

## **Statement of Priorities (DSP Focus) - Budget 2023**

The past 30 months have seen significant disruption to the lives of family carers and those they support. This included the withdrawal of services and difficulties accessing social, educational and health supports. Increased loneliness and isolation has been reported by family carers<sup>1</sup>, likely to due to the need for some to to cocoon or at the very least significantly reduce their social lives in order to stay safe and well. Many family carers across the country have continued to isolate in order to protect their loved ones from the risks of Covid-19.

In addition, we come to Budget 2023 facing what many have termed a 'Cost of Living Crisis', which has seen annual inflation climb to 7.8% in the year to May 2022<sup>2</sup>, with an estimated increase to 9.6% in June according to EuroStat<sup>3</sup>. Energy prices have seen steep rises in recent months – of up to 100% from some suppliers<sup>4</sup>.

Since the announcement of Budget 2022, two significant primary research reports have been published which highlight the increased costs of disability and caring. Firstly, the DSP itself published the Cost of Disability in Ireland Research Report in December 2021, which concludes that people with disabilities may face costs of up to €12,300 per annum (with an average of between €9,482 to €11,734)<sup>5</sup>. This does not include the costs of unmet need, which are unmet precisely because they are not currently affordable<sup>6</sup>.

Secondly, Family Carers Ireland, in collaboration with the Vincentian Partnership for Social Justice published their study in early 2022, which calculates a Minimum essential Standard of Living for a family of a person with a profound disability. The conclusion of that study highlights additional costs of up to €308 per week over and above those costs incurred by the same family without a disability<sup>7</sup>.

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<sup>1</sup> Family Carers Ireland, "The State of Caring 2022" (Family Carers Ireland, 2022); Alzheimer Society of Ireland, "Caring and Coping with Dementia During Covid19: Experiences of People Living with Dementia and Family Carers," n.d.; Dominique Phillips et al., "The Invisible Workforce during the COVID-19 Pandemic: Family Carers at the Frontline," *HRB Open Research* 3 (2020): 24, <https://doi.org/10.12688/hrbopenres.13059.1>.

<sup>2</sup> Central Statistics Office, "Consumer Price Index May 2022" (Central Statistics Office, 2022), <https://www.cso.ie/en/releasesandpublications/er/cpi/consumerpriceindexmay2022/>.

<sup>3</sup> <https://ec.europa.eu/eurostat/documents/2995521/14644614/2-01072022-AP-EN.pdf/72dcf5e4-56cb-5b8c-1a1f-d342666b8657?t=1656592347325>.

<sup>4</sup> <https://www.bonkers.ie/blog/gas-electricity/why-are-energy-prices-increasing/>

<sup>5</sup> Indecon International Research Economists, "The Cost of Disability in Ireland," 2021, <https://bit.ly/3HrLA4s>.

<sup>6</sup> 'Unmet need' refers to additional costs of items or services which participants in the research were asked to estimate. The reason these costs remain 'unmet' and must be estimated is because the participants were simply unable to afford them, and so were not included in existing family or personal budgets. Full details are available in the previously referenced report.

<sup>7</sup> Bernadette MacMahon, Hannah Boylan, and Robert Thornton, "Care at Home: Costs of Care Arising from Disability" (Family Carers Ireland, 2022).

The additional costs of disability and caring as reported in both of these research reports are significant. This Care Alliance Ireland Pre-Budget Statement for Budget 2023 summarises three key priorities which, would continue to progress the development of services and supports for Ireland's nearly 500,000 family carers.

**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 DSP, 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: This submission should not 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.)*

**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**
- **Increased funding for online and blended supports for family carers**

### **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)<sup>8</sup>. Income support is a lynchpin for many full-time family carers in Ireland today. Due to the all-encompassing nature of a great deal of the care provided, many family carers have taken an extended break from their paid employment in order to care for their loved ones. This means that they are generally dependent on income support to manage their day-to-day finances. Family carers, in general, are at higher risk of poverty than non-carers<sup>9</sup> with research a number of years ago in the UK finding that 72% of family carers were worse off as a consequence of their caring role. Recent research from Family Carers Ireland found that 68% of family carers experience financial distress, with 13% in arrears with their rent or mortgage (in contrast to 7% of the general population)<sup>10</sup>. It is clear, therefore, that protecting and expanding income support schemes are vital for ensuring that family carers can continue to perform their roles with some level of financial security.

In light of the recent Basic Income for the Arts (BIA) pilot scheme which provides a payment of €325 per week to artists, there is an opportunity to rethink how financial supports are provided to those caring for friends and family at home. The Programme for Government commits to creating a pilot scheme for a Universal Basic Income within the life of the current Government. Additionally, in 2020 the National and Social Economic Council (NESC) recommended the development of a 'participation income' to recognise the contribution of those who are not currently working in the economy, but who are making a contribution to society in some other way – for example by caring for family or friends, or undertaking significant volunteer work<sup>11</sup>.

Many family carers see the various income supports for family carers (i.e. the Carer Support Grant, Carers Benefit and Domiciliary Care Allowance) as a payment for the work they do, as opposed to a payment to keep them out of poverty. For this reason the means

<sup>8</sup> 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); MacMahon, Boylan, and Thornton, 'Care at Home: Costs of Care Arising from Disability' (2022).

<sup>9</sup> OECD, "The Impact of Caring on Family Carers," in *Help Wanted? Providing and Paying for Long-Term Care* (OECD, 2011).

