



OLDER & BOLDER

SUBMISSION TO THE REVIEW OF THE NURSING HOMES SUPPORT SCHEME

JULY 2012

Older & Bolder is an alliance of eight NGOs in the age sector in Ireland. The members of the alliance are : Active Retirement Ireland, Age & Opportunity, Alzheimer Society of Ireland, Carers Association, Irish Hospice Foundation, Irish Senior Citizens Parliament, Older Women's Network and Senior Help Line. Our vision is of an Ireland that affirms ageing and the rights of all older people, enabling everyone to live and die with confidence and dignity as equal, respected and involved members of society.

Older & Bolder welcomes the opportunity to make this written submission to the review of the Nursing Home Support Scheme and looks forward to a robust and open review process.

Our submission follows the Department's Terms of Reference for the review:

Taking account of Government policy, demographic trends and the fiscal situation -

1. To examine the on-going sustainability of the Nursing Homes Support Scheme,
2. To examine the overall cost of long-term residential care in public and private nursing homes and the effectiveness of the current methods of negotiating/setting prices,
3. Having regard to 1. and 2. above, to consider the balance of funding between long-term residential care and community based services,
4. To consider the extension of the scheme to community based services and to other sectors (Disability and Mental Health), and
5. To make recommendations for the future operation and management of the scheme.

1) To examine the on-going sustainability of the Nursing Homes Support Scheme

Older & Bolder contends that sustainability is not just about economic choices, on-going sustainability is about political choices underpinned by core values. For Older & Bolder a core value in terms of systems of health and social care is social solidarity and the pooling of risk across the generations.

People of all ages at different stages of their lives may need to access home, community or residential care. Thanks to TILDA and ESRI we now have evidenced-based projections about long term health and social care needs. The next step is not about whether we can or we cannot address these needs but how we will meet these needs.

Our view is that there is duty on the State to uphold the right to care at all stages of the continuum of care – which incorporates self-care, community care, long-term residential care and end-of-life care.

Right to Care

There is a fundamental problem in that the right to health and personal social services is not defined in Irish legislation. The impact of this lack of definition, clarity and legal entitlement is severe on older people and of great concern to Older & Bolder. The effects are experienced by older people in need of both nursing home care and home and community services.

Five per cent of older Irish people require long-term nursing home care. This group comprises people of advanced age with high levels of disability, frailty and complex needs. The reality is that the Nursing Home Support Scheme enacted in 2009 is budget-capped and does not confer an entitlement to financial support for nursing home care.

The view that the Fair Deal legislation supersedes the Health Act 1970 which obliged the State to provide nursing home care has been challenged by the Ombudsman. From human rights, legislative and policy perspectives, the situation is a quagmire and results in uncertain access to appropriate care for a highly vulnerable group of older people¹.

There is no statutory entitlement to home care and community care services. Access to such services for older people is discretionary and unequal. Influencing factors include: geographic location, ability to pay, category of illness. This results in severe hardship for community-residing older people who are challenged by illness, frailty, disability, social isolation. Older & Bolder believes the right to care, at all stages of the continuum of care, must be put on a statutory footing..

2) To examine the overall cost of long-term residential care in public and private nursing homes and the effectiveness of the current methods of negotiating/setting prices,

An informed public debate on the effectiveness of the current methods of negotiating/setting prices for long-term residential care will depend on access to accurate and meaningful data. Some areas where national and local data is needed include

- Unit costs of care for both public or private residential centres
- Calculations of the costs of care for residents with higher and lower levels of dependency
- Staff-patient ratios for residents with different levels of dependency
- Calculations on the cost of incorporating basic supports (additional dressings, continence pads etc) and services (therapies, meaningful activities) into the overall package of care

¹ Tangible evidence of denial of care is provided by the crisis in mid 2011 with the Fair Deal Nursing Home Scheme and the acknowledgement by the Minister for Equality, Disability, Mental Health and Older People on May 31 2011 that 4,500 people were on a waiting list for admission to nursing home care.

