

**Submission to The Oireachtas Committee on the Future of Healthcare**

**Care Alliance Ireland**

**August 2016**

**Executive Summary**

There are approximately 187,000 Family Carers in the Republic of Ireland, made up of those individuals who provide care and support to a family member or friend with a long-term illness, disability or mental health difficulty (Central Statistics Office, 2011). 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.

The focus of the Care Alliance Ireland submission to the Oireachtas Committee on the Future of Healthcare in Ireland is to highlight the integral part that Family Carers play in the Irish health system, and how vital their contribution is. It is also essential to note that Family Carers are more likely than non-carers to themselves be customers of the health system, given the higher likelihood that they will experience poorer mental, physical and emotional health compared to non-carers.

Whilst challenges abound in the establishment of a complete and well-functioning healthcare system in Ireland, two key overarching challenges experienced by Family Carers are identified and possible solutions articulated in this document. Those challenges and solutions may be summarised as:

- 1) The added cost of disability and caring, including the increased need for access to services and supports due to this higher financial impact.
- 2) The requirement for sectoral budgets to be unified to provide a single functioning and responsive health service which responds to the needs of its users in a timely fashion, thus saving money and time overall.

We are available to the Committee to give more detailed oral evidence on any aspects of our submission or on topics relating to Family Carers.

## Introduction

There are approximately 187,000 Family Carers in the Republic of Ireland, being those individuals who provide care and support to a family member or friend with a long-term illness, disability or mental health difficulty (Central Statistics Office, 2011). Family Carer support is provided by a number of organisations, including those dedicated solely to carer support and other organisations who support carers as part of their response to individuals with specific conditions. The need for Family Carers to provide support to people in the home is continuing to grow both in Ireland and internationally, and will continue to do so over the coming years. A number of factors are at play, including increasing life expectancy, an ageing population, declining family size and higher rates of labour market participation by women. Census 2011 data point to a significant increase in the number of those providing unpaid care in the home, with a particular growth in the number of older carers (Central Statistics Office, 2012). The ongoing significant increase in Family Care provision, which we expect to continue to be borne out in data from Census 2016, points to an ageing population with an overall increase in care needs.

The cost of the State providing the same level of care as that provided by Family Carers is estimated to be between €2.5 billion and €4 billion annually (Care Alliance Ireland, 2015). As government policy on community-based care strengthens, so too does the requirement for Family Carers to provide care to relatives in the home. In addition, it is clear that the primary desire of people who need care is to receive that care in their own home and community (Donnelly, O'Brien, Begley, & Brennan, 2016). One of the key challenges for health provision in Ireland going forward is to support this majority of individuals who wish to receive care from a family member in their own home, and to support that family member in their responsibilities.

However, it could be strongly argued that at present various governmental policies are in direct conflict with each other. On the one hand, the focus has been on developing supports for Family Carers with respect to the actions contained in the National Carers' Strategy (Department of Health, 2012) and the Programme for Government (Government of Ireland, 2016). On the other hand, there has been a clear priority to increase the availability of and funding for residential care via the Fair Deal Scheme,

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corresponding with a decrease in availability of home care supports (when accounting for demographic changes) (Care Alliance Ireland, 2016a; Donnelly et al., 2016).

Providing care can be enriching and rewarding when expectations placed on Family Carers are reasonable and adequate supports are provided. Research evidence has identified the satisfaction that Family Carers may feel in being able to support the people they care about (Brand, Barry, & Gallagher, 2016). It is, however, crucial that they are given adequate assistance to sustain them in their role. Caring can also be a source of burden and stress. Whilst care to a loved one may be willingly given, there can be costs to many aspects of the Family Carer's life, including emotional, physical, social and financial costs.

Family Carers experience significant impacts due the nature of their caring role. Family Carers are much less likely to rate themselves in good health than are non-carers (O'Sullivan, 2008), and are more likely to experience both poor physical (O'Sullivan, 2008; Stokes, 2010; The Carers Association of Ireland & Royal College of Psychiatrists, 2009) and poor mental health (OECD, 2011; O'Sullivan, 2008). Recent (2015) work in the UK has found that up to 20% of Family Carers consider themselves to have a mental health condition, with 15% considering themselves to have a condition which limits basic physical activity (Tinder Foundation, 2015).

However, Family Carers are in many ways unique consumers of health services, as they are not only "patients", but also function as carers and patient advocates for their loved ones. As such, ensuring a robust and well-functioning health service, which takes accounts of these multi-faceted issues, is critical.

This submission focuses on articulating the key needs of Family Carers, which in many ways are unique to that cohort of individuals. This submission also articulates some of the challenges and possible solutions.

## Key Issues for Family Carers

### 1) The Cost of Disability and Caring

According to research published recently, the estimated economic cost of adult disability is between 35.4% of income (or about €207 per week) and 54.5% (or €276 per week) on average (Cullinan, 2015). These figures highlight the amount of money that disabled households at median income levels need in order to have the same standard of living as a similar non-disabled household.

