



Making Carer's Count

Family Carers Ireland's submission to the Central Statistics Office on the content of Census 2027

Family Carers Ireland

December 2022

Clare Duffy
Policy and Public Affairs Manager
E: cduffy@familycarers.ie / M: 086 7707 231

Family Carers Ireland, Market Square, Tullamore, Co. Offaly
E: info@familycarers.ie / T: 057 9322920 / W: familycarers.ie

Submission to the Central Statistics Office on Questionnaire Content for Census 2021

Family Carers Ireland (FCI) welcomes the opportunity to submit our views to the Central Statistics Office (CSO) on the content of the Census 2027 form, specifically question 23 which relates to the provision of unpaid care. FCI is a national membership charity for carers. For 35 years we have worked to improve supports, services and recognition for anyone living with the challenges of caring for a family member or friend who is ill, frail, disabled or has a mental health difficulty.

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 community¹ with an economic value equivalent to 50 to 90 per cent of the overall cost of long-term care across the EU.² 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 accurate estimates of the numbers of family carers in Ireland and the intensity of care they provide. This is critical to ensuring that appropriate funding and resources are made available to support the practical, social, health, financial and well-being needs of family carers.

Key issues relating to Q23

- Why does the number of family carers identified in the Census (4.1 per cent) vary so considerably from that of the UK (>10 per cent) and other European countries (9 – 18 per cent)?
- Why does the prevalence rate of family carers identified in the Census (4.1 per cent) vary so considerably from the CSO's Irish Health Survey (12.5 per cent)?
- Why does the number of young carers identified in the Census (0.5 per cent) vary so considerably from the WHO Health Behaviour in School-Aged Children 2018 survey which identified 13.3 per cent of Irish children aged 10-17 provide care?

Key issues regarding the enumeration of carers in the Census and suggested changes in Census 2027

Ireland is fortunate to have a question on caring included in the Census of Population. First included in the Irish Census in 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 statistical reports in 2011. Unfortunately, the carer prevalence rates identified through the Census are consistently low and at variance with prevalence rates in other countries. **FCI believes that problems with the wording of question Q23 on care provision have led to the under-enumeration of carers in the Census and have resulted in FCI and others in the sector, now relying on the CSO's Irish Health Survey as the most reliable source of data on carer prevalence³.** The main problems relating to the enumeration of family carers in the Census are summarised below:

(i) Consistently low carer prevalence rates

- The carer prevalence rate identified through the Census is consistently low and at variance with prevalence rates in other countries. The Irish carer prevalence rate in Census 2002 was 4.8 per

¹ Zigante, Valentina. 2018. 'Informal Care in Europe: Exploring Formalisation, Availability and Quality.' Brussels: LSE Consulting for the European Commission, 2018.

² 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>

³ 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

cent and decreased to 4.1 per cent in Census 2011 and Census 2016. By comparison, the Census in Northern Ireland identified 12 per cent of the population as carers, the Census in Denmark identified 13 per cent as carer, while in Sweden 18 per cent are carers⁴.

- The concern regarding this international disparity is heightened due to the significant difference between carer prevalence rates within Ireland as 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.

Action required in Census 2027

Given the significant disparity between carer prevalence rates between Ireland and other countries and in both the Census and the Irish Health Survey, there is an onus on the CSO to investigate the factors contributing to this variance and to ensure that the validity of their data is not undermined. This investigation could mirror the process undertaken by the UK Office for National Statistics in their development of Census questions on unpaid care, which following the 12-week public consultation, engaged with key stakeholders to understand the nuances of specific questions and definitions. For example, in testing the wording of the question on care, respondents identified with “look after” rather than “help or support”, particularly those who care for family members.

(ii) Wording used in Q23

Question 23 is a polar question which asks ‘Do you provide regular unpaid personal help for a friend or family member with a long-term illness, health problem or disability’? It goes on to explain that respondents should ‘include problems which are due to old age’ and explains that ‘personal help includes help with basic tasks such as feeding or dressing’. Respondents who answer yes are then asked to specify how many hours per week they spend caring. While FCI welcomes the explanation that 24/7 care equates to 168 hours, included in Q23 in Census 2022⁵, we believe other aspects of the question wording are problematic on a number of levels.

- Use of the term ‘unpaid’ may discourage recipients of Carer’s Allowance or other social welfare supports from responding positively as they may consider these as a payment for care work and therefore the care is not ‘unpaid’. The pre-Census 2021 research undertaken in the UK confirmed that respondents find the term ‘unpaid’ to be problematic and so it has been removed from the Census question.
- Despite being explained in the question, the use of the term ‘personal help’ may imply assistance with personal or intimate care which is understood to mean help with bathing, toileting or continence care, meaning those providing other forms of more routine or supervisory care may not respond.
- The examples listed of ‘long-term illness, health problem or disability’ and the prompt to include care associated with old age, are not sufficiently broad and may deter carers of adults or children with an intellectual disability (e.g. autism, Asperger’s) or indeed those caring for a loved one with a mental health difficulty from responding.
- The term ‘regular’ is open to different interpretations and could be taken to mean every day, once a week, once a fortnight or indeed regularly throughout the year.

