

Care Alliance Ireland

Statement of Priorities - Budget 2018

The financial downturn in 2008 saw large scale cuts to services and supports for people with disabilities, mental health concerns, long-term illness, and their families. Ten years on, in Budget 2018, we are calling on Government to fully address the negative impacts that these cuts have had on Ireland's 360,000 Family Carers, and fund real change which impacts Family Carers positively. This Pre-Budget Statement for Budget 2018 summarises three key priorities which, if supported in Budget 2018, would continue to progress the development of services and supports for Ireland's nearly 360,000 Family Carers¹.

We have identified three broad priorities for Budget 2018, and into the future. These are:

Priority 1: Funded Policy Development

Priority 2: Funding of Services and Supports

Priority 3: Addressing Poverty and Income Inequality

(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.)

Priority 1: Funded Policy Development

Without a solid policy foundation, the development of services and supports for Family Carers (and those they care for) will be severely hampered and under threat when Governments change in formation. Therefore, our first identified priority is for the funded development of national Carer policy beyond the current status.

Ireland has had a National Carers Strategy since 2012. That strategy identified a large number of goals under 4 key headings:

1. Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for
2. Support carers to manage their physical, mental and emotional health and well-being

¹ Central Statistics Office, 'CSO Releases Irish Health Survey Results', 16 November 2016, <http://bit.ly/2sJ0sYT> 10% of adult population equates to approximately 360,000 people.

3. Support carers to care with confidence through the provision of adequate information, training, services and supports

4. Empower carers to participate as fully as possible in economic and social life

The strategy was developed and implemented during a time of austerity and challenging economic times in Ireland, and as such made some very positive inroads into developing positive supports for Family Carers. Care Alliance Ireland has been involved with the National Carers Strategy Monitoring Group since the Strategy was first published, working with our colleagues in Family Carers Ireland to monitor the progress of these actions across the relevant Government departments².

However, it is clear that this iteration of the Strategy has been taken as far as possible. To that end, we are calling for a fully funded Phase II of the National Carers Strategy to be formulated and published in the coming year. This will include funding across Government departments to progress further actions identified within the Strategy. Many of these actions can be formulated as "low-cost", however the time for "no-cost" strategies has passed.

In addition to a funded National Carers Strategy, it is vital that ALL strategies must be evaluated to ensure that they do not unnecessarily contradict each other. The National Disability Strategy and the existing National Carers Strategy are two examples of national policies which should complement each other, but which (in many cases) do not³.

Priority 2: Funding of Services and Supports

We understand that there is not an unlimited budget for the funding of services and supports across the board in Budget 2018. However, there are a number of initiatives and services which at the outset would require a low level of funding to begin development, and would likely see significant rewards. Other initiatives necessitate much heavier investment. Recent research⁴ places the number of Family Carers in Ireland at almost 360,000, with an average of 45 hours of care provided per week. Consequently, estimating a modest per hour cost of €12 to replace this care, Family Carers contribute some €10bn. in care each year. We feel that there is a compelling case for a modest percentage of this amount to be allocated towards increased supports which would enable Family Carers to continue to provide care to their loved ones. Such an investment would truly speak to the oft-quoted maxim of treating Family Carers as "key partners" in care.

² National Carers Strategy Monitoring Group, 'Family Carers' Scorecard- Assessing the Government's Third National Carers' Strategy Report from the Perspective of Family Carers' (Family Carers Ireland, 2016).

³ Care Alliance Ireland, 'Disability and Family Carer Policy - Challenges and Responses.' (Care Alliance Ireland, 2017). Available at <http://bit.ly/2sb08QL>

⁴ Central Statistics Office, 'CSO Releases Irish Health Survey Results'. <http://bit.ly/2sJOsYT>

a) Home care

Given that a comprehensive consultation and review of Home Care is now underway, we accept that large scale changes to how home care is administered and funded will not be made this fiscal year. We welcome the consultation and the work that the various Departments have undertaken to date to progress this matter. However, we, along with many organisations, are concerned that the announcement of this consultation may be used to postpone any significant tackling of the current waiting lists and inequalities across the country when it comes to the provision of homecare packages for those assessed as having a real need for them to remain living at home - or indeed to return home from a hospital or residential stay⁵.

Whilst we acknowledge that there have been some increases in funding for Home Care in recent years, it is unclear how that increased funding is addressing the increasing demand for home care services. Spending on "older people" as a group has decreased - in 2009 the Government spent €3,514 per capita; by 2015 that was reduced to €2,612⁶. There is some evidence that the actual number of hours of home help per client has reduced materially over the years. In 2000, the figure was estimated at eight hours per client per week (Mercer Ireland, 2002); recent HSE targets suggested a figure of a little over four hours per client per week⁷. Looking at delivery from a utilisation and accessibility perspective, increases in service delivery since 2013 will merely have partially restored the actual percentage of the 65+ group who are in receipt of services to the level that existed in 2008.

