

Care Alliance Ireland

Submission to the Citizens Assembly May 2017

'How we respond to the Challenges and Opportunities of an Ageing Population'

Introduction

It is well known that the population of Ireland is changing, and ageing. Latest Census data indicates that the population aged over 65 has increased by 19.1% since 2011, and that the age dependency rates also increased, again highlighting the ageing population¹.

This ageing population does of course offer many challenges and opportunities across sectors. In this submission, Care Alliance Ireland wishes to focus on the challenges and opportunities which arise from an ageing population from the perspective of Family Carers- both those caring for their ageing friends and relatives, and those Family Carers who are themselves ageing.

Key Issues in Brief

What is a "Family Carer"?

According to the Census of population, a Family Carer is a person who;

"provides regular unpaid personal help for a friend or family member with a long term illness, health problem or disability²."

Most recent figures estimate that there may in the region of 360,000 Family Carers in Ireland. This includes people caring for children and adults³.

Carers of Older People

It is not known exactly how many Family Carers in Ireland provide care or support to an older person (this question is not asked as part of Census data). However those who do provide care can be broadly broken into 3 main groups; **spousal carers, adult child carers and other carers** (including sibling carers and other family members such as nephews, nieces, cousins, etc.). Each of these groups will have specific issues and concerns.

¹ Central Statistics Office, 'Census 2016 Summary Results - Part 1' (Central Statistics Office, 2017), <http://www.cso.ie/en/media/csoie/newsevents/documents/census2016summaryresultspart1/Census2016SummaryPar t1.pdf>.

² Central Statistics Office, 'The Census Form- Each Question in Detail', 2011, <http://www.census.ie/the-census-form/each-question-in-detail.109.1.aspx>.

³ Central Statistics Office, 'CSO Releases Irish Health Survey Results', 16 November 2016, <http://cso.ie/en/media/csoie/newsevents/documents/pressreleases/IHS2015.pdf>.

TILDA data⁴ suggests that for those aged 50 and over, in the region of 50% of care support is provided by a spouse, and one third is provided by a child/child-in-law. Care Alliance Ireland research⁵ suggests a somewhat different breakdown, with less caring for or a partner (26%) and more caring for a child (34%) or a parent/parent-in-law (30%). This may reflect different sampling, and the means tested nature of Carers Allowance⁶.

Older Carers

According to 2011 Census data, there are 24,747, individuals aged 65 and over (13% of the carer population), and 85,034 individuals over the age of 50 who identify as Family Carers (45% of the carer population). The biggest relative percentage increase in caring between 2006 and 2011 was in those aged 65 and over (36%), and in particular those 85 and over (50.4%); whereas the biggest absolute increase in caring (i.e. in numbers caring) was in the 50-54 age cohort (4,523). We anticipate similar if not larger increases again in the numbers of older Family Carers (65 and over) identified in 2016 data when it is released.

Unfortunately, in the TILDA data (2012), focussing as it does on those aged 50 and over in need of care, in over 30% of the data, the age of the carer is not identified. Excluding this 'missing data', then 45% of these 'main carers' were aged 50-64, 23% are aged 65-79 and 4% are aged 80 and over. This suggests that 70% of carers in that sample are aged 50 and over; this is materially different to the census data (45%). This may be explained by a number of factors including the extent of missing age data in the TILDA survey, the way in which both surveys were completed (self-reported for Census, interview for TILDA) and the sampling (Nationwide, all ages for Census; 50 year old in household for TILDA inclusion).

In addition to experiencing the challenges which Family Carers face as a whole (including health, social and financial), older carers face a unique set of challenges related to their own ageing. In addition, this group may have been providing care for many years/decades to a child with a disability, mental health concern or serious illness who is now an adult but who continues to need support.

Challenges and Opportunities

There are multiple challenges and opportunities facing Ireland when contemplating ageing and Family Care. In this section we attempt to succinctly outline key issues

⁴ Kamiya Yumiko et al., 'Profile of Community-Dwelling Older People with Disability and Their Caregivers in Ireland' (TILDA, 2012).

⁵ Liam O'Sullivan, 'Health and Well-Being of Family Carers in Ireland: Results of a Survey of Recipients of the Carer's Allowance' (Combat Poverty Agency, 2008).

