'Guiding support for family carers'



Citizens' Assembly on Gender Equality - Public Consultation

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Submission By: Care Alliance Ireland

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Introduction

Care Alliance Ireland are very pleased to have the opportunity to make a submission to the 2020 Citizens' Assembly on Gender Equality.

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 90+ 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 391,000 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 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 large and small, local, regional and national organisations.

Our comments are concentrated on issues pertaining to family caring and gender, and while we have consulted with our members this submission should not be viewed as representative of the views of our collective membership.





It is important to outline clearly what is meant by the term 'family carer' in this context. The term itself can be contested, and not all researchers, advocates and carers themselves will agree easily on its usage. We in Care Alliance find it useful to differentiate family caring from regular childcare. For this reason, the definition which comes from the 2012 National Carers Strategy is a good starting point;

A carer is someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty¹.

Family carers, in general, experience myriad challenges due to their status as family carers. These include (but are not limited to) social isolation and loneliness², along with mental health difficulties such as increased likelihood of depression and anxiety^{3 4 5}. There is increased likelihood that family carers will experience negative physical health effects, such as back and muscular problems, high blood pressure, heart problems, and stroke⁶, as well as the possibility that existing health conditions will be exacerbated during caring⁷. Family carers are more likely than the general population to live in poverty, with many family carers experiencing a sharp decrease in their earning ability – perhaps

¹ Department of Health, "The National Carers' Strategy" (Department of Health, 2012), 8.

² Liam O'Sullivan, "Health and Well-Being of Family Carers in Ireland: Results of a Survey of Recipients of the Carer's Allowance" (Combat Poverty Agency, 2008).

³ Christina Aggar, Susan Ronaldson and Ian Cameron, 'Self-Esteem in Carers of Frail Older People: Resentment Predicts Anxiety and Depression', *Aging and Mental Health* 15, no. 6 (2011)

⁴ Brennan et al., "De-Stress: A Study to Assess the Health & Wellbeing of Spousal Carers of People with Dementia in Ireland."

⁵ O'Riordan and Kelleher, "A Fine Balance: Mental Health and Family Caring."

⁶ Ann Stokes, "The Caring Reality of Family Carers: An Exploration of the Health Status of Family Carers of People with Parkinson's Disease," 2010, http://www.carealliance.ie/userfiles/file/FullReportFinal.pdf.

⁷ Allie Anderson, "When Looking after a Loved-One Is Too Much: Caring for Carers," *British Journal of Community Nursing* 22, no. 5 (2017).





needing to give up work entirely – as well as bearing the costs of caring and disability $^{8\ 9}$ $_{10\ 11}$

Demographics

Most recent estimates indicate that that are c. 391,000 people in Ireland who provide some level of care to a family member who has a disability, long-term illness, mental health concern or who requires help with daily activities. This represents 1 in 10 adults in Ireland. Full details on how this estimate was calculated, using data available from the Central Statistics Office, are available in our paper 'Estimates for Numbers of Family Carers in Ireland', published in 2019¹². According to Census 2016, 60% of family carers in Ireland are female, with 40% being male. This percentage breakdown is broadly replicated in other studies such as the Irish Health Survey 2015¹³. The percentage of male carers has been increasing gradually at each of the Census's recording caring since 2001.

Assumptions made regarding gender and caring

There are a number of assumptions that are often made when thinking about gender and family caring, not all of which are accurate.

In general, the image that most often comes to mind when asked to think of a family carer, is a woman in her 40's – 50's, caring for an ageing parent, and who is often also raising her own children – with or without the help of a partner. This is borne true in the statistics, as there is a high concentration of female carers in the 40-50 age group

⁸ Carers UK, "The Cost of Caring: How Money Worries Are Pushing Carers to Breaking Point" (Carers UK, 2011)

⁹ John Cullinan, 'The Economic Costs of Disability for Families', *Frontline: The Irish Voice of Intellectual Disability*, no. 97 (2015), http://frontline-ireland.com/economic-costs-disability-families/
¹⁰ John Cullinan and Sean Lyons, 'The Private Economic Costs of Adult Disability' (2014)

¹¹ E O'Shea, 'The Costs of Caring for People with Dementia and Related Cognitive Impairments' (National Council on Ageing and Older People, 2000)

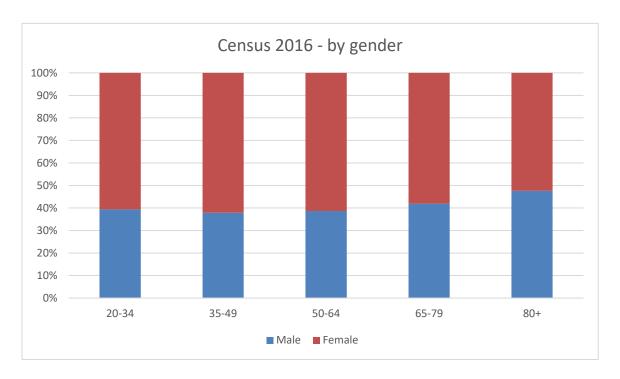
¹² Care Alliance Ireland, "Estimates for Numbers of Family Carers in Ireland" (Care Alliance Ireland, 2019), https://www.carealliance.ie/userfiles/files/Research/Briefing Position Papers/Oct 2019/BriefingPaper Estimates of Family Carers in Ireland Oct2019.pdf.

