

Statement of Priorities (DEASP Focus) - Budget 2021

2020 has been a challenging year for society around the world. Following the onset of Covid19 in late 2019, it was designated as a pandemic by the World Health Organisation in March 2020. The subsequent lockdown and physical distancing measures adopted across Ireland has led to a situation whereby there has been a significant withdrawal of vital health and social care services and supports across disability, mental health and all other sectors. These withdrawals were necessary and understandable in the context of the time. However, for family carers, this continued and extensive unavailability of support services is clearly impacting on them as carers and also on the people they care for. A specific challenge is the timeline for the re-introduction of home support for the thousands of family households, who have experienced forced reductions in, or chosen to reduce, this support due to fears around the transmission of Covid19.

In conceiving this Pre-Budget Statement for Budget 2021, we have been keenly aware that normality will be slow to get back to, if it is possible at all, given the disruption which has taken place in the first months of 2020. We wish to impress upon decision makers to ensure that funding levels and service provision for family carers and those they care for are protected and reinstated to proposed 2020 levels as soon as possible. Many family carers have not left their homes even once since the initial onset of lockdown in March of this year, and have no plans to do so in the short to medium term, until they are confident in relation to the health and safety of their loved ones. In doing so, and in taking on an ever increasing responsibility for the care of their family members, they require increasing levels of support themselves in order to address the significant challenges they face.

Recent research conducted by various organisations in Ireland¹ has shown just how the family carers in Ireland have been effected by Covid19, and how vital it is to their wellbeing that services and supports are brought back online and indeed expanded as soon as possible;

- 84% of respondents worry about not being able to care for their loved one due to getting Covid19.
- 60% of carers worry about a decline in their own mental health and wellbeing
- 56% are worried about their loved one displaying more challenging behaviours
- 43% fear that normal services will not be restored after the outbreak has been contained

¹ Family Carers Ireland, 'Caring Through COVID: Life in Lockdown' (Family Carers Ireland, 2020); Inclusion Ireland, 'COVID-19 and the Impact of the Closure of Day Services on People with Intellectual Disabilities' (Inclusion Ireland, 2020); The Alzheimer Society of Ireland, 'Covid-19: Impact & Need for People With Dementia and Family Carers' (The Alzheimer Society of Ireland, 2020).

- 54% had little to no contact from the day service during the lockdown period

There is a marked increase in family carers experiencing stress, anxiety, depression and other mental health difficulties as a result of Covid19². There are reports of severe delays in responses from health and social care professionals. These are understandable in the context of the situation but do serve to increase anxiety, and in the worst cases lead to a regression in the functional abilities of those being cared for - which in turn heightens the caring responsibilities of family carers across the country.

Notwithstanding the budgetary constraints and challenges the Government is under for Budget 2021, we have included in this Statement some key measures we have been advocating for across a number of budget cycles, including advances in funding for home care and other issues. It is important that we take this opportunity to lay out these asks at this time so that they remain in the consciousness of policy makers. We also acknowledge that a number of these core asks have been included to varying degrees with the Programme for Government which forms the policy basis for this new government in their first Budget cycle.

This Pre-Budget Statement for Budget 2021 summarises three key priorities which, if supported in Budget 2021, would continue to progress the development of services and supports for Ireland’s nearly 391,260 family carers³.

Priority 1: Funded Policy Development

Priority 2: Funding of Services and Supports

Priority 3: Addressing Poverty and Income Inequality

For this submission, we have focussed our attention on the actions and issues most relevant to the remit of the DEASP, as requested. We have included our key asks relevant to other Departments as bullet points for brevity, but are open to discussing these at any stage with relevant representatives.

(Note: we consulted our member organisations in preparing this submission. However, the submission should not to be seen as the collective views of all Care Alliance Ireland members. We expect that many of our member organisations will make, or have made, their own submissions.)

² Stephen Gallagher and Mark Wetherell, ‘Risk of Depression in Family Caregivers: Unintended Consequence of COVID-19’, preprint (Psychiatry and Clinical Psychology, 17 June 2020), <https://doi.org/10.1101/2020.06.15.20131532>.

³ Central Statistics Office, ‘CSO Releases Irish Health Survey Results’, 16 November 2016, <http://bit.ly/2sJOsYT> 10% of adult population equates to approximately 391,260 people, per most up-to-date population figures.

Priority 1: Funded Policy Development

Key Ask:

- **Development of a new National Carers Strategy with dedicated ringfenced funding**

Priority 2: Funding of Services and Supports

Key Asks:

- **Continue to increase funding for respite care**
- **Create an entitlement for one week of respite each year for all family carers in receipt of Carers Allowance, and who are therefore providing full-time care for their loved one.**
- **Address waiting lists for services to children with disabilities**
- **Address silo-ing of services in child and adult disability services, particularly regarding the transition point between leaving school and entering employment/further training for people with disabilities.**
- **Funding of programmes to address the specific needs of family carers from minority populations.**
- **Extend GP Visit Card eligibility to those in receipt of the Carer Support Grant.**
- **Funding of training programmes for family carers caring for a person dying at home**