⁶ Note that the sampling for this study was provided via the Dept. of Social Protection and consisted of recipients of Carers Allowance.

which have been highlighted in our work with Family Carer organisations and the Family Carers they support throughout Ireland. This should not be seen as an exhaustive list. We are available to make further information available to the Assembly if requested.

1) Provision of Home Care

Home care is a topical issue in 2017 Ireland. We in Care Alliance are pleased to have been part of a campaign with 13 other not-for-profit organisations to call for increased funding in the Home Care sector, and indeed for a statutory right to Home Care, on a similar legislative footing to the of the Nursing Home Support Scheme (Fair Deal)⁷. We continue to advocate that for most ageing individuals, correct care and support in the home is their preference, in particular when faced with difficulties which arise for many in their daily lives as they age.

There is a wide discrepancy between the availability of Home Care hours in certain areas of the country. Work undertaken in 2015-2016 suggests that there are wide variations as to how accessible home care hours are, and the methods of prioritisation for home care hours⁸. In addition, 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); the 2016 HSE targets suggest a figure of a little over four hours per client per week. This raises the question of the adequacy of provision at an individual level and may point to the apparent increase in the use of short 15/30-minute home care visits⁹.

Care Alliance Ireland is of the opinion that if assessed as having a need for home care, each individual person, along with their families, should be able to avail of that home care without being pitted in competition for hours with others in their local area. In essence, the Home Care Scheme must become an entirely demand led scheme, with appropriate checks in place to minimise over-provision and waste.

The National Carers Strategy sees Family Carers as “Key Partners in Care”, with Family Carers in Ireland providing well in excess of €4billion worth of care in the home every year. Most Family Carers will continue to provide significant hours of care regardless of the home care hours provided on a statutory basis. However, having a statutory right

⁷ InvestInHomecare Partner Organisations, ‘Leading NGOs Call for Increased Investment in Home Care in Budget 2017’, 27 September 2016, [http://www.carealliance.ie/userfiles/file/Press%20Release%2027th%20September-%20Leading%20NGOs%20Call%20for%20Increased%20Investment%20in%20Home%20Care%20in%20Budget%202017%20\(1\).pdf](http://www.carealliance.ie/userfiles/file/Press%20Release%2027th%20September-%20Leading%20NGOs%20Call%20for%20Increased%20Investment%20in%20Home%20Care%20in%20Budget%202017%20(1).pdf).

⁸ 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), https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_lr_for_web_2.pdf.

⁹ Care Alliance Ireland, ‘Analysis of Home Care Supports Funded by the HSE 2008-2016’ (Care Alliance Ireland, 2016), <http://carealliance.ie/userfiles/file/Briefing%20Paper%201%20%3B%20An%20Analysis%20of%20Home%20Care%20Supp%20Funded%20by%20the%20HSE%202008-2016%20June%202016.pdf>.

to home care for their loved one would make significant progress towards ensuring this vision is achieved. Respect for Family Carers is a key element in any statutory home care programme, and taking account of the key role which Family Carers will continue to play for many of those in receipt of an assessed home care package provided on a statutory basis is vital. In addition, having an adequate level of home care provided, as to the assessed need of the older person, can ensure that ageing individuals can age in place, positively and with the correct supports to allow them to stay embedded within their community, as is the wish of most ageing individuals in Ireland.

2) Intellectual Disability and Ageing

The life expectancy of people with intellectual disability has increased significantly, along with the increase in the ageing population generally. Of those with intellectual disability, 12.4% are now over the age of 55, and includes a 60.3% increase in this age-group between 1996 (when these statistics were first collected) and 2010¹⁰. Better access to health care, a reduction in the number of people living in institutions, and general increases in life expectancy in Ireland are generally accepted to be contributing factors in this increase¹¹. In the next 10 to 15 years, it is estimated that the largest age cohort in the intellectual disability community will be the over-50 age-group¹².

For those Family Carers who have significant caring responsibilities for their family members with intellectual disabilities, it is crucial that service provision for this particular cohort of the ageing population, whose needs are often unique and different to those of the rest of the ageing population, is improved. This includes understanding what retirement for those individuals who have lived at home but attended a day service for many years might look like, along with health provision and increased need for particular residential service provision.

