Personal Work Life Balance Survey as well as including a module on caring in the Quarterly National Household Survey.

## 5. Capturing the hours of care in the Irish Health Survey

Given the under-reporting of carers in the Census of Population, *Family Carers Ireland* now relies on data from the Irish Health Survey as the main source of information on carer prevalence. The Irish Health Survey is managed by the CSO and is the Irish version of the European Health Survey managed by Eurostat. A question on informal caring was included in the first Irish Health Survey in 2015 and again in the 2019 survey. In the 2015 survey care hours were captured through an open-ended question i.e. *how many hours a week do you give care or assistance?* However, in the 2019 survey the CSO amended the question in line with the European Health Survey with regard to how the hours of care were captured, using bands of *'less than 10 hours per week, between 10 and 20 hours per week or more than 20 hours per week'*. This change was problematic for two reasons. Firstly, the change means that 2019 results regarding the number of hours of care provided weekly cannot be compared to survey findings in 2015. It also means that the average hours of care figure – which was 44.7 hours in 2015 – was not available in 2019 and so the replacement cost of care could not be calculated. Finally, the banded hours of care used in 2019 offer little value in terms of data and do not reflect the reality of the hours of care typically provided by a full-time family carer which often exceed 100 hours per week. *Family Carers Ireland* recommends that CSO revert to the original question used in the 2015 Irish Health Survey. We also urge the CSO to consult with caring sector organisations prior to making any change to survey questions relating to family carers.

## 6. Campaign to raise awareness of young carers

Young carers were first enumerated in Census 2011. While the extension of the census question to include young people with caring responsibilities was an important development, the disparity in young carer prevalence between census data and the HBSC survey undermines the credibility of census. Although the two surveys are not directly comparable, there are nonetheless differences in the results. *Family Carers Ireland* recommends that the CSO along with the caring sector undertake an awareness campaign targeted at young carers and their parents in advance of Census 2022.

## 7. Supporting carer identification

The accurate enumeration of carer prevalence is much more complex than making improvements to national surveys or Census questions. Rather, how people conceptualise care and what they understand care activities to be, as well as how they define themselves in relational terms with the cared for person is undoubtedly the greatest challenge towards a more accurate enumeration of family carers. While this paper does not attempt to offer a solution to this significant task, there are a number of learnings that should be taken from it. Firstly, efforts to increase carer identification and ultimately improve their uptake of support need to be sensitive to both the carer and cared-for person's perceptions of their family roles and to the cared-for person's identity. Concerns about the disempowering effect on the cared-for-person of the label 'carer' have been reported in the wider literature on caring<sup>37</sup> and demonstrate the need to balance a respect for existing relationships with efforts to actively recognise and value care.

## 8. Inclusion of care specific questions in the Labour Force Survey

The Labour Force Survey (LFS) is a large-scale, nationwide survey designed to produce quarterly labour force estimates that include the official measure of employment and unemployment in the state. The survey began in January 2016 and replaced the Quarterly National Household Survey (QNHS). *Family Carers Ireland* welcomes the inclusion of care-related questions in the LFS, however feel these could be further strengthened by providing a greater distinction between childcare and caring for a child or adult with specific care needs. We would also welcome the introduction of a dedicated question on the number of people in employment who juggle their work with caring responsibilities i.e. working carers. These data would help inform the development of policies and practices designed to support working carers, including care-related tax reliefs and assist in the implementation of the EU Directive on Work Life Balance for Parents and Carers. We also note that,

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<sup>37</sup> Molyneaux V., Butchard S., Simpson J., Murray C. Reconsidering the term "carer": a critique of the universal adoption of the term "carer" *Ageing & Society*. 2011;**31**:422–437.

similar to the QNHS, it is expected that the LFS will conduct special modules on different social topics each quarter. We encourage the CSO to include a special module to examine the prevalence, issues and experiences of working carers.

### **9. Creation of a Family Carer Register**

In addition to official sources of data on carer prevalence, *Family Carers Ireland* recommends the establishment of a 'Family Carer Register', similar to the model used in the UK. Family carers could self-identify and ask to be placed on the register as well as being identified by healthcare professionals and others who provide support to them and their loved ones. This register would provide a local, regional and national register of family carers, regardless of what financial support they receive, that would assist in the planning and delivery of services and help facilitate the delivery of targeted initiatives such as a Lifetime Carer Pension or a Carer COVID Vaccination Programme. In the UK carer registers are held by GPs, NHS Trusts and Local Councils, however in Ireland could be hosted by *Family Carers Ireland*.

