



All-Party **Oireachtas Group**
on **Dementia**

Report Two

A Statutory Scheme for Home Care

Round Table Event

23rd March 2017

Deputy Mary Butler & Senator Colette Kelleher



Houses of the
Oireachtas
Tithe an Oireachtais

Background

The All-Party Oireachtas Group on Dementia was formed in 2016 to enhance cross party collaboration on dementia issues, to act as a forum for learning and knowledge sharing and ultimately to help improve the lives of people with dementia through better policies and practices. The group is run in partnership with The Alzheimer Society of Ireland, which acts as secretariat for the group.

There is a wide-spread recognition of the need for a fair and equitable network of home care across Ireland. The All-Party Group therefore welcomed the announcement in January 2017 that Minister of State for Mental Health and Older People, Helen McEntee TD, will be launching a consultation process with a view to establishing a new statutory home care scheme.

The group hosted a round table event on 23rd March 2017 to advance the discussion on how we can develop a scheme for home care that is equitable, well-resourced and well-regulated.

This report sets out the key stakeholders involved in this round table discussion and their vision for home care in Ireland.



Speakers and attendees at the round table event on home care

Key Points:

- The meeting highlighted the clear need for a scheme that meets the preferences of people to remain at home and the need to move from an ad hoc, piecemeal approach to home care;
- The proposed statutory scheme for home care will be essential in meeting the needs of those who require support to remain living at home. We must take brave steps in designing this scheme, using the lessons learned from the past and other jurisdictions;
- Home care must be adequately regulated with appropriate licensing and standards;
- In relation to potential funding models for home care, options include private insurance, general taxation and social insurance, which has a number of positive aspects such as visibility, reciprocity and clarity.

Speakers:

- Minister of State for Mental Health and Older People, Helen McEntee TD;
- Dr. Rachel A. Kiersey and Dr. Jean Long, Health Research Board (HRB);
- Senator Colm Burke;
- Professor Eamon O'Shea, Irish Centre for Social Gerontology, NUIG;
- Mr. Michael Fitzgerald, Head of Operations and Service Improvement Services for Older People, HSE;
- Mr. Ronan Smith, Irish Dementia Working Group;
- Mr. Pat McLoughlin, The Alzheimer Society of Ireland;
- Dr. Marita O'Brien, Age Action.

Other Contributors:

- Senator John Dolan;
- Deputy Anne Rabbitte;
- Senator Alice-Mary Higgins;
- Representative for Senator Lorraine Clifford-Lee.



*Mr. Pat McLoughlin, Professor Eamon O'Shea and
Mr. Michael Fitzgerald*



Minister Helen McEntee

Overview

- The Department of Health acknowledges that home care support can be a cost-effective alternative to long-term residential care for some older people. In particular, home care is a vital issue for the 55,000 people living with dementia in Ireland and their families.
- The 'Meeting Older People's Preferences for Care' report was launched in 2016 by The Alzheimer Society of Ireland, the Irish Association of Social Workers (IASW), Age Action and University College Dublin. This report found that the current system is focused on delayed discharge, there is a lack of information around services, and geography not need is determining access to care.
- It is stated Government policy to support people to live at home, but at present we are spending nearly four times more on residential care.
- In Ireland we are coming from a residential care model and it is difficult to move beyond that. If we want to increase home care we need to push resources towards community care.
- In relation to potential funding models, options include private insurance, general taxation and social insurance. Cost sharing is happening across all sections of care and if this is used it should be introduced in the context of collective responsibility.
- If we want to live at home successfully we need a menu of community based care to suit individual needs, which includes broader community based services, such as day care and respite care.
- There was political bravery around the introduction of the Fair Deal Scheme and we need to take brave steps to design a system for home care. If we don't

act now, we could still be talking about this issue in ten years' time. We need to proceed, using the lessons learned from the past and other jurisdictions.

- The Health Research Board has identified six key principles of home care-standards, consultation, transparency, equity, choice and sustainability.



