

There's no place like home

Family Carers Ireland's submission to the Citizens Assembly on how we best respond to the challenges and opportunities of an ageing population?

Family Carers Ireland welcomes the opportunity to submit our views to the Citizens Assembly, on how we respond to the challenges and opportunities of an ageing population. While population ageing has profound implications for all facets of our society, we do not wish to use this submission to name all of them, nor do we want to repeat the broader determinants of positive ageing set out in the National Positive Ageing Strategy and of which FCI are strongly supportive. Rather we will focus on one of the most important issues for consideration by the Assembly - how can our already pressurised health system meet the health and social care needs of an ageing society?

The submission is based on our experience of supporting family carers,¹ who provide an average of 16 million hours of unpaid care each week while saving the State some €10 billion each year in avoided health and social care costs².

Context

An ageing population is one of modern society's great successes and is a testament to medical advances. Better public health policies, preventative healthcare and improved socioeconomic, diet and living conditions have resulted in the rapid growth of the older population. By 2050, the world's population aged over 60 years old is expected to reach 2 billion, while in Ireland the numbers of people over the age of 65 years is projected to almost double to 1million by 2031, with 136,000 of these over the age of 85 years. This population ageing and the recognition that with it comes a prevalence of disability, chronic conditions and a complexity of medical needs, will have serious implications for the future planning, funding and delivery of the health service.

The Challenge³ – an entitlement to nursing home care with no equal entitlement to be cared for at home.

Home is a special place and the majority of older people and those with care needs want to remain at home for as long as possible. However the current funding of long term care in Ireland, specifically the entitlement to residential care under the demand-led provisions of the Nursing Home Support Scheme (Fair Deal), alongside the discretionary basis of home care services, has in effect prioritised residential care over home-based care of older people and has forced the inappropriate placement of many older people into a nursing home, when home care services are unavailable or inadequate to meet their care needs. In short, our current model of long term care gives older people an entitlement to a nursing home bed, but no equal entitlement to be cared for at home.

The Opportunity – Community-based model of care with a statutory entitlement to homecare, and respite

¹ National Carers Strategy (2012) defines a Family Carer as 'someone providing an ongoing significant level of care to a person in need of that care in the home due to illness or disability or frailty'.

² CSO's Irish Health Survey 2015 suggests 10 percent of the population aged over 16 years are carers providing an average of 45 hours of care each week. If extrapolated out to the national population this would mean Ireland has close to 355,000 carers who conservatively save the State some €10 billion each year, based on a replacement cost of €12 p/h. If an hourly rate of €18 p/h was applied (which is the rate charged by FCI) this would equate to a replacement cost of €15 billion.

³ Family Carers Ireland welcome the announcement by Minister Helen McEntee in January 2017 that the Department of Health will undertake a public consultation on a statutory homecare scheme, however we emphasise the important propositions for consideration when weighing any financing arrangement that may be proposed, including the need to exclude 'room and board' components and ensure people entering into home support arrangements are left with an adequate income to meet their daily living costs.

- The policy case

Government policy has long supported initiatives to maintain the care of people in their own homes. The *Care of the Aged Report*⁴ was the first significant report for older people, which recommended that older people should be able to remain in their homes for as long as possible. Subsequently, the NCAOP published *The Years Ahead-A Policy for the Elderly*⁵ in 1988. This emphasised the need to maintain older people at home, with a primary focus on the promotion of dignity and independence. The Irish Health Strategy *Shaping a Healthier Future* in 1994 emphasised ‘the role of GPs, public health nurses, home helps and other primary care professionals in supporting older people and their carers’. The target was that not less than 90% of those over 75 years could continue to live at home. In 2001, the *White Paper on Supporting Voluntary Activity* recommended: ‘Programmes to support informal caregivers including informal networks, basic training and the greater availability of short-term respite care’⁶. In the same year, *Quality and Fairness-A Health System for You* was published with the objective that ‘appropriate care is delivered in the appropriate setting’ and included examples of people receiving services in an inappropriate setting, such as, being cared for in hospitals due to the unavailability of more appropriate facilities or community supports⁷. In the same year, *Primary Care-A New Direction* stated that ‘a variety of supports will be provided to older people, such as health care assistants to support patients in the home, and reduce the need for crisis hospital admissions’⁸. More recently 2012’s *Future Health*⁹ advocated for reforms in social care that would enable older people and people with disabilities to remain in their own homes rather than go into residential care and a Seanad report on the rights of older people recommended that homecare entitlements be clarified and put on a statutory footing, similar to that of Fair Deal¹⁰. The Oireachtas Committee on the Future of Healthcare whose final report is due for publication on April 28th is also expected to reaffirm the longstanding objective to shift to a primary-based model of care, which places care in the home at the centre of our health system and provides for a statutory entitlement to home care services.

