



OÉ Gaillimh
NUI Galway

CESRD Centre for Economic
and Social Research
on Dementia



Policy Dialogue on the New Home Care Scheme

Discussion Document

December 2019

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The content of and views expressed in
this document are solely those of the
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Introduction and context

1. Introduction and context

1.1 Background

The Centre for Economic and Social Research on Dementia (CESRD) at the National University of Ireland (NUI) Galway, works to develop and facilitate new thinking on dementia in Ireland. The research themes of the centre include: personhood within dementia; evaluating and valuing psychosocial interventions; the economics of informal care; and identifying service priorities and resource allocation processes which maximise the capabilities and well-being of people with dementia and their family carers in an efficient and effective way.

The Centre is particularly concerned with policy impact and has organised a series of events throughout 2019 aimed at disseminating evidence to stakeholders in a way that might maximise policy impact; a Policy Symposium, a Dementia Policy Café and a Carer's Assembly. In April, the CESRD in collaboration with the University of Notre Dame, convened a Policy Symposium on Ageing, Social Care and Social Justice. The symposium brought together 50 policymakers, practitioners and researchers, with national and international experts, to consider some of the big questions facing Ireland in the coming decades around resource allocation, priority-setting and social justice in relation to the care and support of dependent older people in Ireland¹. In July, ten people from the Irish Dementia Working Group (IDWG) took part in a Policy Café, where they discussed two issues; diagnosis and home care, in order to identify key messages for policy makers. A summary of the key points from the Policy Café is in Appendix 1 and a short film of the Policy Café will be shared at the

Policy Dialogue meeting. In October, 33 carers of people with dementia took part in a Carer's Assembly, modelled on the Citizen's Assembly, to share their views on dementia care in Ireland and to identify their priorities. A summary of the key points from the Carer's Assembly is in Appendix 2 and a short film of the Carer's Assembly will be shared at the Policy Dialogue meeting. The provision of home care has been a dominant topic throughout these events.

The CESRD approached the Department of Health with a view to testing an approach to facilitating discussion on important policy issues called Policy Dialogue². The Department was interested in collaborating on a Policy Dialogue with a focus on bringing evidence to bear on the discussion of some of the key issues for the new home care scheme. Given the expertise of the CESRD in relation to people with dementia and older people, it was agreed to focus this Policy Dialogue on these areas with an acknowledgement that this does not cover the broader range of people with care needs who may come within the scope of this scheme.

Due to limitations of resources and time, there are many important issues that are not addressed in this discussion document. The issues to be discussed in the Policy Dialogue are by no means the only issues being considered by the Department of Health in relation to the home care scheme, nor is there any established position on these issues within the Department. They are presented here for consideration in a multi-stakeholder format in the context of the home care scheme which is still under development. This Policy Dialogue is one event in the ongoing consultation, meetings and discussions undertaken by the Department of Health on the home care scheme.

¹ Keogh, F., Pierse, M. and O'Shea, E. (2019) *Ageing, Social Care and Social Justice: Policy Symposium Proceedings*. Galway: Centre for Economic and Social Research on Dementia.

² Lavis, J. et al. (2009) *SUPPORT Tools for evidence-informed health Policymaking (STP) 14: Organising and using policy dialogues to support evidence-informed policymaking*. *Health Research Policy and Systems* 2009, 7(Suppl 1):S14. <http://www.health-policy-systems.com/content/7/S1/S14>

1.2 The new Home Care scheme

Enabling people to continue to live independently at home for as long as possible is a long-standing objective of the Government. To advance this, the Government is committed to establishing a new statutory scheme for the financing and regulation of home care services, which the Department of Health is currently progressing.

The development of the scheme is a complex process which will build on international best practice, emerging good practice across the current system of health and social care delivery, the HSE's continual enhancement of existing service provision and the range of views from stakeholders in this area.

