

## 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 questionnaire for Census 2021. We also wish to thank the CSO for their support of the 'Carers Count' campaign in advance of the 2011 and 2016 Censuses which helped build awareness of Question 22 on the prevalence of caregiving and encouraged carers and young carers to self-identify. FCI is a national membership charity for carers. For 26 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. This submission is based on our experience of supporting and advocating for Ireland's 355,000<sup>1</sup> family carers<sup>2</sup>.

### Why Carers Count

Informal caring is of significant and increasing importance in the context of an ageing population, growing pressures on public finances, and increasing life expectancy. Information on the number and distribution of carers is therefore critical to help provide appropriate funding and resources for carers and to develop policies in relation to the provision of home care, respite, day centres, housing adaptation grants and healthcare planning. Indeed objective 1.1 of the National Carers Strategy published in 2012 specifically relates to the role of the CSO in '*strengthening awareness and recognition of the role and contribution of carers at national, regional and local level*' in addition to action 1.1.3. to '*build on the work begun in Census 2011 to establish a comprehensive statistical profile of Family Caring in Ireland*'; and action 2.2.4 to '*investigate and analyse the situation of children and young people undertaking caring roles*'.

In its current form however the census questionnaire has a number of weaknesses in how it captures information relating to carers, both in terms of the wording of the question asked (question 22) which FCI believes has led to significant underreporting and the level of information released (for example in relation to age breakdown and the possibility of cross-tabulation with other questions), both of which notably restrict a more comprehensive analysis of carers which could significantly assist in service planning and delivery.

In the following sections FCI will summarise the specific aspects of the census questionnaire, and question 22 in particular, which could be improved in Census 2021 and provide a menu of practical suggestions that would help ensure a more accurate enumeration of carers and young carers. The submission concludes with suggested rewording for question 22 to address the deficiencies identified.

### 1. Summary of key issues and suggested changes

i. **The wording of Q22:** Question 22 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. FCI believe this wording is problematic on a number of levels.

- The use of the term 'unpaid' may discourage recipients of social welfare supports (i.e. Carers Allowance, Carers Benefit, Carer Support Grant or Domiciliary Care Allowance) from

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<sup>1</sup> CSO Irish Health Survey (2015) shows 10 percent of the population aged over 16 are carers. If extrapolated to the national population, this means Ireland has close to 355,000 carers.

<sup>2</sup> National Carers Strategy (2012) defines a Family Carer as '*someone providing an ongoing significant level of care to a person in need of that care in the home due to illness or disability or frailty*'.

responding positively as some may consider these social transfers as payment for care work and therefore not 'unpaid';

- 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 expectation that respondents will accurately calculate the number of hours of care they provide each week is unrealistic, and will inevitably undermine the final results. In fact FCI are aware of the significant incidence of 'spoiled' questions in Census 2011 and 2016 due to carers writing 24/7 rather than 168 hours each week (i.e. fulltime round-the-clock care).

**Action required for Census 2021:** See section 2 below for suggested question.

- ii. **Underreporting of carers:** A question on the provision of unpaid care was included for the first time in Census 2002. Since then the total number of carers enumerated has increased by 31 percent from 148,754 in 2002 to 195,263 in 2016. While 31 percent may appear to be a reasonable increase, when we consider that during the same period the older population has increased by 46 percent and the number of persons with a disability has doubled, the extent of underreporting by genuine carers becomes apparent. This is further compounded when we consider that during the same period Government has pursued policies of deinstitutionalisation, reorienting care away from institutional settings towards care in the home, thus increasing the requirement for family carers.

**Action required for Census 2021:** The underreporting of carers and issues relating to their lack of self-identification continue to hinder the accurate enumeration of carers in Ireland and the amount of care they provide. FCI welcome the support given by the CSO in advance of the 2011 and 2012 censuses through the 'Carers Count' campaign, and believe a similar, if not intensified campaign must be a feature of Census 2021.

- iii. **Underreporting of young carers:** Young carers were first enumerated in Census 2011. While the extension of the question to include young people with caring responsibilities was an important development, discrepancies between census data and the findings of other academic studies undermines its accuracy. For example, in Census 2016 only 3,800 young carers were identified (a decrease from 4,200 in 2011) however a study, undertaken by University College of Ireland, Galway<sup>3</sup> in the same year (2016), shows that 11.9 percent of 10-17 year olds surveyed (n= 11,870) said they provide regular, unpaid personal help for a family member with a long-term illness, health problem or disability. Extrapolation from the sample to the national population would suggest that some 56,118 young people in the 10-17 year age-group alone provide regular unpaid care. This is in keeping with a study undertaken by Dr Saul Becker, a leading international expert on young carers, who estimates that Ireland could have as many as 28,000 young carers aged under 18 years, and 52,700 aged under 25 years based on comparisons with UK data

**Action required for Census 2021:** (i). Given the significant anomaly in the data emerging on young carers, in contrast to national studies amongst young people themselves (0.4% versus 12%) it will be important to have a dedicated awareness campaign targeted at young carers and delivered

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<sup>3</sup> The Health Behaviour in School-aged Children (HBSC) study which was conducted by researchers in the Health Promotion Research Centre at the National University of Ireland, Galway. Health Behaviour in School-aged Children (HBSC) is a cross-national research study conducted in collaboration with the World Health Organisation (WHO) Regional Office for Europe.

through schools, youth groups and social media. (ii). Undertake a statistical analysis of young carers in the Irish population as committed to in Census 2011<sup>4</sup>.

