

**Submission to the Joint Oireachtas Committee on Gender Equality**

**Care Alliance Ireland**

**March 2021**

**Executive Summary**

1. Care Alliance Ireland welcome the recommendations of the Citizens Assembly
2. We are in agreement that Article 41.2 of the Constitution should be deleted and replaced with gender neutral language to fully reflect the diverse nature of care and caregiving.
3. We believe Article 41.3 should be updated to reflect the modern Ireland we live in and the values of our country. We believe all families should be recognised in the Constitution and afforded rights and protection - not just marital families.
4. The loss of income and the opportunity costs for family carers must be fully investigated and taken into consideration when exploring how to adequately reimburse family carers for their contributions to Irish society
5. More integrated services must be developed to ensure that the services accessed across the lifecourse, such as young person services, schools, adult services, mental health services, and older persons services work together to ensure siloing of supports and care does not continue to occur
6. The diversity of family care in Ireland is not currently fully understood. The impacts of caring responsibilities will be different for male and non-binary carers. The traditional view of caring as a female role is simply no longer accurate, and may in some cases be damaging
7. Research undertaken by Care Alliance Ireland shows that respite is a core issue which must be addressed with immediacy. There is an opportunity to review how respite care is understood and conceptualised, and to explore more appropriate and family-centred respite options

## **Introduction**

8. Many thanks to the Joint Oireachtas Committee on Gender Equality for the invitation to make a submission regarding the specific recommendations arising from the Citizens Assembly on Gender Equality. Given the space and time restrictions of this submission, along with our organisational focus, we have chosen to comment specifically on those most relevant to Ireland's 500,000 family carers.

### **"Article 41.2 of the Constitution should be deleted and replaced with language that is not gender specific and obliges the State to take reasonable measures to support care within the home and wider community."**

9. Care Alliance Ireland are in agreement with the Assembly that this Article, referring as it does to care work, should be retained in spirit, while taking account of the diversity of family caring, including male and non-binary family carers. Deleting the Article and replacing it as suggested by the Assembly above achieves this. With regards to Article 41.3, we believe it should be updated to reflect the modern Ireland we live in and the values of our country. We believe all families should be recognised in the Constitution and afforded rights and protection - not just marital families.

### **"Reform Carers' Allowance by:**

- a. Increasing the level of the income disregard.**
- b. Reimbursing the direct and additional costs associated with caring.**
- c. Increasing the ceiling on the number of hours in paid work outside the home.**
- d. Providing access to State employment and training programmes."**

10. We were pleased to see the income disregard for Carers Allowance raised, along with the capital disregards, as part of the reforms in Budget 2022.
11. Recently completed and published research commissioned by the Dept. of Social Protection found that for households with a person with a disabled person, there was an additional cost of between €8,700 and €12,300 per annum<sup>1</sup>. This does not include the loss of income, and the opportunity costs for family carers who find themselves with family care responsibilities. As such, it is vital that in order to reimburse the direct and additional costs associated with caring, per the above recommendation, these issues are addressed. By enabling family carers to enter the paid labour market or enter education for more hours, it would allow for some of these economic impacts to be addressed. These changes must also ensure that an increase in hours does not negatively impact their eligibility for Carers Allowance (and the subsequent other qualifying supports).
12. With regards to the State education and training programmes, there are a number who do not have Carers Allowance as a qualifying payment (for example the Work Placement Experience Programme (WPEP), JobsPlus (a payment for employers)), however we are

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<sup>1</sup> Indecon International Research Economists, "The Cost of Disability in Ireland," 2021, <https://bit.ly/3HrLA4s>.

pleased to see that in a number of areas this point appears to have been addressed, with Carers Allowance acting as a qualifying payment or counting towards the time receiving state payments for initiatives such as the Back to Education Allowance and Back to Work Enterprise Allowance. These schemes should be more widely advertised as potentially relevant to family carers who have come to the end of their caring role. For many former carers, the caring role comes to an end due to the death or entry into long-term care for their loved one. This should be taken into consideration when examining and making changes to eligibility periods for such programmes.

**"The State should develop an individualised pension solution for carers to ensure they have an adequate income once they reach retirement age."**

13. Our colleagues in Family Carers Ireland have been particularly effective in advocating for this change and others relating to pension provision for family carers; you can read their policy document on the topic on their website (<https://bit.ly/2S6ACNU>).

**"Improve respite provision for carers by:**

**a. Increasing the level of the Carers' Support Grant in the next Budget and keeping it under review to ensure it keeps pace with other increases in social protection payments.**

**b. Providing adequate access to a range of respite services to meet individual needs."**

14. In 2021, we in Care Alliance Ireland partnered with the Institute for Social Science in the 21<sup>st</sup> Century in University College Cork (ISS21), to undertake research with family carers and interested stakeholders in reviewing the objectives of the National Carers Strategy (2012). Unsurprisingly, the top three priority action areas identified by both family carers and other stakeholders (i.e., policymakers, service providers, staff in the not-for-profit sector and researchers) were income supports, supports and services, and respite<sup>2</sup>. This shows a clear need, not just coming from the recommendations of the Citizens Assembly, but also from family carers themselves, along with professionals working in the area, for real reform of the existing systems of respite. This has become even clearer as we emerge in some form from the Covid19 pandemic and have an opportunity to rethink how respite is accessed, and in what forms.