In preparation for the development of the statutory scheme, the Department commissioned the Health Research Board to carry out a review of the home care systems in four European countries³. In addition, the Department conducted a public consultation on home care services, on which a report was published in 2018⁴. These reports will help to ensure that the new scheme is informed both by international experience and by the views of stakeholders, including service-users. In addition, in 2019 the Department has commissioned a review of the management, operation and funding of existing home care service provision, which will provide insight into the strengths and weaknesses of current service provision. More broadly, the Department is currently exploring the options for the design of the scheme and for the regulation of services, as well as preparing for the pilot of the scheme which will be undertaken in 2020. The Department of Health's Sláintecare Implementation Strategy (2018) commits to the introduction of the statutory scheme in 2021.

Within this context, and in order to support Sláintecare's vision of delivering "the right care in the right place at the right time", the new statutory home support scheme will aim to:

- Support Making Every Contact Count (MECC) in line with Healthy Ireland principles;
- Provide equitable access to services based on an assessment of need;
- Ensure a transparent system that operates consistently and fairly across the country;
- Support effective integration with the Nursing Home Support Scheme ('Fair Deal') and other health supports, including nursing, therapies and other primary care services; and
- Provide a high-quality service and public confidence in the standard of the services provided.

1.3 What is a Policy Dialogue?

A Policy Dialogue has been defined as an "interactive knowledge sharing mechanism that allows research evidence to be brought together with the views, experiences and tacit knowledge of those who will be involved in, or affected by, future decisions about high priority issues"⁵. It is a structured process which aims to include policy makers, researchers and other stakeholders (such as clinicians, patient groups etc.) in a process that helps to integrate evidence and data to inform policy development. Given the focus on bringing evidence to bear on policy development, the CESRD is convening this dialogue as an agency with no agenda other than to facilitate evidence-based discussions. The Policy Dialogue is funded through a grant from the Health Research Board (HRB) under the Knowledge Exchange and Dissemination Scheme. There are two key features to the Policy Dialogue – the nature of the conversations and the use of evidence. Dialogue and conversation are characterised as shared

³ https://www.hrb.ie/fileadmin/publications_files/Approaches_to_the_regulation_and_financing_of_home_care_services_in_four_European_countries.pdf and <https://www.gov.ie/en/publication/601dbf-report-on-the-findings-of-the-public-consultation-on-home-care-servi/>.

⁴ Institute of Public Health in Ireland (2018). *Improving Home Care Services in Ireland: An Overview of the Findings of the Department of Health's Public Consultation*. Dublin: Institute of Public Health in Ireland.

⁵ See ref 2 above Lavis, J. et al. 2009

Table 1: Differences between dialogue and debate

Dialogue	Debate
Collaborative	Oppositional
Common ground	Winning
Searches for agreement	Searches for differences
Enlarges perspectives	Affirms perspectives
Causes introspection	Causes critique
Looks for strengths	Looks for weaknesses
Re-evaluates assumptions	Defends assumptions
Listening for meaning	Listening for countering
Remains open-ended	Implies a conclusion

Source: from Lavis et al, (2009)

exploration towards greater understanding, connection, or possibility⁶. This type of forum is designed to use evidence and first-hand knowledge and experience to explore options for policy issues and is very different to debate for example, as outlined in **Table 1**

A second key feature of a Policy Dialogue is the provision of materials in advance so that participants are as informed as possible and can consider evidence as well as bringing their own expertise and experience to the discussions. This discussion document provides some background to the issues to be discussed. To ensure the material is as accessible as possible, two short films have been prepared; one outlining the document in a brief form and the second explaining what a Policy Dialogue is, what to expect and how to prepare for it.

In order to create the conditions for participants to openly discuss 'possibilities' and to be creative, this Policy Dialogue will be held under the *Chatham House Rule*⁷. The rule originated at Chatham House which is the Royal Institute of International Affairs, an independent organisation based in London. The aim of the Chatham House Rule is to encourage openness of discussion and facilitate the sharing of information. It is used as an aid to free discussion of sensitive issues and provides a way for speakers to openly discuss their views in private while allowing the topic and nature of the debate to be made public and contribute to a broader conversation. The rule is that

"participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed".