- The Economic Case

In addition to quality of life factors, there are strong economic arguments to support a community-based model of care. With daily hospital bed rates in excess of €900, average nursing home costs at €128 and average home care costs at €76, it makes economic sense to support care in the home. In addition, international research indicates that relatively modest home services, if provided at the right time, can have a major impact on quality of life, can reduce admissions to residential care and can address capacity issues within hospitals by avoiding unnecessary admissions. FCI acknowledges however, that home care is only feasible where family members are willing and able to provide the necessary care and where the person can be cared for safely within the home.

Figure 2: Cost of Care Comparison (source: HSE National Case Mix)

	Hospital	Nursing Home (avge.) ¹¹	Home Care ¹²
Cost per day	€909	€128	€76
Cost per year	€331,785	€46,720	€27,740

- The Re-balancing Case

The entitlement to residential care under the demand-led provisions of the NHSS (Fair Deal), alongside the discretionary basis of home care services, has in effect prioritised residential care over

⁴ Care of the Aged Report (1968): Department of Health.

⁵ The Years Ahead-A Policy for the Elderly (1988): NCAOP

⁶ White Paper on Supporting Voluntary Activity (2001): Department of Social, Community and Family Affairs.

⁷ Quality and Fairness-A Health System for You (2001): Department of Health and Children, 2001.

⁸ Primary Care-A New Direction (2001): Department of Health and Children.

⁹ Future Health: a Strategic Framework for the Reform of the Health Service (2012): Department of Health.

¹⁰ Seanad Report on The Rights of Older People published 21st June, 2012.

¹¹ Average daily cost of private and public nursing home care.

¹² Based on payment of Carers Allowance (€204 p.w), Carers Support Grant and Home Help for 2 hours per day at €21 p/h.

home-based care of older people and has forced the inappropriate placement of many older people into a nursing home, when home care services were unavailable or inadequate to meet their care needs.

- **The Moral Case**

The health service depends on family carers. Without the 6.2 million hours of unpaid care they provide each week, the service would collapse. The rapidly increasing demand for home care is being met by family carers rather than by the State. Logic would suggest that services to support care in the home should therefore increase in line with demand, but this has not been the case. At best, home care services are being maintained at the previous year's level, and at worst they are being rationed to the extent that even those assessed as needing home support cannot access help until another person dies and hours can be 'recycled'. In fact, the HSE spent less on home care in 2015 (€320m) than in 2008 (€331m), despite a 25% increase in the population aged over 65 years. During the same period however, the HSE increased spending on long-term care from €920m to €988m. This rationing of home care is in addition to the widespread closure of respite beds, cuts to disability and mental health funding, and the withdrawal of important supports such as the Mobility Allowance and Motorised Transport schemes, all of which are forcing carers to fill the ever-increasing gap between home care demands and the limited support available.

- **The Sustainability Case**

Most informal care is provided by family members – partners, parents, adult children, siblings etc. Changes in family structure, whether from having fewer children and starting families later, increased levels of marital disruption and more complex family relationships or greater geographical separation of families, are likely to affect the future availability of informal care and calls into question the sustainability of familial care.

Key Recommendations

- **Create a statutory entitlement to home care:** The 'even playing field' promised by Fair Deal has resulted in even greater disparity by instituting guaranteed access to full funding for residential care while retaining the discretionary nature of home care services. Without legislation to underpin access to home care, provision will remain inequitable, problematic and unreliable. It is critical that Government enact legislation that will give a statutory, demand-led entitlement to home care and place care in the home on an equal footing with nursing home care. In the interim, commit to the amendment of the NHSS to include an alternative package of home supports, where the costs are equal to, or less than the contribution that would be provided for residential care under Fair Deal.
- **Reorient funding from acute care towards community-based care:** The HSE spent €5.4billion on acute care in 2015, almost 39 percent of the total health budget of €13.9billion. A further €988 million was spent on residential care, through the NHSS. Government must gradually reorient health spending away from a hospital-centric model, where care is provided at the most expensive level, towards primary and community care, that delivers the best health outcomes and the best value for money. Such a dramatic shift cannot be achieved in the short-term. Rather, efforts must first focus on reducing patients' use of hospital services, for example by carrying out minor surgery in primary care centres, allowing GPs to have direct access to a range of diagnostic tests and investigations. We must also instigate behavioural changes – in the way GPs refer patients, in how patients themselves make informed decisions about their care and in establishing patients' trust in the primary care system.

