

## **‘There’s no Place Like Home’**

### **Family Carers Ireland’s Submission to the Oireachtas Committee on the Future of Healthcare**

Family Carers Ireland (FCI) welcomes the opportunity to submit our views to the Oireachtas Committee on the Future of Healthcare in Ireland, and to set out what we believe should be the focus of our healthcare system over the next ten years. This submission is based on our experience of supporting family carers,<sup>1</sup> who provide some 6.2 million hours of unpaid care each week while saving the State over €4 billion each year in avoided health and social care costs<sup>2</sup>.

#### **Executive Summary**

- Ireland’s health service is in crisis. Overcrowding, uncontrollable waiting lists, overstretched frontline staff and the widespread culling of vital community-based supports have all contributed to this crisis. Despite the majority of care being provided in the community, we continue to pump almost 40 percent of the total health budget into hospitals, while spending €11m less on home care than we did in 2008, regardless of a 25 percent increase in the older population
- Despite endless Government reports advocating initiatives to support home-based care, and strong economic and moral arguments to do so, practice and policy remain at odds, with access to home care remaining inequitable, problematic and unreliable due to their discretionary basis.
- **FCI recommends a community-based model of care, which places care in the home at the centre of our health system and gives a statutory, demand-led entitlement to home care services for people of all ages, including access to respite. The vision set out in the National Carers’ Strategy ‘to respect carers as key partners in care and to support them to maintain their own health and wellbeing’ is integral to this<sup>3</sup>.**
- This submission does not endorse any particular funding model, either for the health system as a whole or more specifically to support a statutory entitlement to home care. Rather, FCI feel it more appropriate to set out important measures for consideration by the Committee in weighing any financing arrangement that may be proposed in relation to the statutory provision of home care services, 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.
- To operationalise a community-based model of care, Government must prioritise the enactment of home care legislation; redirect the flow of funding from acute to community-based care and pursue hospital avoidance strategies; invest in fully resourced Primary Care Centres; address staff shortages; abolish budget silo’s; and adopt a whole-of-Government approach which shares the responsibility for a successful health strategy with Departments not traditionally associated with healthcare (e.g. Housing, Transport, Social Protection, Jobs).
- FCI supports the approach taken by the Committee in recognising the need for a long-term, cross-party consensus on a strategy for healthcare, and we wish to offer our continued support. There is little doubt that whatever strategy the Committee proposes, family carers will be the cornerstone. We ask that the Committee continue to engage with the caring sector to ensure the needs of carers are reflected in the final strategy.

#### **1. Our Proposal – Community-based Model of Care with a Statutory Entitlement to Home Care Services, including Respite**

Ireland is facing a demographic crisis. There has been a 9 percent increase in the population since 2006. Life expectancy has increased by two and a half years since 2004, driven largely by welcome

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<sup>1</sup> 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’.

<sup>2</sup> Based on Census 2011 and €12 per hour replacement care cost rate.

<sup>3</sup> National Carers’ Strategy ‘Recognised, Supported, Empowered’ (2012): Department of Health.

reductions in mortality rates, and 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. Our ageing population, 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 model of care proposed by the Committee must address these serious demographic pressures and the commensurate need to create a healthcare system that:

- places the home at the heart of healthcare and creates a statutory entitlement to home care for older people, people with a disability and all those with care needs, including access to respite care;
- respects carers as key partners in care and supports their health and wellbeing;
- places medical need rather than fiscal considerations as the principle on which access is based;
- recognises primary care as a point of first contact, and a mechanism to avoid unnecessary hospital admissions;
- fully integrates primary, secondary and community care and provides the right care in the right place at the right time;
- provides uniform standards of care regardless of ability to pay or geographic location;
- ensures value for money while providing quality care;
- provides an optimal balance between formal and informal care;
- is transparent, accountable and delivers better outcomes for patients and their carers.

## 2. The Case for Community-based Model of Care with a Statutory Entitlement to Home Care Services, including Respite

### - The Policy Case<sup>4</sup>:

Government policy has long supported initiatives to maintain the care of people in their own homes. The *Care of the Aged Report*<sup>5</sup> 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*<sup>6</sup> 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’<sup>7</sup>. 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 supports<sup>8</sup>. 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’<sup>9</sup>. More recently *2012’s Future Health*<sup>10</sup> 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

<sup>4</sup> Irish Government and Health Care Policy on Family Carers/Older People’: HSE November 2011.

<sup>5</sup> Care of the Aged Report (1968): Department of Health.

<sup>6</sup> The Years Ahead-A Policy for the Elderly (1988): NCAOP

<sup>7</sup> White Paper on Supporting Voluntary Activity (2001): Department of Social, Community and Family Affairs.