- iv. Discrepancies in carer data:** The significant discrepancy between census data and findings from the CSO's Irish Health Survey 2015 in relation to the prevalence of carers calls into question the validity of the results achieved. The census has consistently identified 4 percent of the population as carers<sup>5</sup>, compared with the Irish Health Survey in 2015 which identified 10 percent of the sample population aged over 16 as carers, providing an average of 45 hrs care each week. If extrapolated to the national population, Ireland could have close to 355,000 carers as opposed to the 195,000 enumerated in Census 2016. Similarly, comparisons of Irish census data on carers with data from the UK census show a similar variation – with a 10 percent prevalence of carers in England and Northern Ireland versus just 4 percent here.

**Action required for Census 2021:** Undertake an analysis of carer prevalence rates across other countries who enumerate carers in their census (Croatia, Italy and UK) and consider reasons for any significant differences.

- v. Age breakdown of young carers not in keeping with policy agenda:** 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 official definition of a *young carer* is 'a child or young person aged 18 or under who helps look after a relative who has a condition, such as a disability, illness, mental health condition, or a drug or alcohol problem'. Likewise it would be helpful if census data could be further presented for *young adult carer* aged between 18–25 who present an additional policy challenges in terms of supporting their transition to higher education and ensuring they are not distanced from the labour market.

**Action required for Census 2021:** Data released by the CSO in relation to young carers and young adult carers should correspond to their official definitions i.e. children and young people aged under 18 with caring responsibilities / young adults aged under 25 with caring responsibilities.

- vi. Greater potential for cross-tabulation, particularly in relation to working carers:**

A notable deficit in relation to the census and carer data is the underutilisation of the possibilities presented by cross-tabulating data, particularly in relation to improving our understanding of working carers i.e. carers who also participate in paid employment. It would be of significant benefit to government departments and those working in policy formation to better understand patterns of employment amongst carers (question 27,28 & 30) and their levels of educational attainment (question 25 & 26). Likewise cross-tabulation with questions relating to the carers own health and wellbeing (questions 16, 17 & 18) would enable better provision of services and supports to meet their needs; while understanding the country of origin, the ethnic group or cultural background of a carer (question 10, 11 & 15) will help us better meet the needs of migrant carers or those who don't speak English fluently and so may need support with form filling etc.

**Action required for Census 2021:** As per action 1.1.3. of the National Carers Strategy to '*establish a comprehensive statistical profile of family caring in Ireland*' the CSO should extend our understanding of the nature, extent and spatial distribution of carers by cross tabulating question 22 with questions

<sup>4</sup> The National Carers Strategy Scorecard 2016 states '*The repeated delay in the planned analysis of children who reported in the 2011 Census that they undertook caring roles is unacceptable and is responsible for the 'regressive' score awarded. This, fourth, progress report promises a report for 2017 and at time of writing (September 2017) this has not been produced. Given that the second Progress Report stated that 'this report is now finalised and will be published shortly' the Monitoring Group cannot help but be frustrated at the delay in its publication. These data could have been used to inform service delivery and strategic responses addressing young carers' roles*'.

<sup>5</sup> Census 2001, 2006, 2011 and 2016.

relating to employment; educational attainment; health and wellbeing and ethnic/cultural background.

**Suggested Wording for Question 22 in Census 2021**

In light of the issues highlighted above, and consistent with the language used in the UK Census and the Irish Health Survey, FCI recommend the wording of question 22 be changed to:

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

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

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

Yes

No

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

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

**In Conclusion**

FCI welcome the opportunity to contribute to the CSO’s consultation on the formation of a new questionnaire for Census 2016. We are acutely aware of the importance of ensuring that the data captured through the census process provides an accurate reflection of the make-up of Irish society and allows for effective policy, planning and decision making. To this end, we ask the CSO to continue to engage with us to ensure the needs of carers are considered in your deliberations and reflected in the final census questionnaire. Finally, on behalf of FCI I wish the CSO every success in your important work and look forward to an improved census as a result of your efforts.

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**Category of organisation:**

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|--|------------------------------|
| Union/ staff representative body                     | <b>Representative Body</b> ✓ |
| Regulatory Body                                      | Patient Interest Group       |
| Public Interest Group                                | Academic institution         |
| <b>Advocacy Body</b> ✓                               | Private Home Care Provider   |
| <b>Voluntary/Not for Profit Home Care Provider</b> ✓ |                              |