- **Establish fully functioning Primary Care Centres:** Primary Care Centres are intended to be the first point of contact within the health service, providing a ‘one-stop shop’ for everything that a patient may need and representing the most local element of healthcare provision. The *Primary Care – A New Direction* Health Strategy stated that primary care was seen as the appropriate setting for the treatment of between 90 and 95 percent of healthcare needs and highlighted the potential for primary care to reduce hospitalisations and facilitate earlier hospital discharge. This plan suggested that 400-600 primary care centres would be required nationally. To date there are 44 functioning Primary Care Centres across the country, with an additional 14 being planned through Ireland’s first health-related Public Private Partnership. While the target set by the Primary Care Strategy may appear optimistic, the creation of an adequate number of fully functioning Primary Care Centres, with the full complement of multidisciplinary staff is an essential component in the creation of a community-based model of care.
- **Hospital avoidance strategies:** We must actively pursue efforts to avoid unnecessary hospital admissions. Initiatives such as those previously mentioned including access to community-based diagnostic testing, and minor surgery will help achieve this, however primary and geriatric care within nursing homes must also be reformed if hospital admissions are to be avoided. For example intravenous cannulations are not permitted in many nursing homes despite the presence of trained nurses, meaning hospital admission becomes necessary.
- **Abolish Health Budget Silos:** Patient journeys cannot be considered in the silos of acute, primary or social care, but rather as an integrated, interdependent system. In this way, parochialism and the myopia of focusing on individual budgets will be removed, and replaced with a more holistic view of patients care. An activity-based funding model, rather than one based on historical budgets, should be deployed across the health service and not only confined to acute hospitals.
- **Adopt a Whole-of-Government Approach:** We must unite in our approach to population ageing and ensure absolute cohesion, irrespective of changing Ministers or Governments. In a similar way, Departments not traditionally associated with healthcare must play their part. The reorientation of healthcare towards community-based care will involve the Department of Housing as it requires investment in accessible environments, and schemes to support the adaptation of homes for the elderly and disabled; it will involve the Department of Social Protection as more carers will require financial assistance; it will involve the Department of Jobs and the Department of Education as it will be necessary to have a skilled workforce to support a growing home care market; and it will involve the Department of Transport to support the mobility of people being cared for within their local communities who need reliable access to supports and services.
- **Address staff shortages:** Action must be taken to address staff shortages in key medical specialties such as general practice and psychiatry as well as amongst allied health professions. Work incentives and student bursaries must be created to encourage doctors and specialist clinicians to remain in Ireland. Likewise, efficiencies could be created by the reconfiguration of staff structures. For example, freeing up nurses by using trained healthcare assistants to deliver low-level nursing tasks.
- **Promote employment in the home care sector:** In 2009 the Irish home care market was worth €340million, with projections suggesting it could be worth as much as €568million by 2021. Preparing for the elder boom and the projected increase in the prevalence of disability and chronic conditions, and promoting quality employment within the sector is a significant challenge for Ireland over the coming years. Failing to do so will have implications for labour supply and the delivery of the health strategy.

- **Care Act:** Government should move towards enacting a ‘Care Act’ which will set out in law the State’s obligations in relation to the provision of care to our elderly and disabled population and their responsibilities in meeting their needs.

Other Considerations for the Assembly

- Legislation giving an entitlement to home care will stand or fall on the funding model chosen. The considerations in relation to the criteria underpinning the chosen funding model will be critical.
- GPs, Public Health Nurses and other social care staff are already overworked and under-resourced. It will be critical to secure their support in the roll-out of a community-based health strategy.
- Being able to identify a patient uniquely is essential in the provision of high quality, integrated healthcare. The Health Identifiers Bill 2013 and the impending introduction of a health identifiers will be a critical building block in the health reform programme.
- Examine the role assistive technology, telecare and reablement supports can play in helping people remain at home.
- The support of family carers will be critical to the implementation of any health strategy and as such it is important that their views are listened to during the consultation process. Family Carers Ireland would welcome the opportunity to attend a hearing of the Assembly.

In Conclusion

Family Carers Ireland congratulate the Assembly on recognising population ageing as one of the most important issues facing Ireland’s future. There can be little doubt that however we face the challenges and opportunities our ageing population presents, families and carers will be the cornerstone of our success. To this end, we ask that the Assembly continue to engage with the caring sector to ensure the needs of carers are considered in your deliberations and reflected in your final recommendations. Finally, on behalf of Family Carers Ireland I wish the Assembly every success in your work and look forward to a more inclusive and age friendly society as a result of your efforts.