Priority 3: Addressing poverty and income inequality

It has been shown that there is an economic cost to having, or caring for someone who has, a disability or long-term health condition (be that physical or mental health)⁴. Income support is a lynchpin for many family carers in Ireland today. Due to the all-encompassing nature of a great deal of the care provided, many family carers have taken a break from their paid employment in order to care for their loved ones. This means that they are dependent on income support to manage their day-to-day finances. Family carers, in general, are at higher risk of poverty than non-carers⁵ with research a number of years

⁴ Carers UK, 'The Cost of Caring: How Money Worries Are Pushing Carers to Breaking Point' (Carers UK, 2011); John Cullinan, 'The Economic Costs of Disability for Families', *Frontline: The Irish Voice of Intellectual Disability*, no. 97 (2015); John Cullinan and Sean Lyons, 'The Private Economic Costs of Adult Disability' (Disability through the Lifecourse: ESRI Research Conference, Economic and Social Research Institute, 2014).

⁵ OECD, 'The Impact of Caring on Family Carers', in *Help Wanted? Providing and Paying for Long-Term Care* (OECD, 2011).

ago in the UK finding that 72% of family carers were worse off as a consequence of their caring role⁶. A similar study in Ireland found that over two-thirds of family carers found it difficult to make ends meet⁷, with a 2014 study by the Neurological Alliance of Ireland finding that 45% of family carers of people with a neurological condition had been impacted by the economic impact of caring and the condition on daily life⁸. It is clear, therefore, that protecting and expanding income support schemes are vital for ensuring that family carers can continue to perform their roles, which provide the bedrock of care in Ireland.

In 2018 the then Minister for Employment Affairs and Social Protection, Regina Doherty committed, as part of the Pre-Budget process, to a significant study of the cost of disability and caring. Whilst we were pleased to be invited by INDECON to review the survey materials and make representation on the study, we remain disappointed that the research does not actively name and prioritise the investigation of the additional costs of caring explicitly. We look forward to the results of this research (although we remain disappointed at the very slow pace it is proceeding) but are not confident that it will truly examine the costs of caring, given that the respondents targeted are those in response of specific disability payments with a few short questions pertaining to their family carers.

Covid19 has had a significant impact upon the financial situation of family carers. Research by Family Carers Ireland found that more than one third (39%) of respondents worry about the financial costs and implications of the pandemic. Almost half (48%) requested more financial support to help them with the additional costs of caring during COVID-19⁹. Therefore, ensuring continuity of financial supports and where possible increasing them or increasing access to them will be of critical importance.

Carers Support Grant

We acknowledge that the Carer Support Grant is a considerable and welcome economic boost for family carers (in particular those who may not qualify for other financial supports). However, this grant is a once-off payment which is distributed once each year to those in receipt of Carer’s Allowance/Benefit (along with those who have applied for the grant in isolation). It is paid, to those on a list of income support measures on a single date in June. Therefore, those who may have been caring for a loved one for 11 out of the preceding 12 months do not receive the payment.

⁶ Carers UK, ‘Real Change Not Short Change’ (Carers UK, 2007).

⁷ E O’Shea, ‘The Costs of Caring for People with Dementia and Related Cognitive Impairments’ (National Council on Ageing and Older People, 2000).

⁸ Neurological Alliance of Ireland, ‘“Living with a Neurological Condition in Ireland”: Report on the Findings of a National Survey 2014’ (Neurological Alliance Of Ireland, 2014).

<http://bit.ly/1kJjWDw>.

⁹ Family Carers Ireland, ‘Caring Through COVID: Life in Lockdown’.

In general, there are two reasons for a family carer to no longer be in receipt of Carer’s Allowance or Benefit: the death of the person they care for or their entry into long-term care. Both of these significant occurrences are characterised by bereavement and high levels of stress, and sometimes financial outlay. If the person they cared for at home has moved to residential care, in many cases the family carer continues to provide a significant level of care, with regular, often daily, visits.

In addition, there are many family carers whose caring responsibilities are episodic and unpredictable in nature, for example those family carers supporting a person with a chronic condition (who may experience periods of wellness and illness), and those supporting loved ones with mental health conditions which are often cyclical in nature. The arbitrary timing of this payment means that these family carers may miss out on the payment which they are entitled to in all other ways, but whose administration is not flexible enough to take note of this cyclical nature to their caring role.

The renaming of the grant in Budget 2016 acknowledged that its purpose is to support family carers in whatever manner they see fit. To compliment this, we strongly suggest that the Carer’s Support Grant should be administered on a pro-rata basis¹⁰, which would lessen both carer stress and income inequality, and would speak to a number of actions at the core of the National Carers’ Strategy¹¹. An increase in the level of the Grant would also be welcome, noting the cost of caring/disability¹², along with increases in certain household costs (such as rent/mortgage and ancillary costs), and indeed the increased costs experienced by family carers during Covid19.

