

**Care Alliance Ireland**

**Statement of Priorities - Budget 2019**

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 2019, 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 2019 summarises three key priorities which, if supported in Budget 2019, would continue to progress the development of services and supports for Ireland's nearly 360,000 family carers<sup>1</sup>.

Last year, 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 year, 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

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<sup>1</sup> Central Statistics Office, 'CSO Releases Irish Health Survey Results', 16 November 2016, <http://bit.ly/2sJOsYT>. 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, but in spite of this made some very positive inroads into developing enhanced supports for family carers. Care Alliance Ireland has been involved over the years 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.

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 Inclusion Strategy and the existing National Carers Strategy are two examples of national policies which should complement each other, but which (in many cases) do not<sup>2</sup>.

We acknowledge the recent announcement under the Dormant Accounts Funds of €1.9m to support with Family Carer measures. This is however once off funding and its long terms impact and reach will be limited for this reason.

- **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 2019. However, there are a number of initiatives and services which at the outset would require a very modest level of funding to begin development, and would likely see significant rewards. Other initiatives necessitate more significant investment. The most recent research<sup>3</sup> 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

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

<sup>3</sup> Central Statistics Office, ‘CSO Releases Irish Health Survey Results’. <http://bit.ly/2sJOsYT>

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.

#### a) Home care

Given that a comprehensive review of Home Care provision in Ireland is now underway, we accept that large scale changes to how home care is administered and funded will not be made in the coming year. We welcome the consultation and the work that the various Departments have undertaken to date to progress this matter and look forward to further engagement in this regard. However, we, along with many organisations, are concerned that this consultation process may be used to postpone any significant tackling of the current waiting lists of over 6,000 individuals and inequalities in access 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 stay<sup>4</sup>.

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 €2,612<sup>5</sup>, with some modest increases likely since then. 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); HSE targets from the 2018 service plan suggest a figure of 6.5 hours home care per client per week<sup>6</sup>. 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. al<sup>7</sup>) 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,

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<sup>4</sup> 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>

<sup>5</sup> All-Party Oireachtas Group on Dementia, ‘Report Two: A Statutory Scheme for Home Care-Round Table Event’ (Houses of the Oireachtas, March 2017).

<sup>6</sup> HSE Service Plan 2018 p 115.

<sup>7</sup> 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)

### 'Guiding support for family carers'

even to undertake daily tasks such as shopping or banking. As the structure of home care supports such as home help and home care packages are bundled together for the first time in 2018, under the banner of home support services, it is difficult to quantify the actual increases and their projected impact on supply and receipt of home supports. Approximately 17,094m home support hours are expected to be delivered to 50,500 people at any time. In addition, Intensive Home Care Packages will be delivered to approximately 235 people at any time and will deliver approximately 360,000 hours in the full year<sup>8</sup>. However, the 2018 National Service Plan itself notes;

*The additional resources made available in 2018 are welcome, but demand for these services will continue to exceed the funded levels (P46)*<sup>9</sup>.

In addition, we are aware of regular instances of 30 minute "slots" being part of HCP's, which in reality are impractical for many families and those in need of such high levels of assistance to remain living at home<sup>10</sup>.

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 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 6000<sup>11</sup> - cannot be allowed to remain static or regress during the period of this consultation on the future of Home Care. We therefore call for a material increase in the funding levels available for Home Care Packages in Budget 2019. We repeat our recommendation made for Budget 2018, which recommends that the HSE sets a 2019 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+.

- **Key Ask: Provide adequate funding to address increasing waiting lists for home care and home supports**

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<sup>8</sup> Health Service Executive, 'FOI Request C144/18 RE: Home Care Package Waiting Lists', 2018.

<sup>9</sup> Health Service Executive, 'HSE National Service Plan 2018' (HSE, 2017).

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

<sup>11</sup> Health Service Executive, 'FOI Request C144/18 RE: Home Care Package Waiting Lists'.

