

Submission re: Cost of Disability/ Cost of Caring**August 2019**

Care Alliance Ireland is pleased to submit this short overview of key issues, as we see them, pertaining to the ‘Cost of Caring’.

In the past we, along with our members and colleagues across the sector, have worked to highlight the various additional costs which both people with disabilities and family carers routinely experience, relative to the general population. In some cases, these costs affect the whole family/household unit.

Our fundamental premise is that you cannot look at the cost of disability without looking at the cost of caring to the wider family/household unit; disability and caring are two sides of the same coin, and do not exist in isolation.

There are, as will be discussed in the following sections, significant potential economic impacts of these issues for family carers across the country. There are several key pieces of research and policy that we have been involved in in the past number of years that are relevant to any discussion of this nature, and references to these are included throughout, and in the Appendix to this document.

As requested, this document presents an overview of key themes which we believe the review should examine in greater detail, rather than going into significant detail ourselves. If the research team would like more information about any of the topics discussed, we in Care Alliance are happy to discuss further.

Note: We in Care Alliance are of the opinion that there has been significant underreporting of caring roles and responsibilities in the Census to date. The most recent Census figure indicates that 195,263 people across the country provide care in such a manner¹. However, another CSO study² which took place within 12 months of the 2016 Census asked more in-depth questions, and from that we have extrapolated

¹ Central Statistics Office, “Census 2016 Summary Results - Part 1” (Central Statistics Office, 2017).

² Central Statistics Office, “Irish Health Survey (IHS) 2015 Results” (Central Statistics Office, 2016), <https://www.cso.ie/en/releasesandpublications/ep/p-ihs/irishhealthsurvey2015/ct/>.

that 1 in 10 adults are providing care to a family member or friend. This then equates to in the region of 375,000 family carers based on the latest population estimates. This figure of 10% of the adult population providing care is more in line with reported family carer prevalence in other western countries, and we are confident in its robustness.

Therefore, all estimations of figures in this document is based on this 10% population level of family care provision across the country.

Economic costs of caring

Large numbers of people with disabilities rely on family members to support them to live their lives to their full, generally at home³. The opportunity cost of caring for family carers, detailed below, is a significant issue that warrants analysis within this report. It is important to note that there are a number of studies from the past decade which continually indicate that family carers across Ireland and internationally list economic concerns as a key worry they experience on a regular basis. For example, a recent report published by Family Carers Ireland, UCD and the Irish College of Psychiatrists⁴ found that 75% of family carers worry about money – a significant increase from 49% in a similar study carried out a decade previously. In the UK, almost 40% of family carers say they are 'struggling to make ends meet'. The same study indicates that those caring for longer periods experience increased financial worries⁵ – which may be due to the extra costs of providing care necessitating use of savings over a prolonged period, and more intensive care as people age. There are examples within these reports of carers using their savings, pension funds and even selling their homes in order to continue to provide care for loved ones. Issues such as this must be included in any analysis, in particular from an Irish perspective.

³ Sarah Hourigan, Sarah Fanagan, and Caraiosa Kelly, "Annual Report of the National Intellectual Disability Database Committee 2017," HRB Statistics Series (Dublin: Health Research Board, 2018); Anne Doyle and Anne Marie Carew, "Annual Report of the National Physical and Sensory Disability Database Committee 2017," HRB Statistics Series (Dublin: Health Research Board, 2018).

⁴ Family Carers Ireland, College of Psychiatrists of Ireland, and UCD, "Paying the Price: The Physical, Mental and Psychological Impact of Caring" (Family Carers Ireland, 2019).

⁵ Carers UK, "State of Caring - A Snapshot of Unpaid Care in the UK (2019)" (Carers UK, 2019).

Replacement cost of caring per hour

There are up to 375,000 individuals across Ireland providing care to a person with a disability, mental health concern, chronic illness or age-related concerns. All of these can be viewed as 'disabling conditions', which can require care and support in different intensities and in differing forms. Some, such as certain mental health and chronic pain conditions, can also be 'cyclical' in nature, requiring period of intense caring, followed by periods where this is unnecessary.

For some, they will provide round the clock, heavy medical care, and for others it will entail significant support with the various Activities of Daily Living (ADL's) such as washing, cooking, cleaning, socialising, etc. Estimates for how much it would cost to pay family carers in line with home care workers for the work they do are different depending on how they are calculated. However most recent estimates from our colleagues in Family Carers Ireland place this value at approximately €10bn. They have come to this estimate by taking the hours of care provided according to CSO figures and multiplying that by a modest hourly rate⁶. If the Exchequer was required to pay care workers to undertake all the hours of care which family carers report undertaking, therefore, this would be the approximate cost. However, we believe that more thorough research with data from varied sources would be beneficial to the sector to add clarity and granularity to our understanding of the replacement costs of family care, and to collate the work being done to calculate this cost from the perspective of those caring for individuals with different conditions both nationally and internationally⁷.

Additional costs borne by family carers

We in Care Alliance believe that there are significant economic costs for family carers which may or may not be captured if looking purely at the costs of disability.

⁶ Family Carers Ireland, "Family Carers Ireland Pre-Budget Submission - Budget 2018" (Family Carers Ireland, 2017).

⁷ See Appendix for some international studies which may be of interest in this regard.

Utilities and travel costs

The occurrence of disability often coincides with increased levels of medical need – in particular when including chronic pain, illness and ageing concerns within a definition of disability. As such, family members and carers are often in the position of needing to travel with the person they care for to medical appointments etc. For example, a recent paper published by Care Alliance indicates that rural locations - along the western seaboard in particular - has the highest concentration per head of population of family carers in Ireland, along with the longest travel times to hospitals, GP's and pharmacies. For family carers in those regions, travel costs will be significantly higher than in the rest of the country due to the increased need for them to accompany many of their cared-for persons to appointments etc. which in turn increases travel costs and car upkeep etc. The cost of this for families is significant, in particular in light of the refusal of the Dept. of Health to fulfil their commitment to introduce the Transport Support Scheme announced in 2014 as a replacement for the Mobility Allowance and Motorised Transport Grant.