Key asks:

- **Increase Carer Support Grant to €2,000 per annum**
- **Pay Carer Support Grant on a pro-rata basis**

Adaptation grants

The unavailability and inequality of different adaption grants schemes has led to significant distress for many people with disabilities and long-term conditions, and their family carers. Our member organisations repeatedly raise the issue of the lack of availability and transparency of the Housing Adaptation Grants in particular. Without funding becoming available in a timely and responsive manner to make specific and critical adaptations to their homes, many families are forced to either care for their loved ones in completely unsuitable housing, or to refuse to allow their loved ones to remain in, or return to, the

¹⁰ For example in 2 six-monthly instalments

¹¹ Caroline Crowley, ‘Making the Respite Care Grant a pro Rata Payment’, 2015.

¹² O’Shea, ‘The Costs of Caring for People with Dementia and Related Cognitive Impairments’; Cullinan, ‘The Economic Costs of Disability for Families’; Cullinan and Lyons, ‘The Private Economic Costs of Adult Disability’.

family home, necessitating entry into residential care inappropriately. This in turn has a huge effect on the expenditure of the hospital or residential setting, when a smaller amount of funding would have significantly increased the quality of life of the person with a disability and their family carers.

In addition, the repeated lack of introduction to an alternative scheme to the Motorised Transport Grant (closed to new applicants since 2013) is disappointing. This particularly affects rural and isolated family carers who did not apply for the scheme before it was closed seven years ago. Many of our member groups are supporting individual family carers and family groups who remain considerably isolated because of the combined lack of a replacement scheme, and the lack of accessible public transport in rural locations.

As the country begins to recover from Covid19, and access to public transport remains curtailed or unsafe for those in vulnerable populations, access to appropriate private transport is increasingly important. More family carers are relying on private, secure transport more than ever, making this particular point critical – in particular noting the continued lack of publication of a new scheme in direct opposition to statements made by previous Ministers.

Key asks:

- **Increase funding to the Housing Adaptation Grant, and increase transparency across funding areas**
- **Introduce the Transport Support Scheme announced in 2014 as a replacement for the Mobility Allowance and Motorised Transport Grant as a matter of urgency**

Bereavement costs

The discontinuation of the Bereavement Grant in early 2014 has had a significant knock-on effect on the transition to post-caring. We urge that the Bereavement Grant be reintroduced for the families of those in receipt of Disability Allowance, Carer’s Allowance and half-rate Carer’s Allowance.

In addition, research on the personal and family costs, including funeral costs, should be undertaken to inform Government policy and foster a cross-departmental strategic approach to issues arising at end of life. Policies on supports available for bereavement and funeral costs should be reviewed to ensure that they are appropriate and accessible to those in most need.

- **Key Ask: Reintroduce the Bereavement Grant**

Carers Allowance & Benefit

Carers Allowance and Benefit remain the sole payment for which the recipient must record evidence of working full-time (at least 35 hours per week) in order to qualify. This also does not take into consideration that many family carers in receipt of Carers Allowance or Benefit provide far more than 35 hours of care per week – with research indicating that 82% of family carers care for more than 50 hours per week¹³. We support the ask which Family Carers Ireland have been advocating for some time now, which is to reform the means test for family carers, including an increase of the income disregard when calculating eligibility.

In addition, Carers Allowance remains a taxable source of income, something which our members have highlighted as inappropriate given the extra costs of caring outlined earlier.

We would also support the recognition of the contribution and personal sacrifice of lifetime carers (those caring in excess of 20 years) by putting in place mechanisms to maximise their entitlement to a Contributory State Pension when they reach retirement age.

Key asks:

- **Reform the Means Test for Carers Allowance, and increase the income disregards when calculating eligibility.**
- **Remove Carers Allowance as a taxable source of income**

Conclusion

Budget 2021 will, by necessity, take a very different approach than initially planned, given the significant challenges in recovery posed by Covid19. We understand that it will take time to fully return to normality within the health and social care sector. However, it must be noted that the family carers of Ireland, and those they care for, have made significant sacrifices in order to stay safe and well, and prevent the situation worsening. Many family carers have not left their homes even once since the initial onset of lockdown in March of this year, and have no plans to do so in the short to medium term, until they are confident in relation to the health and safety of their loved ones. In doing so, and in taking on an ever increasing responsibility for the care of their family members, they require increasing levels of support themselves in order to address the significant challenges they face.

As always, it is crucial that the Government is guided in its decisions on family carers by the three key principles laid out in the National Carers’ Strategy, namely: recognition, support and empowerment.

¹³ Family Carers Ireland, College of Psychiatrists of Ireland, and UCD (2019), ‘Paying the Price: The Physical, Mental and Psychological Impact of Caring’.

Whilst the income supports available to family carers go some way towards assisting them in their role, major gaps persist. Care Alliance Ireland believes strongly in the value of the state providing a comprehensive suite of supports for family carers, across a range of departments and agencies. We call upon Government as a whole to prioritise the publication of the second version of the National Carers’ Strategy, with ring-fenced funding for the actions contained within it, and a related implementation plan, using the successful National Disability Strategy Implementation Plan (National Disability Strategy Implementation Group, 2013) as a model.

Background Information on Care Alliance Ireland

There are approximately 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.

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 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.

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.

By focusing on these functions we enable more of our member’s resources to go directly to coal face services.

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