There is evidence (somewhat anecdotal, however addressed in part by research undertaken by Donnelly et. al⁸) that individuals and families are finding it increasingly difficult to access appropriate Home Care Packages for their loved ones, and there is wide disparity as to their availability at local level. This is forcing people out of their homes and communities, making it very difficult for Family Carers to have any form of respite, even to undertake daily tasks such as shopping or banking. We are pleased to see a projected increase, albeit it very modest, in Home Care Packages (HCP) in the 2017 Service Plan for the HSE⁹, however this projected outturn of 16,750 individuals in receipt of a HCP does not detail the overall number of hours being provided. In addition, we are aware of regular instances of 30 minute "slots" being part of HCP's, which in reality are

⁵ S Donnelly et al., "'I'd Prefer to Stay at Home but I Don't Have a Choice": Meeting Older People's Preference for Care: Policy, but What about Practice?' (University College Dublin, 2016), <http://bit.ly/2tgx9xi>

⁶ All-Party Oireachtas Group on Dementia, 'Report Two: A Statutory Scheme for Home Care- Round Table Event' (Houses of the Oireachtas, March 2017).

⁷ Care Alliance Ireland, 'Analysis of Home Care Supports Funded by the HSE 2008-2016'. <http://bit.ly/2cZhd9y>

⁸ Donnelly et al., "'I'd Prefer to Stay at Home but I Don't Have a Choice": Meeting Older People's Preference for Care: Policy, but What about Practice?' (University College Dublin, 2016), <http://bit.ly/2tgx9xi>

⁹ Health Service Executive, 'HSE National Service Plan 2017', 2016.

impractical for many families and those in need of such high levels of assistance to remain living at home¹⁰.

Waiting lists for Home Care Packages and home help hours - which latest available figures indicate are standing at in excess of 4000¹¹ - cannot be allowed to remain static or regress during the period of this consultation on the future of Home Care. We therefore call for an increase in the funding levels available for Home Care Packages in Budget 2018. We repeat our recommendation made for Budget 2017, which recommends that the HSE sets a 2017 goal of reaching the 2011 target level of public provision of home care per person aged 65+. In the medium term, we recommend that the HSE sets a goal of reaching the 2008 level of public provision of home care per person aged 65+. We also support our member organisation, the Alzheimer Society of Ireland's call for an investment of €40 million for home care supports for people with dementia.

b) Respite care

Respite care is regarded as a key support for the health and wellbeing of Family Carers, and is often cited by them as vital to their ability to continue to provide care to their loved ones. However, the availability of respite care on the ground is decreasing, and clearly demonstrated when asking Family Carers to speak about their challenges¹². Budget 2018 must increase funding for the provision of flexible respite options, including in-home and emergency respite for people of all ages, ensuring equity of access irrespective of where a person lives. It should be demand-led rather than resource-led.

Three particular elements of respite care have been identified by Family Carers and organisations which support them, which must be addressed in Budget 2018 are:

- i) Respite places
- ii) Respite staff
- iii) Statutory right to respite care.

The provision of respite care in Ireland remains low across the country, despite attempts to incorporate the topic in the National Carers Strategy (2012) for development. We direct readers to the reports of the National Carers Strategy Monitoring Group from the last number of years to highlight how critical the situation is - respite provision has regressed significantly in recent years, and it not being sufficiently addressed in policy or

¹⁰ Care Alliance Ireland, 'Analysis of Home Care Supports Funded by the HSE 2008-2016' (Care Alliance Ireland, 2016). <http://bit.ly/2cZhd9y>

¹¹ 'Elderly Face "Geographical Lottery" over Home Help Delays', *Irish Independent*, 27 March 2017 <http://bit.ly/2ttmYUE>. Figures for December 2016 indicate 2,342 were waiting for a home care package at the end of December, compared to 1,400 a year earlier. Another 2,039 were waiting for home help nationally.

¹² Anecdotal feedback visible on the National Carers Week Facebook page, and via discussion with colleagues in various support organisations.

at a funding level¹³. Along with access to Home Care as discussed above, access to respite care must be addressed in Budget 2018.

c) Disability services

Funding for essential disability services has been cut by €136 million since 2008¹⁴. This does not include cuts to vital supports such as Personal Assistance Services, the Mobility Allowance Scheme and the Motorised Transport Grant¹⁵. This erosion of supports has led to incredibly trying times for the Family Carers of people with a disability or extra support need. Funding must be restored to the disability budget to address the serious deficits in disability services that exist and ensure that people with a disability can live with autonomy, dignity and independence. This includes access to speech & language therapists, occupational therapists, Special Needs Assistants and related therapies. Waiting lists for these services remain long and inaccessible, forcing many parents of children with special needs and those caring for older people with disabilities to pay privately for therapies which they have been assessed as having a recorded need. Investment in these services is critical for Budget 2018.

d) Supporting minority carers

As we all know, Ireland is continually becoming a more diverse society, with the most recent figures from Census 2016 indicating that 17.3% of Irish residents were born outside of Ireland¹⁶. In addition, the age profile of those born in a country other than Ireland is increasing steeply. It therefore stands to reason that these individuals may be providing or in need of care themselves in coming years. At the current time, we are unaware of specific support programmes which exist to address the growing likelihood of non-Irish Family Carers, and in particular those of non-European background, whose cultural differences from Irish and European Family Carers may impact on their caring role, and the supports which they can access. In addition, 12.9% of the population do not speak English at home.