1.4 Scope of the Policy Dialogue

Four topics will be discussed at the Policy Dialogue:

1. **The Home Care Continuum** - what should be the scope of home care under the new scheme, i.e. what services and supports should be covered by the scheme? For example, should home support stay largely as it is and focus on personal care and/or clinical care needs, or should it cover a wider range of social and psychosocial needs? This topic is outlined in Section 2 of the document.
2. **Care planning and organisation of care delivery** - how do we create a home care system that ensures care is tailored to the individual needs of the person and their family carer; and that care is organised in a co-ordinated and integrated way? This topic is outlined in Section 3 of the document.
3. **Regulating for quality** - how do we develop and support a regulatory environment that ensures flexible, high quality, safe home care is available to those who need it most? This topic is outlined in Section 4 of the document.

⁶ <http://www.co-intelligence.org/P-dialogue.html>

⁷ <https://www.chathamhouse.org/chatham-house-rule>

4. Funding - how can we ensure that there is enough money to fund good quality home care into the future? Should older people have to contribute anything towards the cost of their own care? This topic is outlined in Section 5 of the document.

We acknowledge that these are just some of the key issues that are important in the development of the home care scheme and many issues will not be addressed. These four topics were selected in the following way. Firstly, they are key features of home care which emerged from the public consultation on home care undertaken in 2017⁸. Secondly, they are some of the issues that emerged in the events described above: the policy symposium, the dementia Policy Café and the Carer's Assembly. Thirdly, they are issues which are the subject of research in the CESRD and for which an evidence base is being established in Ireland. Finally, they are issues which are central to the consideration of the Department of Health in developing the new scheme. Other issues have been identified in the report of the public consultation and in other reports and will doubtless be considered in other forums and discussions.

The dialogue has a focus on older people and people with dementia. We know that home care is a vital support for people with other needs, however, the evidence and expertise of the CESRD is in the area of people with dementia and older people hence the focus for this event. It is likely that the content of the discussions at the dialogue will have strong relevance for all recipients of home care, but this does not preclude the discussion of these issues for other groups. As mentioned already, this Policy Dialogue is just one of many interactions that have already taken place and which will be taking place as part of the process of developing the home care scheme.

1.5 Goals of the Policy Dialogue

Participants to this Policy Dialogue include a range of perspectives: service users; advocacy groups; academics; service providers; and Government departments. Taking on board this range of perspectives, the aim of the day is to obtain participants' views on the four topics referenced above and, through open discussion, provide further insight into what consensus might look like in these areas.

In particular, views on the following broad questions are sought:

- In developing the new home care scheme, how can we best ensure that the range of health and social care services people rely on to live at home are well-coordinated and focused on meeting the needs of the individual;
- How the state can best work in partnership with citizens to ensure that people's care needs are met and that they can continue to live in their homes and communities for as long as possible;
- How to ensure the safety and well-being of service-users, and to ensure that services are good quality, while also supporting the provision of care on a more informal basis, e.g. by family, neighbours and friends, and through innovative initiatives, such as home-sharing (through which carers are accommodated in the homes of people with care needs in return for providing care and companionship);
- How to ensure that the funding of home care is fair, affordable for everyone, and sustainable in the longer term.

These views will inform the development of the new scheme as well as enriching the evidence-base for research in this area in Ireland.

A report will be produced by the CESRD which will summarise the discussions from the day and which will contribute to the development of the new scheme.

1.6 Provision of home care in Ireland

1.6.1 Overview of home care services

In the public consultation on home care, the Department of Health used a definition of home care from the Health Research Board evidence review:

"Home care in Ireland is typically understood as home help services, which include cleaning, cooking and other light household tasks that a person is unable to do themselves due to old age or disability. The scope of home help has subsequently developed to include more personal care assistance such as support with personal hygiene, washing, and dressing also"⁹.

With regard to home care provision, a distinction is usually made between informal and formal (professional) home care. The former refers to care provided by family members, friends, neighbours and others who provide regular unpaid care. Formal home care involves a mix of funders and providers, with the largest funder in Ireland being the HSE. These categories are described further in **Table 2**.