## 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 challenges<sup>12</sup>. Budget 2019 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 2019 are:

i) Respite places

ii) Respite staff

iii) Statutory right to respite care.

There appears to be a significant variation in respite provision over short periods of time. This can be seen in the most recent figures obtained by our colleagues in Family Carers Ireland<sup>13</sup> which indicate that levels of respite care available has dropped from 2017 to 2018 (comparing Q1 2017 with Q1 2018). Family carers also repeatedly report the inability to access respite for those they care for when necessary, including for emergencies. According to the reviews of the National Carer Strategy Monitoring Group (of which Care Alliance are a member along with Family Carers Ireland and individual family carers), respite provision has significantly regressed throughout the lifetime of the National Carers Strategy<sup>14</sup>. Data from HSE annual reports suggests there has been a reduction of approximately 35% in overnight respite care between 2013 and 2017 from 243,000 overnights to 158,000<sup>15</sup>.

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

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

<sup>13</sup> 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/>.

<sup>14</sup> National Carers Strategy Monitoring Group, 'Family Carers' Scorecard Assessing the Government's Fourth National Carers' Strategy Report from the Perspective of Family Carers' (Family Carers Ireland, 2017), <http://familycarers.ie/wp-content/uploads/2016/01/Family-Carers-Scorecard-110917.docx>.

<sup>15</sup> Sources: <https://www.hse.ie/eng/services/publications/corporate/hse-annual-report-and-financial-statements-2017-pdf.pdf> (p103) and <https://www.hse.ie/eng/services/publications/corporate/annualrpt2013.pdf> (p37)

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<sup>16</sup>. Along with access to Home Care as discussed above, access to respite care must be addressed in Budget 2019.

**Key asks:**

- **Increased funding for respite care**
- **Remove the ‘postcode lottery’ element of respite care provision which varies from area to area.**
- **For Budget 2019, to create a legal 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. The long-term aim, across upcoming Budgets, should be to provide four weeks such leave.**

c) Disability services

Funding for essential disability services was cut by €136 million between 2008 and 2016<sup>17</sup>. This does not include cuts to vital supports such as Personal Assistance Services, the Mobility Allowance Scheme and the Motorised Transport Grant<sup>18</sup>. We acknowledge the recent service improvements in 2017 and 2018, however this erosion of supports from 2008-2016. has led to incredibly trying times for the family carers of people with a disability or extra support need.

We acknowledge that there have been recent service improvements in 2017 and 2018. However, levels of funding remain less in many cases than before the fiscal crisis. Funding must be restored to the disability budget to address the serious emerging deficits in disability services that exist, with particular regard to demographic shifts. 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.

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

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<sup>16</sup> 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).

<sup>17</sup> Disable Inequality, ‘Making Disability a Priority in Election 2016’ (Disability Federation of Ireland, 2016), <http://bit.ly/2tpWoMc>

<sup>18</sup> Ibid.

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.

Investment in these services is critical for Budget 2019.

**Key asks:**

- **Restore the disability services budget to pre-2008 levels**
- **Address waiting lists for services to children with disabilities**
- **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 Ireland<sup>19</sup>. 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 (whose numbers in Census 2016 stand to make up nearly 8% of all family carers in Ireland<sup>20</sup>), 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. Recent work undertaken by Care Alliance Ireland has shown that 7% of family carers in Ireland speak a language other than English at home, and almost 1/5 of all family carers do not identify as Catholic<sup>21</sup>.

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.**

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<sup>19</sup> Central Statistics Office, 'Census 2016 Summary Results - Part 1' (Central Statistics Office, 2017), <http://bit.ly/2tQNWbD>

<sup>20</sup> Central Statistics Office, 'Census 2016' (Ireland: Central Statistics Office, 2017).

<sup>21</sup> Care Alliance Ireland, 'Family caring and minority populations' 2018.