In multiple studies Family Carers have been identified as far more likely to experience poverty than other sectors of society (Carers UK, 2011; OECD, 2011), with the impacts of providing significant levels of care clear. Recent Irish research discovered that 64% of Family Carers to an individual with a neurological condition reported a significant fall in family income since the onset of the condition (Neurological Alliance of Ireland, 2014). There is evidence that the additional costs of caring for someone include higher waste and water charges, increased heating and lighting bills (due to the use of specialised health equipment) and the cost of specialised aids and appliances, all of which add to the financial burden.

Member organisations of Care Alliance Ireland have given us details of instances where families have been forced to use up savings and large percentages of weekly incomings to provide for such items, due to the fact that the Department of Health and HSE budgets do not provide help with such costs, or due to increased waiting lists.

### 2) Access to Vital Health Services and Supports

Family Carers act as advocates for those they care for, and often face an uphill battle to access the vital supports and services which, if available, would enable them to care for their loved one with dignity at home<sup>1</sup>. As discussed at the beginning of this submission, Family Carers in Ireland provide an estimated €4 billion worth of care annually, significantly reducing the State's outlay in 1-to-1 care costs. However, Family Carers are rarely trained professionals, and in order for their loved ones to remain at home (which, as discussed, is overwhelmingly the wish of the majority of people

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<sup>1</sup> These services/supports include adequate home care, respite care, aids, appliances, mental health support, etc.

receiving care (Donnelly et al., 2016)), Family Carers need these supports to be readily available. Unfortunately, they are not always available or available at adequate levels in the current formulation of the health service.

In the case of Home Care Packages (recently the topic of a number of comprehensive research and briefing documents (Care Alliance Ireland, 2016a; Donnelly et al., 2016), it is clear that at the most basic level, investment in the scheme is not sufficient to meet current needs. The HSE spent 3% less on home care in 2015 (€320 million) than it did in 2008 (€331 million), despite a 25% increase in the population aged over 65 years over the same period (Donnelly et al., 2016). People are finding it increasingly difficult to access appropriate Home Care Packages for their loved ones, and there is wide disparity in relation to availability at local level. Our figures suggest that an additional resourcing of €31m over and above current published targets would simply reach the 2011 target level of public provision of home care per person aged 65+. In order to reach 2008 targets, an additional €72 million would be required in 2016, rising to €116m in 2019 (Care Alliance Ireland, 2016a, 2016b).

This is an illustrative example of the challenges facing Family Carers in relation to accessing services and supports. Similar examples can be found in the areas of respite, accessing suitable residential care (for loved ones with and without intellectual disability or cognitive impairments), accessing speech and language therapy, physiotherapy, occupational therapy, etc. The scope of this submission does not allow for more detail; however, many concrete examples of carers' experiences are available from our member organisations, such as Family Carers Ireland<sup>2</sup>.

### 3) Focus on Wellbeing not on Illness

As outlined above, Family Carers can experience serious health consequences arising from their caring role (O'Sullivan, 2008; Stokes, 2010; The Carers Association of Ireland & Royal College of Psychiatrists, 2009; Tinder Foundation, 2015). These health issues are exacerbated by a healthcare system which in practice focuses on illness rather than wellness. Many Family Carers have experienced being told that the person they care for

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<sup>2</sup> <http://familycarers.ie/about-us/carers-stories/>

is not “ill” enough or “disabled” enough to avail of supports and services which would ensure they continue to live as independent a life as possible. Often families have no choice but to wait until their loved one is debilitated in some way before they can access these supports. Moving from a focus on illness to a focus on wellness enables supports to be put in place at an earlier stage of the ageing or illness process, ensuring that small, short-term outlay translates to increased savings in the long term.

A good example of this is highlighted in the case study of “Joan”<sup>3</sup>, an older lady who was expected to need long-term care as she was unsteady on her feet and unable to care for herself. Before entering the long-term care which her family thought was inevitable, Joan was able to access two weeks of respite and rehabilitation, and along with a small allowance of two hours of home care over five days a week, has remained happily in her own home. It is clear that the short-term expense of two weeks of respite and rehabilitation, coupled with a relatively modest allocation of home care hours (at a cost of approximately €40 per week<sup>4</sup>), has drastically improved the lives of Joan and her family, and saved the State thousands of euros by avoiding her entry into long-term care at a cost of upwards of €1000 per week<sup>5</sup>.

In addition to the focus on wellness for the person receiving care, it is vital that any new health plan includes steps to ensure that the wellness of Family Carers is prioritised. Family Carers cannot continue to care indefinitely without access to respite, time off, appropriate health interventions, etc. A key step towards ensuring that Family Carers’ own health and wellness needs are met is to ensure that, when rolled out nationally, the recommendations for Family Carers who have been assessed as having a specific need in a Carers Needs Assessment have a right to support for that need.