Currently, there are no charges for home care services. Eligibility is not means tested or 'limited' in any other way and is provided to people over 65 (and some people under 65) based on an assessment of need. Home care is provided on a fixed budget allocation, meaning it is what is termed a 'supply-led' service – there is a certain amount of supply (determined by funding allocated each year) and it is rationed out (e.g. by using waiting lists or stretching the number of hours across clients)¹⁰.

“Approximately 17 million home support hours were provided for 50,500 people aged 65 years and over in Ireland in 2018”

⁸ See reference 4 above: Institute of Public Health in Ireland (2018)

⁹ See reference 4 above: Institute of Public Health in Ireland (2018)

¹⁰ Timoney, A. (2018) Home Care for Older People: Seven Policy Challenges. Dublin: Houses of the Oireachtas.

Table 2: Structure and description of home support provision

Provider	Description
Informal	
Family / friend caregiver - Unpaid	The bulk of home care is provided by family members / friends mostly in an unpaid capacity. Informal care includes both hands-on care, monitoring and supervision and taking a role in managing/co-ordinating with formal care providers.
Formal (Professional) home care	
Health Service Executive (HSE) Includes home support provided under three arrangements: (i) Arranged by the HSE and provided by HSE staff (ii) Arranged by the HSE and provided under contract by approved voluntary service providers (iii) Arranged by the HSE and provided under contract by approved for-profit private providers	Home support service – since 2018 the home help service and home care packages have been streamlined into a single home support service. There is a single application and decision making process for this service. Intensive Home Care Packages (IHCPs) – provide a high level of care to people with complex needs including people in acute hospital who need a high level of support to return home and people living at home who are at significant risk of admission to long-stay residential care. Approximately 200 IHCPs are allocated each year.
Private	
Arranged by the individual/family and funded by them	Fee-per-service care provided by voluntary or private providers or other agencies. Care can also be provided through a private arrangement between an individual carer and the family. Approximately one in five carers providing this type of care, not attached to an agency.

Updated and adapted from Timoney (2018) and Mazars (2016) ¹¹

While the home support service in Ireland is mainly used by older people, it is also provided, in a limited way, to some people with disabilities and others with identified care needs, including, for example, people leaving hospital who need support.

Approximately 17m home support hours were provided for 50,500 people over 65 in 2018 and this is projected to increase to 17.9m hours in 2019 to 53,000 people over 65. Average weekly hours per recipient in 2018 were 6.5. However, there was significant variation by Community Healthcare Organisation (CHO) with a range of 4.5 hours per person per week to 10.3 hours per person per week. Almost eight per cent of people over 65 received home support (HS) hours in 2018, again with

significant variation by CHO (4.7% to 12%)¹². Rating the provision of home care hours by the over 65 population in CHOs allows us to examine variation adjusted for actual population. This shows that, for example, CHO 9 has 78 per cent more publicly funded home support hours per person over 65 than CHO 6¹³.

A recent report from the ESRI has also noted substantial variations in primary, community and long-term care supply across regions in Ireland, including public home care¹⁴. Even when adjusted for need there is variation. This report concluded that in order to achieve equity in supply, considerable increases in supply of non-acute care would be required in many counties.

¹¹ Mazars (2016) Activity and resource review: Home care services. <http://hdl.handle.net/10147/621444>

¹² HSE (2018) Community Healthcare Operational Plan. Dublin: Health Service Executive.

¹³ Keogh, F., Pierse, T., and O’Shea, E. (2019) Dementia services in Ireland 2018: Audit of community-based health and social care services used by people with dementia. Galway: CESRD

¹⁴ Walsh et al (2019). Geographical profile of healthcare needs and non-acute healthcare supply in Ireland. Dublin. ESRI.