<sup>10</sup> Family Carers Ireland, "The State of Caring 2022."

<sup>11</sup> National Economic and Social Council (NESC), "The Future of the Irish Social Welfare System: Participation and Protection" (National Economic and Social Council, 2020).

test for Carers Allowance in particular can be very distressing, as can reviews of their means as a household. For them, the care needs of those they support have not changed – and if they have, it is more likely to have increased in intensity over time. If the Government is truly seeking to acknowledge the considerable work that family carers undertake on a daily basis, and to show appreciation for that contribution, enhancements to the income supports schemes available to family carers are an appropriate place to begin.

### Carers Support Grant

We acknowledge that the Carer Support Grant is a considerable and welcome economic boost for family carers (in particular for 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 others who have applied for the grant in its own right). 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.

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 life events are characterised by bereavement and high levels of stress, and sometimes quite considerable 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 have an option for recipients to choose to be administered on a pro-rata basis – perhaps in two six-monthly instalments. This would lessen both carer stress and income inequality, and would speak to a number of actions at the core of the National Carers' Strategy<sup>12</sup>.

We acknowledge and welcome the increase in Budget 2021 of the rate of the payment to €1,850, to take account of the increased financial pressure family carers experienced

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<sup>12</sup> Caroline Crowley, 'Making the Respite Care Grant a pro Rata Payment', 2015.

during the Covid19 pandemic. We suggest continuing this to increase the payment to €2,000 per annum to account for these pressures continuing into the future, in particular in light of the significant increases in inflation and the increased cost of living.

### Key asks:

- **Increase Carer Support Grant to €2,000 per annum**
- **Facilitate the payment of the Carer Support Grant on a pro-rata basis**

### Adaptation grants

Reported difficulties in accessing and availing of different adaption grants schemes such as those for home adaptations and transport 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, although we do acknowledge the announcement of increased funding to the grants (to €81.25 million). Concerns have been raised recently that the upper level of payment for the Housing Adaptation Grant, capped at €30,000 is simply not adequate for the work needed in many cases to adapt a home for a person with a disability<sup>13</sup>.

We welcome the commitment in Housing for All (2021) to 'review the range of housing grants for the suitable adaptation of existing housing'<sup>14</sup>; however we note that the timeline for this action has passed (Q4 2021), yet we have been unable to find any reference to this review in publications available. This review must take place as a matter of urgency to understand the current and future costs of such adaptation works, to reform the system and to make it fit for purpose.

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 effects rural and isolated family carers who did not apply for the scheme before it was closed nine 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 adequate accessible public transport in rural locations. This continues to be an issue raised by our member organisations for those they represent and support.

Covid19 continues to be a threat to those with underlying health conditions - and many of those in vulnerable populations do not feel comfortable or safe travelling on public

<sup>13</sup> See for example <https://www.limerickpost.ie/2022/04/04/call-to-raise-limit-on-housing-adaptation-grants/>

<sup>14</sup> Department of Housing, Local Government and Heritage, "Housing For All - A New Housing Plan for Ireland" (Government of Ireland, 2021).

transport. Therefore, access to appropriate private transport is increasingly important. Family carers are relying on private transport more than ever, making this particular point critical – in particular noting the continued lack of publication of a new scheme at odds with statements made by previous Ministers.

### Key asks:

- **Undertake the review of the range of grants available to assist with meeting specific housing needs, as committed to in Housing For All.**
- **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

We acknowledge the measures that were taken in Budget 2022 to widen the eligibility net for those in receipt of Carers Allowance by increasing the weekly income and capital disregards.

However, Carers Allowance and Benefit remain the sole state income support 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 week<sup>15</sup>.

<sup>15</sup> Family Carers Ireland, College of Psychiatrists of Ireland, and UCD (2019), 'Paying the Price: The Physical, Mental and Psychological Impact of Caring'.

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

We support the call of our colleagues in Family Carers Ireland for a review of the Carers Allowance Scheme in light of recommendations from the National Economic and Social Council research concerning a Participation Income for carers, the commitment to the introduction of a pilot Universal Basic Income scheme in the Programme for Government and the recently introduced pilot scheme for a Basic Income for the Arts.

### Key asks:

- **Remove Carers Allowance as a taxable source of income**
- **Review the Carers Allowance scheme**

### Conclusion

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. In some instances, family carers have not left their homes since the initial onset of lockdown in March of 2020 (or have done so minimally), 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. Others have significantly curtailed indoor socialising or other activities. 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.

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 once again, as a whole, to prioritise the publication of the second version of the National Carers’ Strategy<sup>16</sup>, with ring-fenced funding for the actions contained within it, and a related implementation plan, using the

<sup>16</sup> Note that in early 2021 Care Alliance Ireland in partnership with ISS21 in University College Cork undertook research to evaluate the relevance of the 42 actions within the current National Carers Strategy for 2021. This report is available on our website;

<https://www.carealliance.ie/userfiles/files/CarerEngageNCSReport2021.pdf>

successful National Disability Strategy Implementation Plan (National Disability Strategy Implementation Group, 2013) as a model.

## 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.

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 work with organisations to provide better information and supports 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 deliver a number of online carer specific projects; namely an Online Family Carer Support Project, a Back to Work Project, and a Technology Skills Development Project. We commission relevant research that supports focused and quality interventions in the lives of family carers.

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