

Alliance Ireland submission to the Central Statistics Office

Census 2027

Submitted: January 2023

Introduction

We are pleased to have the opportunity to make this submission on the upcoming Census, due for administration in 2027. However, we must stress our concern that we are being asked to make this submission before the detailed results of Census 2022 are available. We do, of course, understand the need for advance planning for change in the next Census, and the tight timetable for that. However, we in Care Alliance Ireland are particularly keen to receive the results from Q.23 of Census 2022, as it pertains directly to enumerating the quantum of family care taking place across Ireland. In order to understand how the changes that were integrated into Census 2022 to this question have impacted the reporting of family carers in Ireland, the data relating to caring in Ireland will need to be made available prior to our organisation being fully able to contribute to this entire process of consultation. We understand from recent communication with one of your colleagues in the CSO that we will have further opportunities to specifically address this issue as the consultation process moves forward¹. This is to be welcomed.

As a result, this submission will focus on some key concerns that were not sufficiently addressed in the changes made to this question for Census 2022. To that end, we will reiterate a number of points that we made in our submission for Census 2021 (as it was initially scheduled to be)².

¹ Email exchange which took place 12th & 13th December 2022, via the email address: census2027consultation@cso.ie

² https://www.carealliance.ie/userfiles/files/Care_Alliance_Ireland_CS0_Submission_Nov17.pdf

Key Issues

Lack of consistency across national and international surveys

For many years, we and colleagues across the sector have been concerned with the significant disparity between Irish family carer statistics as enumerated by the Census, and those in similar nations across the world. Whilst we must wait for the data from Census 2022 to be published to understand if these disparities have been lessened by changes made for the Census, it is worth noting that both our organisation, Care Alliance Ireland, and our colleagues in Family Carers Ireland have expressed a lack of confidence in the reports of carer prevalence stemming directly from the Census³ – which in 2016 showed a prevalence of 4.1% in comparison to other similar countries such as the UK (which has a carer prevalence of 10.3%), Canada (26.6%), the United States (20%) and France (12.7%)⁴.

Not only is there a significant disparity across nations when looking at carer prevalence rates internationally, there is significant disparity to date in research undertaken using slightly varying methodologies within Ireland and administered by the CSO. For example, the Irish Health Survey (2019) estimated that *'13% of persons aged 15 years and over provide care (excluding professional activities) to another person at least once a week by virtue of that other person's suffering from some age problem, chronic health condition or infirmity'*⁵. Such large discrepancies must be thoroughly researched to ascertain the reason for such large differences.

³ Family Carers Ireland, 'Counting Carers: Carer Prevalence in Ireland - Working Paper 1' (Family Carers Ireland, 2021); Care Alliance Ireland, 'Estimates for Numbers of Family Carers in Ireland' (Care Alliance Ireland, 2019)

⁴ International Alliance of Caregiver Organizations, 'Global State of Caring' (IACO, 2021).

⁵ Central Statistics Office, 'Irish Health Survey 2019 - Carers and Social Supports' (Dublin: Central Statistics Office, 2020).

Young carers

As our colleagues in Family Carers Ireland have identified in their submission to this consultation⁶, there are a number of challenges in collecting data on the topic of young carers.

There is significant stigma attached by many to the idea of needing care in the first instance, but in particular to the notion of young family members caring for their parents or other members of the family⁷. In turn, this will likely have an impact on the level of disclosure of caring by young people in the Census returns, given that each return is usually completed by the 'householder' – i.e. a parent, most likely.

When young people are directly asked if they provide care or help to a family member with a disability or health concern the number of those reporting that they do is much higher than in the Census. For example in the Health Behaviour in School Aged Children study (HBSC) 2018, the prevalence of young people reporting that they provided such care was 13.3% for 10-17 year olds. Census 2016, however, reported a mere 0.5% of school aged children identifying as a carer.

Specific wording concerns

Given that Census 2022 contained a slightly changed wording for the question regarding family caring, we will reserve our analysis until the data from the question becomes available. However, we recommend that thorough research takes place with family carers themselves to ascertain the most appropriate language to encourage those providing care to state this in their Census return.

⁶ Family Carers Ireland, 'Making Carer's Count - Family Carers Ireland's Submission to the Central Statistics Office on the Content of Census 2027', 2022.

⁷ Care Alliance Ireland, "'We Need to Talk About It" – Stigma and Family Care', 2016.

We have written at length on the topic of language use in family care⁸ and would be happy to assist the CSO in this regard.