<sup>8</sup> Quality and Fairness-A Health System for You (2001): Department of Health and Children, 2001.

<sup>9</sup> Primary Care-A New Direction (2001): Department of Health and Children.

<sup>10</sup> Future Health: a Strategic Framework for the Reform of the Health Service (2012): Department of Health.

Seanad report on the rights of older people recommended that home care entitlements be clarified and put on a statutory footing, similar to that of Fair Deal<sup>11</sup>.

**- 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)

	<b>Hospital</b>	<b>Nursing Home (avge.)<sup>12</sup></b>	<b>Home Care<sup>13</sup></b>
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 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.

<sup>11</sup> Seanad Report on The Rights of Older People published 21st June, 2012.

<sup>12</sup> Average daily cost of private and public nursing home care.

<sup>13</sup> Based on payment of Carers Allowance (€204 p.w), Carers Support Grant and Home Help for 2 hours per day at €21 p/h.

## 2. Funding Models

FCI does not intend to use this submission to endorse any particular funding model, either for the health system as a whole or more specifically to support a statutory entitlement to home care. Rather, we feel it more appropriate to set out important propositions for consideration by the Committee when weighing any financing arrangement that may be proposed in relation to the statutory provision of home care services. Furthermore, we acknowledge that persons seeking home care support may also have family members or friends in receipt of Carers Allowance for their care or may receive some other form of care-related State support (e.g. Housing Adaptation Grant, Carer Tax Credit, tax rebates under the Disabled Driver's and Passenger's Scheme etc). FCI also acknowledges that home is not always the most appropriate care setting, not only for environmental reasons, but also when the costs of providing care safely within the home are so high that it becomes economically unviable. Proposals we ask the Committee to consider in relation to the funding of home care services include:

- Eligibility for home care should be based on a transparent assessment of medical need and applied consistently across the country.
- People under 65 years with an assessed need should also be eligible.
- Family members should not be means-tested or expected to contribute to the cost of their loved one's care (as with NHSS).
- There should be a significant savings disregard in the assessment of means.
- Funding arrangements should be 'locked' so that people are not exposed to future price inflation.
- Any consideration of a co-payment model must exclude the family home from reckonable assets as the 'room and board' portion of care costs remains with the caree.
- Likewise any consideration of a co-payment model must leave the caree with an adequate income to cover the costs of running their household and cannot make a contribution that would leave them with a disposable income so low they are at risk of poverty.

**Example:** A 79 year old with €222 pension, €40K savings and home valued at €100K would make a contribution of €326 (€182 deferred) to his nursing home care under the current Fair Deal regime.

Table 3: Fair Deal

	Income	Liquid Assets	Principal Residence
Fair Deal	80% income	€36k/€72k disregarded single/couple. Balance@7.5% p.a	Residence @ 7.5% p.a. up to max 22.5%
Financial Assessment	€176.60	(€4000x7.5%) €5.76	€144
Weekly Contribution	€326.36 (€182.36 deferred loan)		

If the same gentleman applied for a package of home care support the same funding model could not apply. If we replace the 80 percent contribution used in Fair Deal with a hypothetical 20 percent of weekly income, it would mean the pensioner would make a €50 contribution to his weekly care costs.

Table 4: Home Care Support

	Income	Liquid Assets	Principal Residence
Home Care Support	20% income	€36k/€72k disregarded single/couple. Balance@7.5% p.a	Not applicable as Room and Board provided by caree
Financial Assessment	€44.40	(€4000x7.5%) €5.76	€0
Weekly Contribution	€50.16		

## Key Recommendations

### For Government

- **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:** The health strategy 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. More seriously, anecdotal evidence suggests that the fear of a HIQA investigation following the death of an older person while in a nursing home, can result in patients being unnecessarily admitted to hospital when they are close to death to avoid such an investigation.
- **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:** The health strategy must unite Government 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.

#### **Other Considerations for the Committee**

- Use the resources available to the Committee to estimate the cost of providing a statutory entitlement to home care services for people of all ages and ensure funding is ring-fenced for its implementation.
- 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 (section 2 above) 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 Committee

### **In Conclusion**

FCI supports the approach taken by the Committee in recognising the need for a long-term, cross-party consensus on a health strategy. There can be little doubt that whatever strategy the Committee proposes, family carers will be the cornerstone of its implementation and success. To this end, we ask that the Committee continue to engage with the caring sector to ensure the needs of carers are considered in your deliberations and reflected in the final strategy. Finally, on behalf of Family Carers Ireland I wish the Committee every success in your work and look forward to an improved healthcare system as a result of your efforts.