¹³ Central Statistics Office, "Irish Health Survey (IHS) 2015 Results" (Central Statistics Office, 2016), https://www.cso.ie/en/releasesandpublications/ep/p-ihs/irishhealthsurvey2015/ct/.



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according to the Census¹⁴. This cohort of carers are often described as sandwich carers. However, when looking at carers who are older than this, the gender gap begins to close;

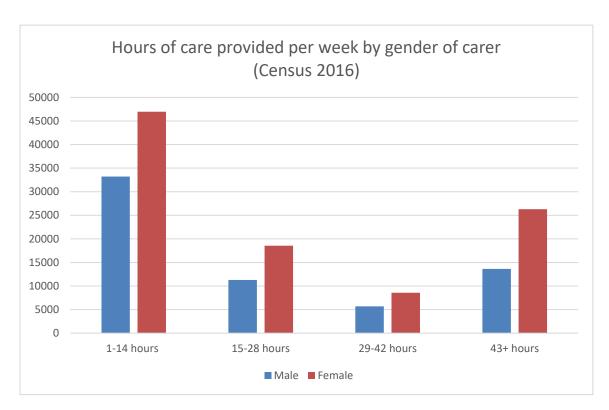


By age 80+ there is a much more even split of care between male and female.

¹⁴ Central Statistics Office, "Census 2016 Summary Results - Part 2" (Central Statistics Office, 2017).



However, when the intensity of caring is examined, it becomes clear that female carers provide significantly more hours of care – in particular at the higher intensities of care¹⁵;



Core Issues

Caring as 'women's work'

There have been estimates made regarding the value of care that family carers provide the State – most recent figures that have been calculated, conservatively indicate this is likely to be in excess of €10bn per annum¹⁶.

Internationally and historically, caring has been a gendered activity. That much is clear from the demographics outlined above. Care and caring has long been established as a predominantly female occupation, with the work of caring and the attributes of caregivers

¹⁵ Central Statistics Office.

¹⁶ Family Carers Ireland, "Family Carers Ireland Pre-Budget Submission - Budget 2018" (Family Carers Ireland, 2017). This figure was calculated from initial figures released as part of the Irish Health Survey in 2016 (355,000 carers), based on a replacement care cost of €12 p/h.





being feminised and consequently of low status, and receiving little recognition¹⁷. Whist this is changing, there is still an element of gendering involved in how caring is viewed.

Traditionally, care work is often seen as 'women's work' – indeed much of the modern 'carers movement' has developed from a push to have the value of the work of female family carers recognised¹⁸. Due to this feminisation of caring, and the resultant lack of status and recognition for caregiving activities, male family carers may experience significant stigma, not unlike the stigma faced by fathers who wished to become more involved in their children's care and development in previous decades. There are many who see a man who engages in caregiving activities as weak, or feminine, regardless of the relationship to the cared-for person. In addition, there have been cases of young male carers experiencing homophobia (regardless of their sexuality) due at least in part to their caregiving role¹⁹ ²⁰.

Following from this, relatively few male carers seem to publicly identify themselves as such, or to take part in carer support groups, etc. Just 11% of the followers of the National Carers Week Facebook page, for example, are male²¹. This can be partially accounted for by the differing types of support which men, traditionally, prefer. Whilst female carers enjoy speaking with others about challenges, and daily routines and tasks, many men prefer to share an activity unrelated to their caring role²². Male carers have reported a 1.6 times greater chance of a lower quality of life than female carers²³.

 $\underline{\text{http://carealliance.ie/userfiles/file/Masculinities}\%20\&\%20Care\%20in\%20Personal\%20Life;\%20Hanlon.pdf}$

¹⁷ Niall Hanlon, "Masculinities, Caregiving & Equality" (20 Years of Family Carer Research in Ireland, Dublin, November 21, 2015),

¹⁸ Victoria Molyneaux et al., "Reconsidering the Term 'Carer': A Critique of the Universal Adoption of the Term 'Carer," Ageing and Society 31, no. 3 (2011): 422–37.

¹⁹ Care Alliance Ireland, "'We Need to Talk About It' – Stigma and Family Care," 2016.

²⁰ Zoe Hughes, "Family Caring and Minority Populations" (Care Alliance Ireland, 2018), https://www.carealliance.ie/userfiles/file/Family Caring Minority Populations CAI 2018.pdf.