The Accenture report highlights the fragility of the Fair Deal information systems.

“One of the biggest challenges has been management and reporting on public beds particularly getting reliable data on Fair Deal beds and occupancy at *national level*. This data is a prerequisite for Fair Deal to operate as intended²”.

Older & Bolder echoes Accenture’s call for “*full visibility and transparency around public beds at national as well as regional level to implement Fair Deal*”.

Making this data available publically will be key to facilitating a transparent and informed public debate on the future development of the Fair Deal model. The availability of such data would also facilitate better decision making around the planning and provision of respite, rehabilitation and day care facilities.

Regarding our feedback to Terms of Reference points 3-5 we have chosen to respond to them together to avoid repetition.

- 3) Having regard to 1. and 2. above, to consider the balance of funding between long-term residential care and community based services,**
- 4) To consider the extension of the scheme to community based services and to other sectors (Disability and Mental Health), and**
- 5) To make recommendations for the future operation and management of the scheme.**

Principles for financing the care of older people

A study on the financing of long term care for older people outlined principles against which potential financial schemes for the care of older people might be evaluated³. Though conducted in 1994 the principles outlined in this study remain acutely relevant to this current review.

- 1) The funding of long-term care should be comprehensive
- 2) Funding should not determine care requirements; rather care requirements should determine funding
- 3) There should be a built-in bias towards home care solutions while retaining a capacity for financing care in institutionalised settings
- 4) Payment mechanisms should be prospective and case management should be used to determine needs
- 5) Access should be based on need and should not be impeded by an inability to pay

² Accenture, Funding Fair Deal High Level Issue Analysis. Report presented by Accenture to the Minister for Health. 30 November 2011

³ O’Shea, E. and Hughes, J. (1994) The Economics and Financing of Long-Term Care of the Elderly in Ireland, Report No. 35, Dublin: National Council for the Elderly

- 6) Efficiency and the quality of care should be enhanced rather than diminished by the funding system

The Continuum of Care

The advice for more than 20 years has been that policymakers need to plan to meet a continuum of care needs among the older population. Home and community care services are at one end of the continuum and nursing home care are at the other end.

Accenture in its analysis of Funding Fair Deal set out a key concern around the relative prioritising of residential care within the overall continuum of care services. “A key premise of Fair Deal was that in essence it was a Scheme of last resort – people would only access residential care when they needed to. This was contingent on the availability of other services to support people either in their home or in intermediate, non-acute care. This was a central consideration in the policy documents supporting Fair Deal to ensure that people would not access LTRC prematurely with consequences for the individual and the future sustainability of the Scheme. A critical future concern is to ensure that Fair Deal does not become the easiest point of access in the context of constrained community services⁴”.

Older & Bolder share Accenture’s concern that planning of access to and funding of community care services be given due priority within the continuum of care.

Within the overall continuum of care Government policy has now recognised the need to move towards a primary health care model where health services (GP, Local Health Nurse, Physiotherapist, Chiropodist etc) link-up effectively at a local level and where community and hospital services work together efficiently. While, in most villages and towns in Ireland this is not a reality Older & Bolder welcomes the recent Government announcement (17/08/12) that primary care facilities will be developed at twenty locations across the country. Older & Bolder appreciates that this represents a commitment to primary care. In particular we welcome the use of the Haase-Pratschke Deprivation Index to identify which areas are least well served and to better inform the provision of posts.

- In addition to a comprehensive review of the Fair Deal scheme we now need an audit of community care services so that we can map the services that are available, identify the deficits, plan effectively for the future and introduce greater transparency into an opaque system. The HSE’s existing HealthStat system should be developed to provide this much needed information. Ultimately, if used effectively, this information could reduce premature admissions to nursing homes and unnecessary stays in expensive acute hospital beds.
- Those of us with multiple chronic conditions should be supported to manage our own health locally. Diagnosis and management of conditions such as dementia, stroke, falls, incontinence, bone health and immobility should be available in the community.
- Community care services, though patchy, are vital and existing levels of service must be retained. These budgets are under threat; they must be protected against cuts and safeguarded from pressures in other parts of the health system.