1.6.2 Informal carers

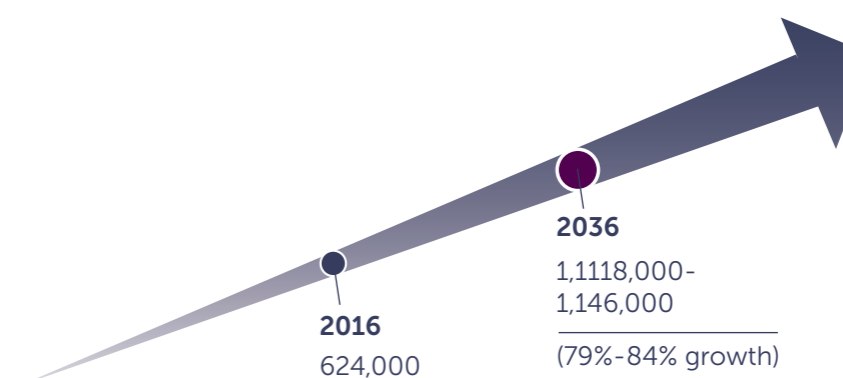
Publicly-funded home care is an important element of home care provision. Home care for older people cannot, however, happen without informal or family carers. There are over 195,000 carers (people providing regular unpaid help for a friend / family member) providing at least 6.6 million hours of care per week¹⁵. Almost 1,800 carers are aged over 85 years. Many family members are committed to providing this care but the need for more support for family carers has been strongly articulated^{16,17}. The care provided also has an economic value, estimated at €807m per annum for informal carers of people with dementia alone, accounting for approximately 48% of the total annual cost (almost €2bn) of caring for people with dementia¹⁸. There is also evidence that privately-purchased home care is increasing in Ireland, with estimates that private home help provides approximately one-quarter of all home help hours¹⁹. Almost half of the people with dementia who were in receipt of an intensive home care package (IHCP) paid an average of €391 for private home care in addition to the support from the IHCP²⁰.

1.6.3 Future requirements

It is projected that the population of Ireland will continue to increase in the coming decades and that the number of people aged 65 years and older will be in the region of 1.1 million people by 2036 and 1.4 million people by 2046 (i.e. people born in 1981) (See **Figure 1**). Similarly, the population aged 80 years and older is projected to increase to around 340,000 by 2036.

Home support is recognised as an essential service at the individual level. However, it is also a core element of the interdependent array of services within the wider health system. This is acknowledged in the recent significant *Health Service Capacity Review 2018*, which undertook a detailed analysis of health demand and capacity requirements in Ireland to 2031²¹. The review examined two scenarios; a baseline status quo scenario and a reform scenario. It demonstrated the potential impact on capacity across the health service of three inter-linked reforms, one of which is ‘an improved model of care that repositions the health service towards a community-based care model with a specific focus on older persons’ (p4)²². Some of the

Figure 1: Population over 65 years and projected increase



¹⁵ CSO (2017) Census of Population 2016: Profile 9 Health, Disability and Carers. Cork: Central Statistics Office.

¹⁶ Family Carers Ireland (2017) Budget 2017: Achieving fairness for family carers. Offaly: Family Carers Ireland

¹⁷ Alzheimer Society of Ireland (2013) Submission on the National Dementia Strategy. Dublin: ASI

¹⁸ Pierse, T. and O’Shea, E. The Economic and Financing of Dementia in Ireland. In: O’Shea, E., Cahill, S. and Pierce, M. (2017) Developing and Implementing Dementia Policy. Galway: CESRD

¹⁹ Wren, M.-A., Keegan, C., Walsh, B., Bergin, A., Eighan, J., Brick, A., Connolly, S., Watson, D. and Banks, S. (2017) Projections of Demand for Healthcare in Ireland, 2015-2030: First Report from the Hippocrates Model. Dublin: ESRI.

²⁰ Keogh, F. et al (2018) Supporting Older People with Complex Needs at Home : Report 2 :What works for People with Dementia. Dublin : Genio. <https://cesrd.ie/wp-content/uploads/2019/11/Supporting-Older-People-with-Complex-Needs-at-Home-Report-2-What-Works-for-People-with-Dementia.pdf>

²¹ PA Consulting (2018) Health Service Capacity Review 2018: Review of Health Demand and Capacity Requirements in Ireland to 2031 - Findings and Recommendations. Dublin: Department of Health.

