

Care Alliance Ireland

Statement of Priorities - Budget 2020

This Pre-Budget Statement for Budget 2020 summarises three key priorities which, if supported in Budget 2020, would continue to progress the development of services and supports for Ireland's nearly 375,000 family carers¹.

In 2017, for Budget 2018 we identified three broad priorities for that budget, and as so many of these have not been addressed adequately in the intervening two years, we continue to advocate for them here, 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/2sJOsYT> 10% of adult population equates to approximately 375,000 people based on the latest population estimates for 2019.

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 despite this there have been some very positive inroads made into developing 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 departments.

We understand that current plans are in place to develop a cross-sectoral Health and Social Care Strategy. We tentatively welcome this – particularly in light of the potential of such a strategy to address the often silo-ed nature of supports and policies for family carers and the wider ageing/disability community. However, without firm details about topics for inclusion, and without dedicated funding being made available specifically for developing new supports for family carers, we continue to call for a funded, refreshed National Carers Strategy.

- **Key ask: development of a new National Carers Strategy with dedicated ringfenced funding**

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 2020. 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. The most recent research² places the number of family carers in Ireland at almost 375,000, 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 in excess of €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 Central Statistics Office. <http://bit.ly/2sJOsYT>

a) Home care

Given that a comprehensive and drawn out review of Home Care provision in Ireland is now underway we continue to await the results of the public consultation which took place in 2017. We understand that significant changes to methods of delivery, operations and funding may not take place as part of Budget 2020. We welcome the ongoing 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 this consultation process may result in unnecessary delays to any significant tackling of the current waiting lists, which exceed 7,000 currently; or to address the 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 stay³. We would direct readers to our 2018 report⁴ on levels of unmet need, the disparity of waiting times, and funding issues within the home care support scheme and across the different CHO's for further details.

We appreciate that there will always be fiscal pressures on the system, however we, along with many of our member organisation and colleagues across the country, remain concerned at the most recent announcement that waiting lists for the Home Support Scheme are effectively closed for the next 6 months in order for the HSE to live within their 2019 allocated budgets. We note that such expectations are not made of hospital budgets. This effective closing of waiting lists to us, seems a regressive action to take. Indeed, there appears to be evidence that this action, although not an official shutting of waiting lists, has led to a significant increase of waiting lists for home care, which increased to 7,217 at the end of June 2019, from 6,238 at the end of March⁵.

We, along with others in the "Right to Home Care" coalition (of which we are members) argue that there are increases necessary in funding for the Home Support Scheme to give expression to Slaintecare, which seeks to enable the provision of 'the majority of care and or closer to home'.

In consulting with our member organisations in preparing this submission, it is clear that the issue of home care provision is a common and significant concern for those working in the sector. Family carers themselves consistently identify the need for high quality home care, delivered at realistic levels across the country to those who have an identified need, as a key support to enable them to care successfully for their loved ones, and as

³ 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>

⁴ Care Alliance Ireland, 'Briefing Paper 2: Public Provision of Home Care in Ireland - Update', October 2018.

⁵ <https://www.thejournal.ie/increase-waiting-list-home-help-hours-4736677-Jul2019/>

a key support to enable those loved ones to remain at home in the community for as long as possible.

Waiting lists for Home Care Packages and home help hours - which latest available figures indicate are standing at in excess of 7,000- cannot be allowed to remain or indeed increase during the period of this consultation on the future of Home Care – and the solution to this is not to simply close those lists to new applicants. We therefore call for a material increase in the funding levels available for Home Care Packages in Budget 2020. In partnership with our colleagues across the sector in the Right To Home Care collation we are asking for an further investment of €110m to take consideration of the increases in population, the method of calculation of need used by Slaintecare and the average cost of home support hours for those currently on the waiting list for home supports.

Key Asks:

- **Reverse the recent decision to restrict access to home care and home help, which is an effective closure of waiting lists to new applicants**
- **Provide funding of an additional €110m to address increasing waiting lists for home care and home supports**

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 continues to decrease, which can be seen in figures released in late 2018.⁶ HSE Performance data for Q1 2019 report further significant reductions in the provision of overnight respite care⁷. Budget 2020 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 2020 are:

i) Respite places

⁶ Family Carers Ireland, ‘Family Carers Ireland Express Concern as Emerging Figures Show Provision of Respite Care Is on a Steady Decrease’, 15 August 2018, <https://familycarers.ie/dramatic-drop-in-respite-care-sessions-since-2017-is-unacceptable/>.

⁷ See <https://www.hse.ie/eng/services/publications/performance-reports/2019-performance-reports.html>. Website accessed 12th August 2019

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 at a funding level, which can be seen in successive reviews of the actions in the National Carers Strategy⁸, despite some funding increases in recent years. These investments are simply not enough to keep up with demand and need for respite for both people with disabilities and their families. Along with access to Home Care as discussed above, access to respite care must be addressed in Budget 2020.

Key asks:

- **Continue to increase funding for respite care**
- **Address variations across local authority and county areas which appear to impact upon access to respite and other services**
- **Create an entitlement for one week each year for all family carers in receipt of Carers Allowance, and who are therefore providing full-time care for their loved one.**

c) Disability services

Although there have been increasing in funding across the Disability budget over the last number of years, our colleagues across the sector have highlighted that due to demographic increases and increasing demands on services that these budgetary responses have not been sufficient to truly meet the needs of Ireland's disabled community, and their families. Funding must be restored to the disability budget, with an eye to these increases in demand, 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.

⁸ National Carers Strategy Monitoring Group, 'National Carers' Strategy Scorecard 2017: Assessing Government's Fifth Annual Progress Report from the Perspective of Family Carers' (Family Carers Ireland, 2018).