⁴ Accenture, Funding Fair Deal High Level Issue Analysis. Report presented by Accenture to the Minister for Health. 30 November 2011.

HSE Directorates

At the time of writing (18 July 2012) the Minister for Health Dr James Reilly announced the publication of the Health Service Executive (Governance) Bill 2012 which, amongst other functions, abolishes the Board structure of the HSE replacing it with seven directorates.

If all our health needs are to be addressed effectively within a functioning continuum of care, these directorates must function collaboratively and promote integrated working between the management and staff within and across directorates.

Of particular importance will be

- Assignment of management responsibility and authority in the new directorates for the planning, financing and delivery of home and community care services to older people;
- Clear, consistent and equitable pathways to community care services and entitlements for older people regardless of where they live;
- Care and case management arrangements for older people at the margins of community/residential care;
- Access within Primary Care Teams (PCTs) to gerontological expertise and support;
- Communication pathways between staff in PCTs, social care services and acute hospitals; and
- Adequate public financing of social care supports and services for older people.
- Assurance that on-the-ground experience feeds into how social care and community care directorates will work together.

Right to Community Care

Older people who need and receive community care (e.g. Home Help, respite, Home Care Packages, hospice home care services) value this support enormously.

However, access is discretionary, unequal and problematic. The root of this issue is the lack of legislation to underpin access to these services. Since access is discretionary, it is extremely difficult for individuals, families and carers to get information and reliable access at critical points e.g. discharge from hospital, onset of disability, diagnosis of long-term or life-limiting illness.

Older & Bolder stands with the Ombudsman who observes that “people do not know where they stand in terms of their entitlements and in terms of the HSE’s obligations to provide services⁵”. Older & Bolder calls for the development of long-promised legislation to establish a clear right to community care. This will finally provide clarity and security to individuals and families for whom this is currently causing unnecessary anxiety.

⁵ Health Policy – An Ombudsman Perspective, address by Emily O’Reilly at Mater University Hospital Conference, 09.09.2011, www.ombudsman.ie

Right to Information

As the NESF highlighted in their 2005 report *Care for Older People*, a right to information already exists in Ireland under the Freedom of Information (FOI) legislation, which obliges public bodies to publish: the rules, procedures, practices, guidelines and interpretations used by them and the precedents kept by them for the purposes of decisions, determinations or recommendations in relation to schemes administered by them; and c information about the way such schemes are administered.

However, it is a matter of serious concern to note that neither the Department of Health and Children nor the HSE have published details of how people qualify for services such as home helps. They give general information but do not publish information about the criterion or criteria used for establishing service prioritisation. This means that it is not possible to know whether or not an individual was treated correctly and, among other things, reduces the possibility of seeking a remedy.

Right to Assessment of Need

Older people, their families and carers must have clear, consistent and equitable pathways to community care entitlements and services regardless of where they live. This includes access to a uniform assessment of their own needs and the needs of their carers; and access to a register of professional home-carers. This point is one tenet of Older & Bolder's Make Home Work Charter which is receiving wide support from local and national groups around the country (see appendix for copy of Charter).

Older & Bolder understands the HSE is currently piloting a Single Assessment Tool. "The introduction of a single assessment tool will assist the HSE to further key strategic objectives, i.e. meet needs in the most appropriate setting; enhance quality and efficiency; promote value for money; facilitate access to long-term residential care or a home care package; and enable older people to remain at home for as long as possible"⁶.

Older & Bolder welcomes this development and calls for a clear timeline for a final decision on the Single Assessment Tool and for the implementation of the tool across community and residential care nationwide. Once rolled out, macro data from this tool should be made available publically in due course.