Many families have reported that they have been told, by services and the HSE, that a “bed will be found” for their loved ones once they pass away¹³. This is simply not good enough, and flies against international good practice examples whereby families and the State work together to plan for the future needs of this cohort. Indeed, this also does not take into account the needs and wishes of those ageing with an intellectual

¹⁰ M McCarron et al., ‘Growing Older with an Intellectual Disability in Ireland 2011: First Results from The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing’ (School of Nursing and Midwifery, Trinity College Dublin, 2011).

¹¹ Ibid.; Eilish Burke, Phillip McCallion, and Mary McCarron, eds., ‘Advancing Years, Different Challenges: Wave 2 IDS-TILDA. Findings on the Ageing of People with an Intellectual Disability’ (School of Nursing and Midwifery, Trinity College Dublin, 2014), http://www.idstilda.tcd.ie/assets/pdf/Wave_2_Report_October_2014.pdf; P Quinn, *Understanding Disability: A Lifespan Approach* (California: SAGE, 1998).

¹² McCarron et al., ‘Growing Older with an Intellectual Disability in Ireland 2011: First Results from The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing’.

¹³ Via 1-1 conversations with family members of people with intellectual disability and/or significant care needs

disability, contrary to both Irish national policy¹⁴ and the UN Convention on the Rights of People with Disabilities¹⁵.

Recent research has confirmed that some parents of people with intellectual disability do not wish to pass on this caring responsibility to their other children, and that many other families do not discuss future planning for their children with intellectual disabilities, which further impacts on the care and support which can be given, and the outcomes in to the future for those ageing individuals¹⁶.

In addition to care being provided to ageing individuals with intellectual disabilities, Care Alliance Ireland has become aware in recent years that growing numbers of adults with intellectual disabilities are they themselves becoming carers for the ageing parents. This developing mutuality of care is going unaddressed by service providers and policy makers, but will no doubt increase in frequency as our population continues to age, and as the policy of deinstitutionalisation and family living (in contrast to residential placements being available for those with intellectual disabilities, as in the past) continues.

We would direct readers to a discussion document we in Care Alliance Ireland published in December 2015 for further discussion of this particular topic¹⁷.

3) The National Carer Strategy and related policies

Given the statistical data on ageing and caring outlined above, it is clear that ageing and caring are intertwined. Not all carers are caring due to reasons associated with ageing, however all carers are themselves ageing. In the case of parent or sibling carers, the caring responsibility does not decrease with time- in fact the opposite is often the case, as those for whom care is provided also age. As such, the policy decisions being made and the implementation of those policies is clearly a challenge and an opportunity for society in regards to ageing well.

The National Carers Strategy was published in 2012, and at the time (during the financial crisis), it was envisioned as a cost-neutral strategy. The policy contains four National Goals and 42 specific actions, designed to create traction toward the overarching vision of the strategy, which is that;

¹⁴ Department of Justice, Equality & Law Reform, ‘National Disability Strategy’ (Dublin, 2004); National Disability Strategy Implementation Group, ‘National Disability Strategy Implementation Plan’ (Dublin, 2013).

¹⁵ United Nations, ‘United Nations Convention of the Rights of Persons with Disabilities’, 2006.

¹⁶ Attracta Lafferty et al., ‘Family Carers’ Experiences of Caring for a Person with Intellectual Disability’ (UCD, 2016); Damien Brennan et al., ‘Understanding Family Strategies That Enable Long Term and Sustainable Home Environments for Older People with an Intellectual Disability’ (TCD School of Nursing & Midwifery, 2016); Maire Leane, Anna Kingston, and Claire Edwards, ‘Adult Siblings of Individuals with Intellectual Disability/ Autistic Spectrum Disorder: Relationships, Roles & Support Needs’ (UCC, 2016).

¹⁷ Care Alliance Ireland, ‘Intellectual Disability, Caring and Role Reversal’ (Care Alliance Ireland, 2015).

"Carers will be recognised and respected as key care partners. They will be supported to maintain their own health and well-being and to care with confidence. They will be empowered to participate as fully as possible in economic and social life."