Some of our member organisations have highlighted the difficulties being experienced at the transition point between leaving school and entering adult services, with few places being made available, in particular for people with autism and Asperger's Syndrome. Whilst Care Alliance remain in support of the broad policy of deinstitutionalisation and integration of people with disabilities into mainstream education, services and employment this policy can only work when needs are addressed and families supported at key points along the way.

Our colleagues in the Disability Federation of Ireland, in their Pre-Budget Statement for Budget 2020⁹ have called for the following, which we support them in;

- An investment of €50m to begin to provide better community supports across departments with responsibility for education, training, employment, transport, housing and assistive technology.
- A Multi-Annual Investment Programme of €211m each year for five years 2020-2024 for community services for people with disabilities.

Investment in these services is critical for Budget 2020.

Key asks:

- **Implement the recommendations from the Disability Federation of Ireland regarding funding**
- **Address silo-ing of services in children and adult disability services, particularly regarding the transition point between leaving school and entering employment/further training for people with disabilities.**

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 Ireland¹⁰. 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

⁹ Disability Federation of Ireland, 'Call for a Budget That Responds to the Needs of ALL People with Disabilities - DFI Pre-Budget Submission 2020' (Disability Federation of Ireland, 2019).

¹⁰ Central Statistics Office, 'Census 2016 Summary Results - Part 1' (Central Statistics Office, 2017), <http://bit.ly/2tQNWbD>

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.

- **Key ask: Funding of programmes to address the specific needs of family carers from minority populations.**

e) Address health concerns of family carers

Recent research published by Family Carers Ireland, UCD and the Irish College of Psychiatrists¹¹ indicates that the health of family carers has reached a new low in Ireland. Some of the highlights of this research include;

- 48% of family carers have been diagnosed with a mental health condition
- 67% of family carers reported physical ill-health
- 68% of family carers felt that their health had suffered as a direct result of caring
- 75% of family carers said they are worried about their own health and wellbeing

In addition, recent research we in Care Alliance Ireland have published which specifically investigated family carers' use of online technologies suggests that many family carers remain isolated and may not be able to leave the house for extended periods of time¹². This has an impact of the mental and physical health of family carers, further necessitating some support in this area.

We acknowledge that since September 2018, all carers in receipt of Carers Benefit or Carers Allowance have qualified to automatically receive a free GP Visit Card. This is of course welcome. However, a significant proportion of Ireland's full-time family carers do not qualify for these payments, and are also experiencing the potentially negative health impacts of caring. We therefore recommend that the GP Visit card eligibility be extended to all those in receipt of the Carers Support Grant.

- **Key ask: Extend GP Visit Card eligibility to those in receipt of the Carers Respite Grant.**

¹¹ 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).

¹² Zoe Hughes, 'Online Resources: What Family Carers Think' (Care Alliance Ireland, 2019).

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)¹³. 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-carers¹⁴ 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 role¹⁵. A similar study in Ireland found that over two-thirds of family carers found it difficult to make ends meet¹⁶, 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 life¹⁷. 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.

We note that in response to recommendations made by a number of organisations during the last Pre-budget cycle, research into the cost of disability has been recently commissioned by the Department of Employment Affairs and Social Protection. However, we were disappointed to see that the tender announcement did not mention the cost of caring in any way. The groups who made submissions on this topic, and representations at the annual DEASP forum in 2019 were very clear that the cost of caring should be included in any study relating to the cost of disability. Indeed, the Minister herself agreed to its inclusion in this particular review at that Forum.

¹³ 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).

¹⁴ OECD, 'The Impact of Caring on Family Carers', in *Help Wanted? Providing and Paying for Long-Term Care* (OECD, 2011).

¹⁵ Carers UK, 'Real Change Not Short Change' (Carers UK, 2007).

¹⁶ E O'Shea, 'The Costs of Caring for People with Dementia and Related Cognitive Impairments' (National Council on Ageing and Older People, 2000).

¹⁷ 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>.

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 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 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 basis¹⁸, which would lessen both carer stress and income inequality, and would speak to a number of actions at the core of the National Carers' Strategy¹⁹. An increase in the level of the Grant would also be welcome, noting the cost of caring/disability²⁰, along with increases in certain household costs (such as rent/mortgage and ancillary costs). We recommend an increase to €2,000 to account for increasing costs of accessing respite care privately.

¹⁸ For example in 2 six-monthly instalments

¹⁹ Caroline Crowley, 'Making the Respite Care Grant a pro Rata Payment', 2015.
<http://bit.ly/2uJZ32P>

²⁰ 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'.

Key asks:

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

b) Adaptation grants

The unavailability and inequality of different adaptation 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 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.

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**

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.

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

d) 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.

- **Key ask: Increase the hours that those in receipt of Carers Allowance can work or study to 18.5 per week**

e) 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 €6.25 per hour, which is less than 2/3 of the minimum wage. 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 recent research indicating that 82% of family carers care for more than 50 hours per week²¹. We therefore advocate for an increase in Carer's Allowance and Carer's Benefit at the same rate of increase in the average wage, which equates to 3.3%²². This would bring the basic Carers Allowance weekly rate (for a family carer aged under 66 caring for 1 person) to €226.23 and the equivalent Carers Benefit to €227.26.

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.

²¹ Family Carers Ireland, College of Psychiatrists of Ireland, and UCD, 'Paying the Price: The Physical, Mental and Psychological Impact of Caring'.

²² Central Statistics Office, 'Earnings and Labour Costs Annual 2018', 2019, <https://www.cso.ie/en/statistics/earnings/earningsandlabourcosts/>.

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:

- **Increase Carer’s Allowance and Carer’s Benefit in line with the latest increase in average wage rates, which would equate to €226.23 and €227.26 respectively.**
- **Remove Carers Allowance as a taxable source of income**

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 375,000 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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