### **Next steps**

This working paper is the first in a series of papers which will examine carer prevalence, the intensity of care provision, the valuation of care and the mutuality of caregiving using various data sources. These papers will be published periodically and will be available at [www.familycarers.ie](http://www.familycarers.ie)

## About Family Carers Ireland

*Family Carers Ireland* is the national charity dedicated to supporting the 500,000 family carers across the country who care for a loved one, including children or adults with physical or intellectual disabilities, frail older people, those with palliative care needs or those living with chronic illnesses, mental ill-health or addiction. Our vision is an Ireland in which family carers are properly recognised, supported and empowered. Established in 2016 through the merger of the Carers Association and Caring for Carers, we provide a range of services and supports for family carers through our network of Support Centres nationwide and advocate on behalf of family carers at local, regional and national level. Family Carers Ireland believes *no one should have to care alone* and offers a vast range of supports and services for family carers nationwide.

**Please see below some quick links to the services and supports offered by FCI.**

- [Learn](#) who FCI is as an organisation
- Learn about the [supports](#) that are available for family carers including free counselling, family carer events, young carer support etc.
- [Learn](#) about your Rights & Entitlements incl. Carers Leave & Carers Benefit, Grants available etc.
- [Access](#) free interactive e-learning modules, created with experts to help you in your caring role
- [Join](#) our FREE Emergency Scheme, which helps you, the family carer plan in the event of an emergency, such as contracting Covid-19
- [Enquire](#) about the provision of professional in-home care support in your area
- Freephone our [Careline](#) on 1800 24 07 24. We are always here to lend an ear, as ***we believe no one should have to care alone.***
- Join a community of family carers by becoming a member for €20 per year. Read about the benefits of having an FCI card [here](#).
- Join other family carers in our safe and secure [online forum](#) sharing tips, information and ask questions.
- Get in touch. We have excellent Carer Support Managers who will guide and assist you locally. Find your nearest Carer Support Centre [here](#). Please note our Centres are still closed due to Government guidelines but all Managers are still contactable.

## Take part in future research:

Family Carers Ireland is dedicated to developing and supporting research that has relevance and meaning for family carers, research that influences social policy and enhances the quality of life of family carers and the people they care for. If you would like to take part in future research projects, we would be delighted to add you to our family carer directory. Please email us with your consent to be contacted at [ndunne@familycarers.ie](mailto:ndunne@familycarers.ie). Your contact details will be kept private and confidential.

[www.familycarers.ie](http://www.familycarers.ie)

**FREephone Careline 1800 24 07 24**

## Appendix 1:

### Replacement cost based on Census 2016 carer prevalence 4.1 percent and mid-point hours

While the under-enumeration of carers in Census 2016 is broadly accepted, by using mid-point hours for each band of care hours provided, we estimate that the replacement value of the 195,263 carers enumerated in 2016 would cost more than **€8bn each year** based on an hourly replacement value of €20. This method uses an average hourly care provision of 38.7hrs for the 24,327 carers who did not specify how many hours of care they provide in the census form.

Table 2: Census 2016 mid-point hours

	Carers	Mid point	Total Hours pa	Replacement Cost @ €20
1-6 hours	44,843	3.5hrs	8,161,426	€163,228,520
7-12 hours	34,475	9.5hrs	17,030,650	€340,613,000
13-18 hours	12,203	15.5hrs	9,835,618	€196,712,360
19-24 hours	19,963	21.5hrs	22,318,634	€446,372,680
25-30 hours	8,657	27.5hrs	12,379,510	€247,590,200
31-36 hours	2,636	33.5hrs	4,591,912	€91,838,240
37-42 hours	6,974	39.5hrs	14,324,596	€286,491,920
43-48 hours	1,884	45.5hrs	44,575,440	€891,508,800
49 or more hours	39,301	108.5	221,736,242	€4,434,724,840
Not Stated	24,327	38.7hrs	48,955,654.8	€97,913,096
Total Carers / Ave hrs	195,263	38.7hrs	403,909,683	€8,078,193,656



Family  
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