Action required in Census 2027

To address the issues highlighted above, and consistent with the language used in the UK Census (see Appendix 1), FCI recommends the wording of Q23 be changed to:

⁴ Until 2012, population-based data on informal caring was not been available. In 2012, the National Board of Health and welfare was commissioned by the government to carry out a study on informal care to persons with disabilities and older people, covering the whole country and for the adult population. The study showed that 18% of the 18+ population provides help, support and care on a regular basis, corresponding to over 1.3 million people.

⁵ Because the findings of Census 2022 have not yet been released we are not in a position to see what effect the explanation of care hours has had on the data.

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, mental health difficulty or addiction
- 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

Given the immense importance of family-provided care to the delivery and sustainability of health, community and primary care services, FCI recommends that consideration be given to further expanding Q23 to gather additional information in relation to the relationship between the carer and the person(s) requiring care and the nature of their condition⁶. This information is critical to the planning and delivery of carer support, and cannot otherwise be gathered through cross-tabulation with other Census questions.

To whom do you give this support? They are my:

(You can select more than one where you are caring for more than one person)

- Child
- Parent
- Sibling
- Spouse / Partner
- Other relative
- Neighbour/friend

Why does this person require this support?

(Please choose the persons primary diagnosis. You can select more than one where you are caring for more than one person)

- Physical disability
- Intellectual disability
- Neurodiversity (e.g. autism, ADHD, dyspraxia)
- Cognitive impairment (E.g. dementia)
- Mental health difficulty
- Chronic condition
- Problems related to old-age
- Other

⁶ The suggestion reflects the recommendation put forward by Care Alliance Ireland in 2018.

(iii) Problems with enumerating young carers

- The enumeration of young carers in the Census is problematic as the Census requires the parent or head of household to disclose their child's caring role. Experience has shown that some parents/guardians may be reluctant to do this as they don't want to disclose their child's caregiving role or simply don't recognise the care their child provides.
- This helps explain discrepancies between surveys completed by adults and those completed by young people. Census 2016 identified 6,108 carers under 18, a total of 0.5 per cent of the child population. By comparison, the nationally representative 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.
- Despite a 3.8 per cent increase in the population aged 18 years and under, the number of young carers enumerated in the Census dropped by 28 per cent between Census 2011 and Census 2016 from 8,472 to 6,108.
- Census data in relation to young carers is currently presented in terms of young people aged 15 years or under, which is problematic from a policy perspective where the definition of a *young carer* is '*a young carer is a child or young person under 18 years whose life is affected in a significant way by the need to provide care for a family or household member who has an illness, disability, addiction or other care requirement*'⁷. Likewise, it would be helpful if census data could be further presented for *young adult carer* aged between 18–24 who present additional policy challenges in terms of supporting their transition to higher education and ensuring they are not distanced from the labour market.

Action required in Census 2027

- Data released by the CSO in relation to young carers and young adult carers should correspond to their official definitions i.e. children aged under 18 with caring responsibilities / young adults aged 18-24 with caring responsibilities.
- FCI accepts the challenges beyond the control of the CSO in enumerating young carers, however, we believe that there are opportunities to increase the effectiveness of the Census by increasing public awareness of the value of including the care provided by young people when completing the form. This targeted campaign could be delivered by FCI with the support of the CSO.
- It is clear that surveys completed by young people themselves are more likely to provide a more accurate picture of the extent of their caregiving and for this reason, FCI encourages the CSO to work with their partners Scoilnet and the Department of Education in having a question on young carers including in the Census at School. This will enable a much better picture of the number of young carers in schools, and has the potential to significantly increase awareness, identification and support. We note that from January 2023 the School Census in the UK will include a question on young carers for the first time.

(iv). Problems experienced by households where a person has a disability

Some families report difficulty completing the Census form in respect of a member of the household who has a disability. This is particularly the case where the person is an adult with an intellectual disability. In these cases, families find it difficult to answer questions in respect of the person with a disability in relation to education, work and 'childcare' as they felt their situations are difficult to capture in terms of the day centres and the supported employment they engage in. In some cases, families report having to use the child care section intended for those under 15 to be able to include all the details of their loved one's care. They also experience difficulty with identifying the 'highest

⁷ NUIG/Department of Health (2010): Study of Young Carers in the Irish Population.

level of education’ since their loved one did not participate in mainstream education, however they don’t want to select “no formal education” as the person did participate in a supported education/Individual Educational Plan.

Action required in Census 2027

- The contents of the Census 2027 form must be disability proofed to ensure that people with a disability and their specific needs and life circumstances are reflected across all questions. This should be done in collaboration with people with a disability, their families and representative bodies.
- The Assisted Decision Making (Capacity) Act 2015 is due to be fully commenced in early 2023. The Act reforms the law relating to persons who require or may require assistance in exercising their decision-making capacity. Consideration should be given as to whether the commencement of the Act will require a change to any existing question or if there would be value in including an additional question regarding the provisions of the Act.