²¹ Correct on 26/02/2020

²² West Cork Carers, "Male Carers Ireland's Unsung Heroes," *Irish Examiner*, August 29, 2013, http://www.irishexaminer.com/farming/life/male-carers-irelands-unsung-heroes-241296.html.

²³ O'Sullivan, "Health and Well-Being of Family Carers in Ireland: Results of a Survey of Recipients of the Carer's Allowance."





Ribeiro, Paul and Nogueira's study²⁴ indicated that men fail to identify with the term 'carer', seeing the tasks and status involved in caring duties as part of a relationship. In that study, participants integrated their 'caring' identity with their sense of masculinity, taking pride in that role. In other studies, male carers appear to have developed a vision of masculinity that not only de-emphasised certain traditionally 'masculine' elements (such as not revealing emotions etc.), but which also emphasised others, such as taking charge, and 'male-to-male' bonding²⁵. More recent work in Ireland has shown that male carers, when telling their personal stories, were resisting traditional discourses surrounding masculinity. For example, they expressed satisfaction in skills learnt as part of their caring role which are traditionally not associated with masculine behaviour, such as dealing with household tasks. The gentle and tender way in which men described their involvement with and responsibility for intimate personal care also de-emphasised hegemonic masculinity²⁶.

Article 41.2 of Bunreacht na hEireann

Article 41.2 of the Irish Constitution²⁷ states:

- 1. In particular, the State recognises that by her life within the home, woman gives to the State a support without which the common good cannot be achieved.
- 2. The State shall, therefore, endeavour to ensure that mothers shall not be obliged by economic necessity to engage in labour to the neglect of their duties in the home.

²⁴ O Ribeiro, C Paul, and C Nogueira, "Real Men, Real Husbands: Caregiving and Masculinities in Later Life," *Journal of Aging Studies* 21, no. 4 (2007): 302–13.

²⁵ L Campbell and M Carroll, "The Incomplete Revolution: Theorizing Gender When Studying Men Who Provide Care to Aging Parents.," *Men and Masculinities* 9, no. 4 (2007): 491–508.

²⁶ Ann Stokes, "A Never-Ending Love Story: A Narrative Exploration into the Experiences of Men Who Provide Care in the Context of Dementia" (Unpublished PhD Thesis, Dublin, University of Dublin, Trinity College Dublin, 2015).

²⁷ Government of Ireland, "Bunreacht Na HÉireann: Constitution of Ireland" (Irish Stationary Office, 1937).





It is clear that the time has come to make some change to this particular Article within the Constitution, written as it was 82 years ago, at a very different time in history. Whilst there have been calls to remove, wholesale, the Article from the Constitution, we in Care Alliance Ireland favour amending the Article to reflect a more holistic view of caring within the home, and to reflect a more balanced gender view of caring. We have two main reasons for advocating the amendment of this Article, over and above removal.

We in Care Alliance are not in a position to discuss the Constitutional impacts of this Article as regard legislation, as that is not our particular area of expertise. However, we firmly believe that the recognition of unpaid care work within the community at Constitutional level is an important part of the recognition of the value of family care – which is considerable not just in monetary terms (as previously discussed), but also with regards to the value for those receiving care within their communities and families for as long as is feasible. This is in keeping with more recent policy documents based upon good practice, such as the National Carers Strategy, the National Ageing Strategy, the National Dementia Strategy and others.

The second reason to advocate amendment is to recognise the diversity within care – such as care undertaken by men, non-binary individuals and those women who are not mothers and are providing care to adults and children in the home. By continuing to restrict this recognition at Constitutional level, the State remains complicit in the invisibility of male and non-binary family carers.

Access to supports for men and non-binary carers

Whilst the challenges which male and non-binary family carers often face will be very similar to those faced by female carers, the methods of supports available to them will be different, and may not be the most appropriate. For example, many social events aimed at family carers will take the form of a coffee morning, a pamper day, or other more traditionally 'female' orientated activities. As the research evidence base on the



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specific supports and experiences of male and non-binary carers is sparse²⁸, it is an area that needs to be investigated, in particular in an Irish context.

Conclusion

As previously stated, we in Care Alliance are very pleased to have the opportunity to make this submission to the Citizens Assembly on Gender Equality, with a particular focus on issues of gender and care. We acknowledge that the bulk of care for older people, people with disabilities and long-term conditions etc. are provided by women across Ireland. However, it is crucial for the significant contributions of Ireland's male and non-binary family carers to be acknowledged, and indeed for their particular challenges to be discussed and solutions to those challenges proposed.

²⁸ Nan Greenwood and Raymond Smith, "Barriers and Facilitators for Male Carers in Accessing Formal and Informal Support: A Systematic Review," *Maturitas* 82, no. 2 (October 2015): 162–69, https://doi.org/10.1016/j.maturitas.2015.07.013.