Senator Colette Kelleher



Senator Colm Burke and Deputy Mary Butler

Aim of Home Care Round Table

Ms. Mary Butler TD, Co-Chair of the All-Party Oireachtas Group on Dementia & Fianna Fáil Spokesperson on Older People

- There is wide-spread recognition of the need for a fair and equitable network of home care across Ireland and today's event is a unique opportunity to bring together key stakeholders to discuss where we are and where we need to go.
- The Department of Health acknowledges that home care support can be a cost-effective alternative to long-term residential care for some older people. In particular, home care is a vital issue for the 55,000 people living with dementia in Ireland and their families. The majority of people with dementia want to live at home and to do this they need access to flexible home care that meets individual needs.
- The aim of this event is to advance the discussion on how we can develop a scheme for home care that is equitable, well-resourced and well-regulated.

Home Care in Ireland - Challenges and Solutions: Learning from Other Places

Minister of State for Mental Health and Older People, Helen McEntee T.D.

- With an ageing population we need access to better data so that we can adequately assess the level of funding required for home care. We all agree that not enough money is being spent on home care at the moment. The current budget for older people is €765 million.
- The Department of Health asked the Health Research Board to examine the provision and regulation of home care in other jurisdictions and the report they have prepared will be very important in determining what a statutory scheme for home care could look like and how it could be regulated.
- The upcoming consultation process will provide an opportunity for everyone, including organisations working directly with older people and the All-Party Oireachtas Group on Dementia, to have their say and we will progress this process as soon as possible.

Dr. Jean Long and Dr. Rachel A. Kiersey, Health Research Board (HRB)

- The HRB examined the provision of home care in four jurisdictions- Germany, the Netherlands, Sweden and Scotland. All four jurisdictions have a governance framework, with a national overarching policy, legislation and regulation.
- Germany and the Netherlands have long established long-term care insurance schemes and there is an increasing reliance on co-payments (particularly in Germany) to fulfil all home care service needs. Scotland and Sweden have their own country-specific universal home care schemes, with an increasing reliance on co-payments (usually fixed or capped) to fulfil all home care service needs.
- All four jurisdictions have a defined needs assessment and include home help services in their basket of services. This research has identified six principles of home care- standards, consultation, transparency, equity, choice and sustainability.

Homecare Entitlement and Regulation

Senator Colm Burke

- The number of people retiring will increase dramatically in coming years and home care will become even more important so we need to deal with this issue now. At present, there is nothing to prevent a person with a criminal record becoming a home care provider and Senator Burke brought forward a Bill in the Seanad to address current gaps in the regulation of home care.

- Another issue we need to address is the provision of home care in rural areas. In some areas there aren't enough home care workers to meet the level of need. It will not be possible for the State to meet all of the costs associated with home care and we need to work on educating the public on that.

Planning and Paying for Homecare

Professor Eamon O'Shea, NUIG

- As the number of older people in Ireland has increased, spending on this group per capita has decreased and we need to recover this spending. In 2009 it was €3,514 and by 2015 spending had reduced to €2,612 per capita.
- Although stated policy is a community support model for older people, we are coming from a residential care model and it is difficult to move beyond that. If we want to increase home care we need to push resources towards community care and support. People want certainty, if there is no statutory scheme for home care they will be drawn to the Fair Deal scheme.
- An important question to consider is what is a family's responsibility with regard to the care of an older loved one? What do we want and expect families to do? Older people often don't want as much as people think. They want good information, choice, individualisation of care and timely, integrated care.
- Care requirements should determine funding, not the other way around. We need to implement and accelerate the use of the Single Assessment Tool. Need should be seen as the determining factor for care, not geography or funding.
- In relation to potential funding models, options include private insurance, general taxation and social insurance, which has a number of positive aspects such as visibility, reciprocity and clarity. Cost sharing is happening across all sections of care and if this is used it should be introduced in the context of collective responsibility and framed as being about shared values.
- At present we are spending nearly four times more on residential care as community care and this will require additional funding. It is not possible to do what we need to do without more funding. The question is how we can get more funding into the system.

Home Care – Current Provision

Mr. Michael Fitzgerald, HSE

- A lot of money is invested in residential care services. The amount spent on the Fair Deal Scheme is approximately €1 billion and this benefits 23,000 people. In

comparison, approximately €370 million is spent on home care, with 49,000 people receiving home help and 16,700 people receiving home care packages.