Suggested cross-tabulation of Q23

Question 23	Census question	Currently cross tabulated	Should also be cross tabulated
Do you provide regular unpaid personal help or support to a family member, neighbour or friend with a long-term illness, health issue, an issue related to old age or disability?	HQ1 When was your house, flat or apartment built?		
	HQ2 Does your household own or rent?	<input checked="" type="checkbox"/>	
	HQ3 If your accommodation is rented, how much rent?		<input checked="" type="checkbox"/>
	HQ4 How many working smoke alarms?		
	HQ5 How many rooms do you have for use?		
	HQ6 What is the main type of fuel used?		<input checked="" type="checkbox"/>
	HQ7 Does your accommodation use renewable energy?		<input checked="" type="checkbox"/>
	HQ8 Type of piped water supply?		
	HQ9 Type of sewerage facility?		
	HQ10 How many cars are owned or available for use?	<input checked="" type="checkbox"/>	
	HQ11 Type of internet connection?	<input checked="" type="checkbox"/>	
	Q1 What is your name?		
	Q2 What is your sex?	<input checked="" type="checkbox"/>	
	Q3 What is your date of birth?	<input checked="" type="checkbox"/>	
	Q4 Relationship to other persons in the household?	<input checked="" type="checkbox"/>	
	Q5 What is your current marital status?	<input checked="" type="checkbox"/>	
	Q6 What is your place of birth?	<input checked="" type="checkbox"/>	
	Q7 Where do you usually live?	<input checked="" type="checkbox"/>	
	Q8 Where did you usually live one year ago?		
	Q9 Have you ever lived outside ROI for one year or more?		
	Q10 What is your country of citizenship?	<input checked="" type="checkbox"/>	
	Q11 What is your ethnic group/background?	<input checked="" type="checkbox"/>	
	Q12 What is your religion, if any?	<input checked="" type="checkbox"/>	
	Q13 Can you speak Irish?		
Q14 Speak a language other than English/Irish at home?		<input checked="" type="checkbox"/>	
Q15 Any of the following long-lasting conditions?		<input checked="" type="checkbox"/>	
Q16 As a result of any long-lasting condition, do you have difficulty doing any of the following?		<input checked="" type="checkbox"/>	
Q17 How is your health in general?	<input checked="" type="checkbox"/>		
Q18 Do you smoke tobacco products?			
Q19 How do you usually travel to work, school, college or childcare?			
Q20 What time do you usually leave home?			
Q21 How long does your journey take?			
Q22 What time do you usually leave work, school, college or childcare?			
Q24 Engage in voluntary work?			

	Q26 Have you ceased your full-time education?	<input checked="" type="checkbox"/>	
	Q27 Highest level of education/training?	<input checked="" type="checkbox"/>	
	Q28 Present principal status?	<input checked="" type="checkbox"/>	
	Q30 If you are at work, do you ever work from home?		<input checked="" type="checkbox"/>
	Q31 Work as an employee or self-employed?	<input checked="" type="checkbox"/>	
	Q32 What is (was) your occupation in your main job?	<input checked="" type="checkbox"/>	
	Q33 Business of your employer?	<input checked="" type="checkbox"/>	
	Q34 Business of your employer at the place where you work(ed) in your main job?	<input checked="" type="checkbox"/>	
	Q36 Name/address of your work, school or childcare?		
	Q37 If under 15, are you in any type of childcare?		

Not related to the Census 2027 but of note - Irish Health Survey:

A question on unpaid care was first included in the Irish Health Survey in 2015 and again in the 2019 survey. In its 2015 wave, the Irish Health Survey asked respondents to record how many hours of care they provided in an open-ended question (see Appendix 1). However, in the 2019 survey, the question was changed and instead asks 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.


Family Carers Ireland is disappointed by the change for a number of reasons. Firstly, the category of care hours does not reflect the full-time care provided by many family carers who consider themselves to care 24/7 (168 hrs). Secondly, without a figure for the average weekly hours of care, it is not possible to estimate the replacement value of care.

In our correspondence with the CSO in relation to this matter we have been advised that the decision to move to banded care hours was a result of a similar change made by Eurostat. However, Eurostat has advised that the CSO are not obliged to reflect this change in the Irish Health Survey. To the end, we strongly recommend that the CSO revert to the original wording of the question on unpaid care used in the Irish Health Survey 2015.

Appendix 1

Census UK – question related to care

24 Do you look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age?

 Exclude anything you do as part of your paid employment

- No
- Yes, 9 hours a week or less
- Yes, 10 to 19 hours a week
- Yes, 20 to 34 hours a week
- Yes, 35 to 49 hours a week
- Yes, 50 or more hours a week

CSO Irish Health Survey 2015

Provision of informal care or assistance

50 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)?

Yes No

If yes:

51 Are the person or persons concerned family members?

Yes No

52 How many hours a week do you give the care or assistance?

Hours

*Care provided on a 24 hour basis, 7 days a week equates to 168 hours.