There are a number of minority groups whose particular needs are not being sufficiently met or planned for by the services and supports available to Family Carers. These include carers from within the Lesbian, Gay, Bisexual and Transgender (LGBT) community, black and minority ethnic (BME) carers, carers from within the Travelling community, male carers, etc. It is vital to begin to put in place specific supports which address the needs of each of these minority groups of Family Carers.

¹³ National Carers Strategy Monitoring Group, 'Family Carers' Scorecard- Assessing the Government's Third National Carers' Strategy Report from the Perspective of Family Carers'.

¹⁴ Disable Inequality, 'Making Disability a Priority in Election 2016' (Disability Federation of Ireland, 2016), <http://bit.ly/2tpWoMc>

¹⁵ Ibid.

¹⁶ Central Statistics Office, 'Census 2016 Summary Results - Part 1' (Central Statistics Office, 2017), <http://bit.ly/2tQNWbD>

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)¹⁷. 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-carers¹⁸ 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 role¹⁹. A similar study in Ireland found that over two-thirds of family carers found it difficult to make ends meet²⁰, 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 life²¹. 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.

a) Carers Support Grant

We acknowledge that the Carers 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, arguably arbitrarily, to those on a list of income support beneficiaries 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 occurrences are characterised by bereavement and high levels of stress, and sometimes financial outlay. If the person they cared for at home has

¹⁷ 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).

¹⁸ OECD, 'The Impact of Caring on Family Carers', in *Help Wanted? Providing and Paying for Long-Term Care* (OECD, 2011).

¹⁹ Carers UK, 'Real Change Not Short Change' (Carers UK, 2007).

²⁰ E O'Shea, 'The Costs of Caring for People with Dementia and Related Cognitive Impairments' (National Council on Ageing and Older People, 2000).

²¹ 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>.

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 nature 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 basis²², which would lessen both carer stress and income inequality, and would speak to a number of actions at the core of the National Carers’ Strategy²³. An increase in the level of the Grant would also be welcome, noting the cost of caring/disability²⁴, along with increases in certain household costs (such as rent/mortgage and ancillary costs). We recommend an increase to €2000.

b) 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 return to the 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 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 four years ago. Many of our member groups are supporting individual Family

²² For example in 2 six-monthly instalments

²³ Caroline Crowley, ‘Making the Respite Care Grant a pro Rata Payment’, 2015. <http://bit.ly/2uJZ32P>

²⁴ 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’.

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.

c) 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.

d) Telephone Allowance

Along with direct income supports, allied benefits such as the Household Benefits Package are crucial to enable Family Carers to continue caring for their loved ones. The cutting of the Telephone Allowance (to the value of €9.50 per month) was a significant loss to older people and their Family Carers. Isolation is a key issue which Family Carers and those they care for experience on an ongoing basis, and the Telephone Allowance went some way to combatting this. In addition, a landline phone is often a requirement of personal alarms and assisted living devices, which are crucial in allowing many older people to remain living well in their community, supported by Family Carers. Access to these personal alarms and safety devices in turn provides confidence and reassurance to Family Carers that their loved ones are safe and well when they themselves are outside the home attending to other matters. Without these supports, the safety of older people and their ability to remain living at home can be thrown into doubt, once again exacerbating the disparity between official policy and the actual lived experience of families in Ireland today. We thus recommend that the Telephone Allowance is reintroduced in full.

e) Work and caring

Carers Allowance remains the only income support measure which requires the recipient to work full time (i.e. provide full time care) to receive it. Family Carers are restricted to work or study outside the home for only 15 hours per week, before losing their entitlement to the payment. We recommend that the hourly limit during which carers can study or work while receiving social welfare be increased from 15 to 18.5 hours per week. This would ensure that those receiving payments remain under the cut-off for eligibility for Family Income Supplement, but widen the types of employment and study/ training Family carers can undertake. This in turn improves reactivation possibilities when caring ends, easing the transition back into the workplace where possible.

f) Carers Allowance & Benefit

As discussed above, 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. At the current rate of payment, this equates to an hourly payment of €5.82 per hour, which is less than 2/3 of the minimum wage. We advocate for an increase Carer’s Allowance and Carer’s Benefit towards the rates paid in 2009 of €220.50 and €221 respectively.

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.

Conclusion

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 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 360,000 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 85 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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