### 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>22</sup>. 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-carers<sup>23</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<sup>24</sup>. A similar study in Ireland found that over two-thirds of family carers found it difficult to make ends meet<sup>25</sup>, 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 life<sup>26</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, 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

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<sup>22</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).

<sup>23</sup> OECD, 'The Impact of Caring on Family Carers', in *Help Wanted? Providing and Paying for Long-Term Care* (OECD, 2011).

<sup>24</sup> Carers UK, 'Real Change Not Short Change' (Carers UK, 2007).

<sup>25</sup> E O'Shea, 'The Costs of Caring for People with Dementia and Related Cognitive Impairments' (National Council on Ageing and Older People, 2000).

<sup>26</sup> 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 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 six- monthly and pro-rata basis, which 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>27</sup>. An increase in the level of the Grant would also be welcome, noting the cost of caring/disability<sup>28</sup>, along with increases in certain household costs (such as rent/mortgage and ancillary costs). We recommend an increase to €2,000 to account for the increasing costs of accessing respite care privately.

#### **Key asks:**

- **Increase Carer Support Grant to €2000 per annum**
- **Pay Carer Support Grant on a 6 monthly basis**

#### 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. We welcome the recent (July 2018) announcement of €14m for the Disabled Persons Grant Scheme, which was a €2m increase on funding approved in 2017. However, without this 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

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<sup>27</sup> Caroline Crowley, ‘Making the Respite Care Grant a pro Rata Payment’, 2015.

<http://bit.ly/2uJZ32P>

<sup>28</sup> 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’.

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 five 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 Grants and other related programmes, 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**

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, in particular when it comes to economic hardship. Recent research undertaken by our colleagues in the Irish Hospice Foundation found that one in five of bereaved people reported a deterioration in their financial situation after the death of someone close – in addition, those experiencing a deterioration in their financial situation were also experiencing a deterioration in their mental and physical wellbeing<sup>29</sup>. 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.

Policies on supports available for bereavement and funeral costs should also be reviewed to ensure that they are appropriate and accessible to those in most need.

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

d) Telephone Allowance

We would like to acknowledge and welcome the reintroduction of the Telephone Allowance as a payment in Budget 2018, at a marginally higher level than previously. We are disappointed, however, that the payment has been reintroduced as a payment only for those in receipt of Fuel Allowance and the Living Alone Allowance.

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<sup>29</sup> Irish Hospice Foundation, 'Dying Is Everyone's Business: Irish Hospice Foundation Pre-Budget Submission 2019' (Irish Hospice Foundation, 2018).

### 'Guiding support for family carers'

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, even if the person they care for is living with them, and therefore excluded from receiving the benefit. 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.

In addition, the majority of key state information and applications are being moved online to minimise costs and improve efficiencies. This will only further isolate older people and their family carers who may be completely unable to access broadband or mobile internet costs. Increasing the eligibility for the Telephone Allowance would make it easier and more likely for older people and family carers alike to access and utilise these services online.

- **Key ask: Remove the eligibility criteria for receipt of Telephone Allowance that necessitates it only is paid to those in receipt of the Fuel Allowance and the Living Alone Allowance.**

#### 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.

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

#### f) Carers Allowance & Benefit

As discussed above, Carers Allowance and Benefit remain the sole payment for which the recipient must be able to provide evidence, if requested, of providing “full-time care and attention”<sup>30</sup> - essentially working full-time in order to qualify. At the current rate of payment, this equates to an hourly payment of €5.53 per hour<sup>31</sup>, which is less than 2/3 of the minimum wage. We advocate for an increase in 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 some of our member organisations 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:**

- **Increase Carer’s Allowance and Carer’s Benefit towards the rates paid in 2009 of €220.50 and €221 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**

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<sup>30</sup> See <http://www.citizensinformation.ie/>

<sup>31</sup> This has been calculated using the average care hours provided by Irish family carers as identified in Census 2016 (38.7) and the payment for someone under the age of 66 providing care for one person.

### 'Guiding support for family carers'

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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