It is clear, from the work of the National Carers Strategy Monitoring Group¹⁸ (of which Care Alliance Ireland are members, along with Family Carers Ireland and a number of Family Carers), that the cost-neutral strategy must be refreshed, and a budget assigned to progress the actions contained within. Given that 80% of the main caregivers to people over the age of 50 years were themselves aged 50 years and over, clearly having a positive and usable National Carers Strategy which has actions specifically related to carers of older people and older carers themselves, is vital to create a positive ageing environment within the family care arena.

In addition to a refreshed and funded National Carers Strategy, it is vital that all the policies which are developed and will be developed that relate to our ageing population be tied together in a meaningful way. This includes the National Ageing Strategy, the National Dementia Strategy, The National Disability Strategy, etc.

4) Family Carers who are 80+

It is clear, from the data outlined above, that our population is ageing. It is also clear that the number of older carers who may themselves be experiencing age-related health concerns is increasing. Whilst the absolute numbers of carers over the age of 80 are small, their percentage increase between Census dates is a cause for concern. From 2006 to 2011, the number of carers between the age of 80 and 84 rose by 35%. The number of carers aged 85+ rose by 50%¹⁹.

This cohort of Family Carers are they themselves more likely to have a significant health concern themselves, yet are also likely to have to cancel or postpone their own medical appointments and treatment because of their caring responsibilities. A study in the UK in 2011 found that;

- Two thirds of older carers have long-term health problems. Commonly reported conditions are arthritis and joint problems, back problems, heart disease, cancer and depression.

¹⁸ 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); Carers Association Ireland, 'Family Carers' Scorecard: What Has the National Carers Strategy Achieved? An Assessment of Progress from the Perspective of Family Carers.', 2015, [http://www.carersireland.com/userfiles/file/Family%20Carers%20Scorecard%20Full%20Report\(3\).pdf](http://www.carersireland.com/userfiles/file/Family%20Carers%20Scorecard%20Full%20Report(3).pdf).

¹⁹ Central Statistics Office, 'Profile 8: Our Bill of Health (Census 2011)' (Dublin, 2012), <http://www.cso.ie/en/census/census2011reports/census2011profile8ourbillofhealth-healthdisabilityandcarersinireland/>.

'Guiding support for family carers'

- One third of older carers report having cancelled treatment or an operation they needed due to their caring responsibilities.
- 50% reported that their physical health had got worse in the last year, and 70% said specifically that their caring responsibilities had a negative impact on their physical health²⁰.

This has significant impact on how we view the care of older people. Similar to the increase in people with intellectual disability becoming carers themselves (as discussed above), this increase in older carers, and carers who are over the age of 80 in particular, highlights an increase in the mutuality of care. In addition, older carers report significant worry and stress regarding what will happen to their loved one when they can no longer care for them.

We would direct readers to a resource from Carers Trust (UK) which details these issues, and highlights examples of good practice which could be implemented in an Irish context to address some of these issues²¹.

Conclusion

Within this submission to the Citizens Assembly we have outlined a number of key issues, within the context of ageing and Family Care. This is not to be seen as an exhaustive list, nor does it fully describe all of the challenge which the carers of older people, and older carers themselves experience as they age.

There are significant opportunities which also face society at large, in relation to ageing and family Care. Ensuring that older people can age in their communities (according to their wishes), is possible with the correct home care and other supports, as outlined above.

We remain available to the Assembly should further information be required on any of the topics discussed in this Submission.

²⁰ The Princess Royal Trust for Carers, 'Always on Call, Always Concerned' (The Princess Royal Trust for Carers, 2011).

²¹ Ibid.

Background Information on Care Alliance Ireland

There are in the region of 360,000 Family Carers in the Republic of Ireland²². 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 87 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 from our membership base which includes all the carer organisations and virtually all of the disease/disability-specific organisations currently providing services to Ireland's Family Carers. Our membership comprises organisations both large and small, and both regional and national.

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.

Contact

Zoe Hughes, Policy & Research Officer, Care Alliance Ireland

zoe@carealliance.ie

086 883 4942

²² Central Statistics Office, 'CSO Releases Irish Health Survey Results'.