15. The benefits felt by family carers who have access to the Carer Support Grant, whilst appreciated, can not always be fully utilised due to a lack of adequate respite in their locality for the person they care for. Respondents in the above study made particular reference to residential or overnight respite for those providing intense levels of care; this kind of respite was reported to be limited, and often crisis driven rather than planned. There should be no requirement for a crisis point to be reached for either carer

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<sup>2</sup> Maria Pierce et al., "A Review of The National Carers' Strategy (2012): How Relevant Are the Actions In 2021 and for the Future?" (Care Alliance Ireland and Institute of Social Science in the 21st Century, University College Cork., 2021), <https://bit.ly/3K4umMf>.

or cared-for person, in order for respite to be available. Indeed, ensuring regular access to respite can be a protective factor against family carer burnout.

**"Older people and persons with disabilities should:**

- a. Be actively supported and resourced to live independently.**
- b. Have access to person centred financial supports to serve their individual needs.**
- c. Be enabled to participate as fully as possible in decisions on their care needs, based on principles of fairness, respect, equality and dignity.**
- d. Be facilitated and resourced as much as possible if their choice is to be cared for at home."**

16. We recognise that for most older people the most desirable situation is to receive enough support from family and formal care to enable them to live independently for as long as possible. Care in the community supports diversity in local populations in terms of age and composition, while also encouraging inter-generational cooperation.

17. We do acknowledge that from time to time the needs and wishes of older and people with disabilities people can seem at odds with those of their family and caregivers. When this happens, we encourage clear lines of communication, possibly including input from health and social care professionals, to broker these difficulties in a positive manner. We refer readers to a Discussion Paper we published on managing these difficult relationships, which is available on our website at <https://bit.ly/2S7z4mN>.

**"Provision for those who wish to be cared for at home should be improved by:**

- a. Providing a statutory right for payment for home care packages as well as nursing care.**
- b. Increasing the annual home care budget to meet growing demand and reduce waiting lists."**

18. We in Care Alliance continue to advocate on these issues and welcome collaboration across the sector to do so effectively. We will continue to work with the Homecare Coalition in this regard. We have published a number of evidence-based papers on these topics, including *An Analysis of Home Care Supports Funded by the HSE 2008-2016* (available at <https://bit.ly/3aJvfL0>) and a follow-up paper published in 2018 (available at <https://bit.ly/3xuiwp1>).

**"Lifelong care for persons with disabilities who need it should be seamless and there should not be any break in services provided or need to reapply for support when a person turns 18."**

19. Feedback from our member organisations, parents and family carers of people with disabilities consistently report that the experience across transition points in life is particularly challenging. We welcome this recommendation and we include the caveat that lifelong care, in this instance, is not and should not be seen as the sole responsibility of disability specialists. We consistently hear reports of ongoing siloing of

age, health, mental health and disability services, which can often lead to individuals and families 'falling between the cracks'. This is unacceptable in 2022, when a holistic approach across the life course is critical to successful ageing.

**"Make special efforts to improve the visibility of men performing caring roles."**

20. Caring is a gendered activity, and much of the devaluing of care work in Irish society can be traced back to this. According to the latest Census figures, approximately 40% of family carers in Ireland are male. However, the majority of research, the supports available, and the publicity around caring treat female care as the 'standard'. To truly understand the diversity of care provided across Ireland, and to create the correct supports going forward, it is important to acknowledge this. Increasing the visibility of male and non-binary family carers will contribute to addressing the stigma that some non-female carers experience. Read more in our publications on the topic of stigma as related to family care at <https://bit.ly/2QE5Hb8>, and on minority caregivers at <https://bit.ly/3tW0ASI>.

**"Adopt a fully individualised social protection system to reflect the diversity of today's lives and to promote an equal division of paid work and care."**

21. We understand that the key target of this particular recommendation relates to parenting; however, we see scope for this recommendation to work across care in ageing, mental health and disability. In many families it is expected that should care be needed, one of the adult children – usually an unattached daughter – will step in to provide it. We are not suggesting that families be forced into organising care in a specific way; however, working to ensure a more equitable sharing of care between couples and within families is likely to create more positive caring situations for all involved.

**Conclusion**

22. We welcome the recommendations of the Citizens Assembly, and the formation of the Joint Oireachtas Committee on Gender Equality. We understand that the remit of the Committee is broad, and in order to keep this submission succinct we have deliberately kept our responses to the relevant recommendations short. We would welcome further opportunities to discuss these matters with members of the Committee, should that prove helpful.
23. Care Alliance Ireland, along with our member organisations, consistently work towards achieving full recognition of the vital role played by family carers. Valuing the contribution of family carers, which can be estimated in economic terms as being up to €20bn per year, must also take account of the inherently gendered nature of care, and policy must take account of this.
24. We wish the Committee well in their work on this issue.

## Background Information on Care Alliance Ireland

There are approximately 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.

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 of family carers. We achieve this by supporting our 95+ 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. We deliver a number of carer specific projects; namely an Online Family Carer Support Project<sup>3</sup>, a Back to Work Project (Kaleidoscope)<sup>4</sup> and a Technology Skills Development Project (Return Ready)<sup>5</sup>

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. We work with organisations in order that they can enhance the information and supports they provide to family carers. We provide them with opportunities to collaborate on initiatives including National Carers Week, a multi-agency and multi-disciplinary Family Carer Research Group, and joint policy submissions. We actively encourage collaboration in all our projects. We provide cohesion to those organisations working to support family carers. We commission relevant research that supports quality interventions in the lives of family carers.

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<sup>3</sup> <https://www.carealliance.ie/OnlineFamilyCarerSupportGroup>

<sup>4</sup> <https://www.carealliance.ie/Kaleidoscope>

<sup>5</sup> <https://www.carealliance.ie/Return-Ready>