

# **Presentation to the Oireachtas Committee on the Future of Healthcare**

**9<sup>th</sup> November 2016**

## **Dr. Michael Browne, Forum on Long-Term Care for Older People**

Thank you, Chairperson and Good Morning

By way of introduction, I would like to briefly state where I come from on this hugely important matter. I have been involved in research, policy analysis and reflection in this area for over 30 years, firstly as a Research Officer with the National Council on Ageing and Older People during the 1980s and early 1990s and more recently with the Forum on Long-term Care for Older People. I was involved in preparing some background papers for the 1988 seminal report, *The Years Ahead* and, indeed, am of the view that the analysis and agenda for action set out in that report remain current and relevant to the work of this Committee.

In this morning's presentation, I do not intend to go over ground you already know and are only all too familiar with from your deliberations and from your own personal experiences in dealing with constituents in various parts of the country. Rather, I want to focus in on what are the key areas that require concerted attention and action. My colleagues here today Professor Cillian Twomey and Patricia Rickard-Clarke, from their respective professional backgrounds of medicine and law, will be able to provide detailed insight into specific aspects of the challenges facing the health and social care services as they apply to older persons.

I want to make the obvious point at the outset that the Forum on Long-term Care for Older People refers to a relatively small cohort of the older population but a cohort to which any of us here to-day may belong at some future date. This should clearly be an impetus for a whole of society approach to the issue based on the notion of inter-generational solidarity

There are some important pointers to where we are now and where we need to be as a society in terms of providing the type of health and social care infrastructure for our older population that we all aspire to.

Firstly, there is a major discrepancy in the Irish health care system between the way care for people with acute illnesses and those with a slow debilitating illness (such as dementia) is funded – a core question to be addressed by society and by Government is whether or not this is right or equitable.

Secondly, while there is broad acknowledgement of the principle of enabling people to exercise their will and preferences in the way care is provided, the reality is that some people who do need to be in nursing homes end up there not by choice but because of a lack of appropriate community-based alternatives.

Thirdly, the provisions of the Assisted Decision-making (Capacity) Act 2015 are crucial in enabling people with reduced decision-making capacity to exercise their will and preferences and the full implementation of this legislation is of critical importance.

Fourthly, there are some very obvious instances where the level of services available and the way these services are delivered, without good reason, fall short of what is required. For example, there is still much to be done to ensure that the design and location of nursing homes caters for key quality of life considerations – links with the community, maximising individual capacity and catering for individual preferences. Also, people's inability to access the therapies that they require at a level commensurate with need impacts greatly on their quality of life and general well-being and, indeed, on their need to have to avail of expensive acute hospital services.

All of the research evidence and reflected practice suggests that multi-purpose community-based units providing a continuum of support and care (day facilities, sheltered accommodation, nursing units) can contribute enormously to enabling people to live independently or semi-independently. These should be made an integral part of the community care infrastructure – such models could be developed initially in locations where existing public long-term residential care facilities have been deemed to be no longer fit for purpose. Indeed, some of you may be aware of facilities with such potential in your own constituencies.

The potential of appropriately designed housing in the provision of support and care has not been developed to date in Ireland -- there are appropriate models of 'housing with care' that have been developed in other jurisdictions and some in Ireland that can and should be replicated nationwide. Housing and health and social care can no longer remain parallel lines. They must converge. For this to happen we need to focus as much of our energy on local government as on national government; on housing policy as much as health and social care policy. There is a need for Local Authorities to take on much more responsibility for the provision of sheltered and supported housing.

More attention is required to ensure that best gerontological practice is always applied in meeting the specific nursing, medical and personal care requirements of people with complex care needs in both residential care settings and in the community. There is a dearth of appropriately designed and staffed dementia-specific accommodation, including both assisted living housing and full residential care – this gap in provision needs to be addressed as a matter of some urgency. I think it is reasonable to suggest that people with dementia are among the most socially excluded groups in our society.

The question of the respective responsibilities of the State, families and individuals in providing long-term care and support is one that has not been adequately addressed in Ireland to date. I expect that John Dunne, Family Carers Ireland, will have something to say later on this topic.

While the Nursing Home Support Scheme (the so-called 'Fair Deal') is a large area of health expenditure, there is little focus on outcomes, quality of life domains or on catering for the will and preference of people who require nursing home care. The current model of fee negotiation between the National Treatment Purchase Fund and nursing homes is unsatisfactory, not least because it only provides for 'bed and board' and takes no account of different individual care, support and quality of life needs.

The Forum deliberations re-iterated the point that much more can be done at local community level to prevent or delay the onset of conditions that require more extensive and expensive care and support, including, in particular accessible transport and initiatives to combat social isolation and loneliness. It is likely that a community-based social enterprise model of support and care delivery supported by the State has significant potential to target interventions at the lowest appropriate level.

Ireland can learn much from practice in other jurisdictions with particular reference to:

- Legal frameworks relating to people's rights in respect of long-term care
- Models of financing
- The individualised payments approach (targeting resources around individuals)
- The optimal balance between funding for community-based care and for residential care
- The devolved responsibilities of local government (municipalities) in providing long-term care accommodation, support and services
- Integrating mainstream housing provision and specialised accommodation provision
- The use of assistive technology

So what are the key questions that need to be addressed by the Committee?

I suggest five:

- 1) What is the optimal level of support and care we wish to provide for older people with dementia and other chronic conditions?
- 2) What is the likely cost of this care?
- 3) How do we wish to fund it in the short, medium and long-term?
- 4) How do we achieve an appropriate balance between funding provision for acute hospital care and funding for long-term care?
- 5) How can we achieve social and political consensus on these matters?

There are some areas where we need new legislation – the financing of long-term care; providing equality of access to community care and nursing home care; and regulation of home care provision. However, there are many areas where additional legislation is not required but rather a more targeted allocation of resources based on social consensus.

Finally, Chairman, there is a broad consensus on the direction that our approach to supporting older people who need care should take. This includes enabling people to stay at home and in their own communities for as long as possible, the need to cater for people at the lowest appropriate level of complexity and the need to provide high quality residential care when and if this is needed. This requires a greater mix of accommodation choices and the application of best gerontological practice in all situations where older people require care and support.

We know what needs to be done – it has been articulated for at least 30 years. Actually doing it requires new thinking and innovative approaches based on an ethic of solidarity that requires society to provide a long-term health and social care infrastructure that respects the inherent dignity and personhood of all.

As an absolute starting point we need an enhanced budget for support and care in the community and legislation to enable provision and regulation of this.

THANK YOU