Similarly, increased costs from home adaptation, in particular for those ineligible to avail of adaption grants etc must also be examined. It is likely the brunt of these costs are borne by the family of the person with a disability, as many of those who are in need of such adaptation are less likely to be in paid employment, given the low level of employment opportunities for people with disabilities (c. 70% of people with disabilities are not in paid employment⁸). Increased utility bills such as heat and refuse costs associated with disability (for example increased heating due to limited mobility), incontinence issues (refuse, laundry), and increased electricity usage due to the running of essential medical equipment are also issues that should be included in the analysis.

Lost earnings of carers on individuals/families

It is difficult to know how many family carers are juggling work and care responsibilities, however recent work from Family Carers Ireland⁹ suggests that just over one-fifth of

⁸ See <https://www.cso.ie/en/releasesandpublications/ep/p-wbn/thewellbeingofthenation2017/wk/>

⁹ Family Carers Ireland, College of Psychiatrists of Ireland, and UCD, "Paying the Price: The Physical, Mental and Psychological Impact of Caring."

family carers are in paid employment – with the majority of those working (70%) doing so on a part-time basis. This stands in stark contrast to the proportion of the general employed population, for whom part-time work rate is just over 20%¹⁰. Clearly, therefore, the impact of family care on accessing paid employment is significant. In turn, this will impact the ability of former family carers to access employment at a level they previously enjoyed when and if they can return to the workplace fulltime. This opportunity cost impacts their ability to return to their previous income levels and also impacts their future pension provisions. In the long-term, this then impacts the level of support they may or may not need from the state as they age.

We suggest that any examination of this issue also be approached from an opportunity cost perspective. This measures the value in alternative use of time spent caring which is typically valued by productivity losses (or value of leisure time) associated with caring. This is based on the assumption that time spent providing informal care could be alternatively used within the paid workforce or in leisure activities. The value of informal care using the opportunity cost method can be represented as $t_i \times w_i$, where t_i is the time provided by individual 'i' on providing care, and w_i is the net market wage rate of individual 'i'¹¹.

We recommend that researchers and analysts involved in this examination of the costs of disability and caring read our Pre-Budget Statements from recent years, which will also indicate levels of economic pressure and our previously proposed suggestions of actions to take to lessen the negative impacts for family carers. They are all available on our website (http://www.carealliance.ie/publications_submissions).

Impact of loss of earnings on GDP/private business

Family caring responsibilities account for many employees' exit from the workforce – Employers For Carers (UK) has found this to be the reason for leaving work for a surprising number of employees, in particular men in skilled positions¹². This, in turn

¹⁰ OECD, "Part-Time Employment Rate," 2019, <https://data.oecd.org/emp/part-time-employment-rate.htm>.

¹¹ Care Alliance Ireland, "Family Caring in Ireland," 2015.

¹² Family Carers Ireland, "Briefing Paper: Balancing Work and Care: International Challenges and Irish Perspectives" (Family Carers Ireland, 2017).

creates additional costs on private and public sector business needing to recruit and train replacement workers. This point ties in somewhat to the opportunity cost of caring outlined in the previous section. It would be worthwhile discussing the impact of family caring within the workforce/education and training with employers and educators to examine the issue in more detail, and in an Irish context.

Social and health costs of caring

Whilst we appreciate that the main focus of this research is based upon the economic impact of caring, we do believe that the social and health impacts of caring will certainly have an impact on the economic situation of family carers. For example, many family carers are unable to prioritise their own health due to time or indeed economic constraints. This will have a long-term effect on the health system as these carers themselves age and develop disabilities and health conditions such as heart problems, back and joint pain etc., in part because of their caring responsibilities¹³. Up to 75% of family carers in Ireland report being concerned about the own health and wellbeing, and what would happen to the person they care for if they were unable to continue to provide care¹⁴.

¹³ Social Policy Research Unit, York, Carers UK, and Carers Scotland, "Hearts & Minds: The Health Effects of Caring" (Carers UK, 2004), <https://www.york.ac.uk/inst/spru/pubs/pdf/Hearts&Minds.pdf>.

¹⁴ Family Carers Ireland, College of Psychiatrists of Ireland, and UCD, "Paying the Price: The Physical, Mental and Psychological Impact of Caring."

Appendix of useful resources

Care Alliance Ireland. "Family Caring in Ireland," 2015.

Carers UK. "State of Caring - A Snapshot of Unpaid Care in the UK (2019)." Carers UK, 2019.

Central Statistics Office. "Census 2016 Summary Results - Part 1." Central Statistics Office, 2017.

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

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Jutkowitz, E., Kane, R., Gaugler, J., MacLehose, R., Dowd, B., & Kuntz, K. *Societal and Family Lifetime Cost Of Dementia: Implications For Policy.* Journal of the American Geriatric Society, 2017.

OECD. "Part-Time Employment Rate," 2019. <https://data.oecd.org/emp/part-time-employment-rate.htm>.

Social Policy Research Unit, York, Carers UK, and Carers Scotland. "Hearts & Minds: The Health Effects of Caring." Carers UK, 2004. <https://www.york.ac.uk/inst/spru/pubs/pdf/Hearts&Minds.pdf>.

The Cost of Dementia Care in 2018 (US): <https://www.alzheimers.net/the-cost-of-dementia-care/>