An example of such a system is in place in the UK. The Care Act 2014 (Government of the United Kingdom, 2015) lays out specific criteria for assessment and eligibility for

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<sup>3</sup> This case study is included in the report entitled “‘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?” (Donnelly, O’Brien, Begley, & Brennan, 2016; p33).

<sup>4</sup> See figures in “Briefing Paper 1: Analysis of Home Care Supports Funded by the HSE 2008–2016” (Care Alliance Ireland, 2016a).

<sup>5</sup> See figures in “Nursing Homes Support Scheme Maximum Agreed Prices with Private and Voluntary Nursing Homes”, available on the HSE website and updated July 2016 (Health Service Executive, 2016b).

support arising from a Needs Assessment. This Act focusses on “wellbeing”, as outlined above.

## **Key Strategy Issues**

### 1) Unification of Sectoral Budgets

One of the key difficulties which Family Carers and those they care for face is the fragmented nature of funding of health services by the State. Currently, there are multiple discrete funding streams which should interact seamlessly along the journey of care for an individual; however, it is increasingly becoming clear that this is simply not the case. A person receiving care can easily become “stuck” at the interaction points, causing a disruption to their journey through the system. Care Alliance Ireland has become aware, through consultation and discussion with member organisations, of a number of these sticking points. We are aware from concrete examples of the challenges this creates for families. Not only do these “sticking points” create tangible periods of distress and difficulty for families, but they also put undue pressure on the various budgets.

A prime example, introduced above, is the case of Joan, taken from the report into home care by Donnelly et. al. (2016). Joan’s preference was for care in her own home, which was the most economical option, and the preference of all involved; the cost was approximately €40 per week. A long-term care placement for Joan, in the absence of this modest home care, could have cost upwards of €1000 per week. It is clear where the best budgetary use in this instance lay.

Likewise, attention can be drawn to a recent (August 2016) individual case highlighted in the media of a woman in Co. Mayo who had been admitted to hospital with a fractured pelvis and was ready for discharge. However, funds were not available within the community care budget and so she has remained in an acute setting for over 300 days, at a total cost of approximately €280,000 (Crawford, 2016). Discharging her with the full home care package she had been approved for would have cost €16,000 in the same timeframe. Care Alliance Ireland is aware of similar cases which are costing the HSE multiples of thousands from the acute health budget, yet where the individuals involved cannot be discharged into the community or into the disability sector as those budgets

cannot supply the correct support. Flexibility between sectoral budgets is crucial for a streamlined and cost-effective health service which can meet the needs of individual patients and their Family Carers. Anecdotal evidence shows that even when care recipients do enter long-term or acute hospital care, the "carer burden" does not significantly diminish, and may in fact increase, due to the need for support in dealing with medical staff, the need for the Family Carer to communicate information which only he/she may be able to supply.

We welcome recent moves towards the provision of home care on a statutory basis, a standalone flexible and responsive system which reflects current (and also preferred future policy) of enabling people to remain in, and receive care in, their own homes and communities. This element is crucial to a health system which truly acknowledges the contribution of older people and their Family Carers.

## 2) Funding a New System

We understand that the funding of such a new system, which ensures equal access to all regardless of ability to pay, will not be easy. However, as the possibility of people either needing care or having to provide care to a loved one increases with our increasing population age profile, it is clear that a functioning and responsive health system and related policies which patients can rely on as they age or as they develop a mental health condition or disability is crucial. This is an issue which cuts across age, gender, social class and income, and as such is best achieved via a system of increased taxation.

A single GP visit in Ireland costs on average €50. Reports indicate that Family Carers may allow their own health to worsen due to the cost of accessing healthcare, and instead prioritise the costs of care provision. Whilst many Family Carers may hold a medical card or a GP visit card, there are many who do not. As discussed, these are individuals who may be significantly worse off than their contemporaries, both in health and financial terms, because of their caring responsibilities. One immediate recommended policy change would be to provide all full-time Family Carers with a medical card. This could be implemented at a modest enough cost. At the minimum, this cohort should be prioritised in consideration of the further expansion of free GP

care. In the long term, a system of Universal Health Care, free at point of use, should be considered.

## **Conclusion**

This document has outlined some of the key issues which face Family Carers and their loved ones in relation to health policy and provision in Ireland. The focus of the document has been to illustrate the vital need to include the issues which Family Carers see as concerns and which impact their role as Family Carers. It bears repeating that Family Carers contribute up to €4 billion worth of care every year – which is equivalent to about one-third of the entire HSE budget for 2016 (Health Service Executive, 2016a). Ensuring that these issues are planned for within any evolving integrated health policy is vital to the success of that plan. Without Ireland’s 187,000 Family Carers, the health system would be under considerably more strain than it already is in 2016.

We are available to the committee to give more detailed oral evidence on any aspects of our submission or on topics relating to Family Carers.

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