Lack of available context

Whilst it is vital to understand the quantum of caring being provided by friends and family members, just as important is understanding the context in which this care is being provided. Without knowing who is being cared for by family carers, then using the data provided by the Census to plan services etc. is not sufficient. Whilst general family carer supports are vital, and issues such as the health, social, and economic impact on family carers are experienced by the majority of family carers across Ireland, some specificity is needed. The supports and services required by a young family caring for children with complex medical needs is very different to those supporting their spouse with cancer, or those caring for a loved one with dementia at home. Without understanding the demographics of carers alongside those receiving care, too many assumptions can be made. We may assume that the almost 9,000 carers aged 80 and over in Census 2016 were caring for their spouse, however they may also have been caring for their ageing disabled child. The types of support needed in those situations are very different, and the impact on future planning for both those situations is also very different.

Currently, the majority of carer policy, funding and supports are routed through the Department of Health or the Department of Social Protection (in the case of Carers Allowance etc.). Very often, queries will be directed to the Older Persons unit in the Dept. of Health. That, of course, is not appropriate for those families with young children. Until we know who is being cared for by family carers,

⁸ Care Alliance Ireland, 'Defining Carers' (Care Alliance Ireland, 2015); Care Alliance Ireland, 'Defining Carers: Update June 2022' (Care Alliance Ireland, 2022); Zoe Hughes and Liam O'Sullivan, 'Defining and Profiling Family Carers: Reflections from Ireland', *International Journal of Care and Caring* 1, no. 3 (2017): 421–27.

planning will not be accurate or successful. It is also not acceptable to identify the number of Census respondents identifying as disabled as a proxy for this measurement – as there are many more reasons why a person requires significant, ongoing care. Likewise, not all disabled people will need this type of care, and in fact may themselves be a carer for a child, spouse, parent, or friend.

Electronic Option

We in Care Alliance are pleased to support the rollout of an electronic option for completion of Census 2027. As mentioned above, a stigma with regards to both needing and providing care still persists across Ireland. An option which reassures respondents of the security and privacy of their answers, not dependent on the use of local remunerators, is to be welcomed in this regard.

Recommendations

In light of the points we raise above, we have identified three key actions which should be taken in advance of Census 2027.

- 1) Research should be undertaken on the impact of wording choices for any change to the question on family care

As outlined above, there are significant disparities in prevalence rates of caring both internally across CSO administered surveys, and internationally across similar nations to Ireland. Whilst the rewording of Q23 regarding family care for Census 2022 may have made a difference to this disparity, this will not be known until those data are published and analysed. It is unlikely that the relatively minor changes in Census 2022 will result in parity in this area.

Therefore, we recommend significant research directly with family carers, using a participatory methodology, be undertaken to examine the preferences of terminology and question types which will more accurately reflect current family carer preferences in 2027. This research should also include reflections from

international studies and Census questions regarding family carers in other jurisdictions, to aid international comparisons.

2) Consideration must be given specifically to the challenge of accurately gathering data on young carers

Noting issues of language use and the challenges of relying on parental reporting of young carer activity, changes must be made for Census 2027 to more accurately reflect the true quantum of care being delivered by young carers. We refer readers to the submission to this consultation for Census 2027 made by Family Carers Ireland in this regard.

3) Consider a context question for family carers regarding those they care for

As part of our submission to the consultation on Census 2022, we made a recommendation that an addendum question be posed to gather data on the cared-for individuals as part of the caring question. Until the context of care is understood, too many assumptions will continue to be made; such as who is being cared for, how they are being cared for, and a perpetuation of the notion that disabled or ill individuals are not themselves providing care for others. Family care is inherently intersectional, meaning that carers themselves can be disabled, neurodivergent, and/or experiencing mental health difficulties.

Recommended addendum to Q23:

To whom do you give this support (you may choose more than one)

Child

Parent

Sibling

Partner

Other relative

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

Physical disability

Intellectual disability

Neurodiversity (Autism/ ADHD etc.)

Other cognitive impairment (E.g. dementia)

Mental ill health

Long-term illness

Problems related to old-age

Conclusion

Whilst we are unable to make recommendations on exact wording changes required from those made in advance of Census 2022, in the absence of that data being currently available for analysis, this submission has made a number of recommendations for Census 2027 based on currently available information. We look forward to working with the CSO as this consultation process develops over time. We especially look forward to the release of the data related to caring and disability to make more informed inputs into the consultation process.

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

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

There are in the region of 500,000 Family Carers in the Republic of Ireland. Family carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions. We work with our 90+ member organisations and other agencies to support them in their work with family carers.

Our legitimacy derives in part from our membership base which includes a wide range of organisations currently providing services to Ireland's family carers. Our membership is comprised of both large and small, regional and national organisations.

Submitted by

Zoe Hughes

Senior Policy & Research Officer

zoe@carealliance.ie

0868834942