- Residential care has a huge value for people. The difficulty is that residential care is more visible so if you close a hospital or residential bed people may object, but if you lose 1,000 hours of home care from a budget people may not realise.
- If we want to live at home successfully we need a menu of community based care and support to suit individual needs, which includes broader community based services, such as day care and respite care.
- We must take this opportunity to address home care, using learning from the Fair Deal Scheme and dealing with issues around equity, choice and how people can contribute towards the cost of care. The issue of co-payment will be the most difficult political element and we don't want a scheme that requires the HSE to collect money directly from people.
- The assessment used for home care will be important and the Single Assessment Tool will highlight areas where we are not meeting peoples' needs.
- We need to be careful about how we approach regulation. We need licensing and standards, but we will lose services if we go too far with regulation. We also need to be careful about what we include and exclude in the scheme, for example the need to include services and supports for those under the age of 65.

Meeting Peoples Needs

Mr. Ronan Smith, Irish Dementia Working Group

- We must take as much action out of today's event as possible. There is a possibility that we could become paralysed by the scale of work to be done on home care. Action must be taken, even if it is experimental and involves risks.
- Carer burnout is crisis driven and home care packages can bring relief to carers and postpone the need for long-term care. What is needed is action, even if it appears daunting. People with dementia and carers need politicians to be brave.

Mr. Pat McLoughlin, The Alzheimer Society of Ireland

- 48% of the costs associated with dementia are borne by family carers and research shows that carers' own cognitive ability can decline due to stress.

- The Single Assessment Tool needs to be flexible to meet the specific needs of people with dementia and the Understand Together campaign and HSE mapping project will result in more emerging needs.
- It is important not to overregulate this area and to ensure there is ring-fenced funding for home care.

Dr. Marita O'Brien, Age Action

- The 'Meeting Older People's Preferences for Care' report was launched in 2016 by The Alzheimer Society of Ireland, the Irish Association of Social Workers (IASW), Age Action and University College Dublin. This report found that the current system is focused on delayed discharge, there is a lack of information around services, and geography not need is determining access to care.
- The report recommends that ring-fenced budgets be introduced in each CHO area, that a fair and equitable way of administering care is introduced and that funds are matched to socio-demographic needs and health disparities.
- We need a new definition of home care, which currently focuses on personal care and takes a deficit approach, rather than a strengths-based approach which encourages independence.

Summary

Senator Colette Kelleher, Co-Chair of the All-Party Oireachtas Group on Dementia

- We need a system for home care which is rooted in legislation, is regulated and deals with the issues of financing, entitlement and reflects people's preferences. There was political bravery around the introduction of the Fair Deal Scheme and we now need to take brave steps to design a system for home care. If we don't act now, we could still be talking about this issue in ten years' time. We need to proceed, using the lessons learned from the past and other jurisdictions.

Final Comments

- *Pat McLoughlin*: links with the Irish Dementia Working Group and Dementia Carers Campaign Network can ensure the new scheme is grounded in the real needs of people with dementia and their families. Informal family care has been taken for granted, but this can't continue. There must be dedicated resources for home care.
- *Michael Fitzgerald*: the most immediate need is a commitment to increasing resources for home care year on year by €30 – €40 million.

- *Minister McEntee*: a key priority for this year is the need for additional funding for home care. The consultation process will take around eight weeks.
- *Senator Dolan*: when talking about home care, it is important to talk about choice, empowerment and autonomy.
- *Senator Burke*: we need to establish a proper structure for home care or there is a risk someone will seek to enforce their constitutional rights before the Courts.

Conclusion

A scheme for home care is required to meet the demands of a growing older population and the needs of people with dementia and other conditions, and to make good on Government policy to support people's preferences to remain living at home. We need a well-designed system that will allow us to move on from the current bias towards residential care as the only form of certainty and from the current ad hoc system of home care, which is subject to the vagaries of funding.

A consensus emerged at this round table event that we require an infrastructure for home care, similar to the jurisdictions cited in the Health Research Board report (Germany, the Netherlands, Sweden and Scotland). This system must involve putting home care on a legislative basis and statutory footing, including an entitlement to home care; regulation of home care to ensure quality standards and safety; and an agreement on funding which is likely to include co-payment from social insurance or other funding models.

Next Steps

- This report will be circulated and presented to the relevant Ministers and to all party leaders;
- The All-Party Oireachtas Group on Dementia will prepare a submission for the upcoming consultation process on a statutory scheme for home care, following consultation with The Alzheimer Society of Ireland and other civil society organisations;
- Members of the All-Party Oireachtas Group on Dementia will continue to highlight the importance of a statutory scheme for home care and to campaign for increased investment in home care.