Dementia Strategy

Work on the development of a National Dementia Strategy is ongoing. Core elements for both the new Dementia strategy and this review of the provision and financing of residential care and community care include the need for

- Greater emphasis on primary prevention and on ways of avoiding or delaying the illness

⁶ Minister of State at the Department of Health (Deputy Kathleen Lynch): Dáil Written Answers Dáil Éireann Debate Vol. 769 No. 1 Tuesday, 19 June 2012

- Expansion of dedicated and flexible community based services, for example, day care services and family support programmes, for people with dementia and their carers
- Development of small-scale, appropriately designed, residential care units
- Enhanced information systems on the number of people with dementia, severity of the disease, placement patterns and quality of life

The Fair Deal 'package'

Older & Bolder understands that while the Nursing Home Support Scheme funds a range of important care services there are gaps in this package of care for certain basic services and supports. The package should be expanded to cover services such as therapies, additional dressings, continence pads etc., so that residents are kept well as possible for as long as possible. Residents in public residential homes may have access to physiotherapy and chiropody while those in private homes do not have access. Older & Bolder contends that these services should be included in the Fair Deal package and available from all residential homes, be they public or private.

Dying at home

End of life care is an important part of the continuum of care. Most people in Ireland – including those who are terminally ill – would prefer to be cared for and die at home, but most (75%) will actually die in acute hospital or a long stay setting. In order to better meet these preferences projects like the Irish Hospice Foundation's "Cork Pathfinder Project" should be used to explore how health services can be restructured to enable more people to die in or closer to their homes (be they family homes or residential homes).

Access to meaningful activity

A recent Irish study identifies 'activities' as one of the key aspects of quality of life and fundamental to 'finding a home' within residential care settings⁷. This study showed that the absence of 'meaningful activities' left residents feeling frustrated.

According to Nursing Homes Ireland, the rate paid to providers covers nursing care/accommodation, but not costs of 'social programmes'⁸. If provided, they must be paid for by residents or supplied as an add-on by providers. Given that 80% of a person's income is paid to the care home under the Fair Deal, this leaves many residents without the capacity to pay for these activities.

We concur with our alliance member, Age and Opportunity, who affirm that quality of life must be considered on a par with the quality of care. Any review of the Nursing Home Support Scheme must consider the inclusion of 'meaningful activities' within the funding model.

⁷ Cooney, A., 2011. 'Finding home': a grounded theory on how older people 'find home' in long-term care settings. *International Journal of Older People Nursing* 18 April

⁸ Nursing Homes Ireland, 2010. *Annual Private Nursing Homes Survey 2009/2010*. Dublin: Nursing Homes Ireland

Extending 'Fair Deal' scheme to community based services

Older & Bolder favours models of financing health and social care that are underpinned by principles of risk pooling or other forms of collective response to the risk of requiring long-term care.

In considering the extension of the Nursing Home Support Scheme to community based services it must be understood that the 'Fair Deal' model creates a contract between individuals and the state but fails to realise a commitment, as articulated in the lifecycle approach of Towards 2016, to a wider social contract.

While patients with cancer or heart failure receive all of the financing of their treatment in acute hospitals, *Fair Deal* patients who may need long stay care due to Alzheimer's Disease or Stroke are required to contribute towards the cost of their care from the sale of their homes.

A transparent, informed and broad public consultation and debate on the future funding and provision of long term care, both residential and community, is vital.

Public debate should be preceded and informed by an analysis of how different models of funding and provision could meet our community care needs. Older & Bolder calls on the Department to take a lead role in terms of providing detailed projections and relative costs of various models, building on the work already carried out by the Law Reform Commission.

Chapter 3 of the Commission's report on the Legal Aspects of Professional Home Care considers possible models for the future models of long-term home care. This section of the report explores issues related to funding long-term care through taxation, social insurance, universal benefit, universal health insurance, private insurance, individual contributions and the nursing home support scheme.

Finally, the public consultation and debate around long term community and residential care should include the Government's plans for Universal Health Care and the potential of long term community care to be financed with this universal system.