²² As above

key findings of the capacity review which are relevant to a consideration of home care include:

- A broad consensus that it is neither feasible nor appropriate to plan investments around the current pattern of service delivery;
- The full implementation of the three reforms specified would alter the capacity needed across all sectors by 2031 to a 120% increase in homecare (home help hours and homecare packages).

1.6.4 Preferences for care

What older people want

The majority of people over 65 years of age in Ireland report that they are in good health^{23,24}. However, older people who have health and care needs, in general, prefer to stay in their own homes²⁵. It is not just older people who express a preference for home care. A survey of 1,000 people in the general population²⁶ found that, if they needed it in the future, people would most prefer to receive long term care in their own home (81%). Care in a nursing home (29%) was one of the least preferred options among people responding to the survey.

“A survey of 1,000 people in the general population found that, if they needed it in the future, people would most prefer to receive long term care in their own home (81%)”

Views from the dementia Policy Café

In the development of the Policy Café, home care was identified as one of the central topics which people with dementia wanted to discuss that day, along with diagnosis. The central themes that emerged from the discussion of home care are described in Appendix 1 and included: an emphasis on a social model of home care, i.e. support to keep healthy, connected, active and social; the importance of trained and skilled carers; timely support and respecting the autonomy of the person.

Views from the Carer’s Assembly

In the Carer’s Assembly, four themes were discussed in the course of the day; home care, social support, respite care and financial support (see Appendix 2). Of these, home care was ranked as the top priority issue by the carers who attended. Within the homecare services theme, the priority topic, as voted by carers, was: *dementia-specific training for both family carers and professional carers providing homecare support within the home.*



2

The Home Care Continuum

²³ CSO. (2017) *Census of Population 2016: Profile 9 Health, Disability and Carers Dublin and Cork*: Central Statistics Office.

²⁴ *Healthy and Positive Ageing Initiative (2018). Positive Ageing Indicators 2018*. Dublin: Department of Health. <https://assets.gov.ie/9673/f528d4c3856044e9a2b5545230e77a04.pdf>

²⁵ McGee, H. et al. (2005) *One Island - Two Systems: A Comparison of the Health and Social Services Use by Community-dwelling Older People in the Republic of Ireland and Northern Ireland*. Dublin: The Institute of Public Health in Ireland.

²⁶ Browne, M. (2016). *Responding to the Support and Care Needs of our Older Population: Shaping an Agenda for Future Action, Report of the Forum on Long-term Care for Older People*. Dublin: Sage Third Age Ireland.

2. The Home Care Continuum

2.1 Introduction

The current scope of home support has been described in section 1.6.1. The Home Support Service (previously known as Home Help Service or Home Care Package Scheme) provides help and support with every-day tasks to older people living at home. These tasks may include help with:

- getting in and out of bed
- dressing and undressing
- personal care such as showering and shaving²⁷.

This description of home support does not capture many other services and supports that can be provided in the person's home depending on their needs, such as:

- interventions from health and social care professionals (Physiotherapists, Occupational Therapists (OTs) etc.) and nursing care from Public Health Nurses (PHNs);
- aids and appliances;
- services provided in the community which support people living at home such as day care and respite care;
- psychosocial supports such as: home visiting, befriending, social activities (walks, art, choir), cognitive stimulation therapy, dementia café;
- specialist services provided in the community such as mental health services, palliative care services, integrated care for older people, and others.

Most of these services are provided by the HSE through a number of HSE divisions, or by organisations which deliver services under a service arrangement with the HSE.

2.2 Defining home care

There is little clarity as to what constitutes 'home care' – with different definitions in different jurisdictions, different service elements in terms of what constitutes 'home care' and different models or interventions for home care such as reablement and case management²⁸. Home care has often evolved organically and is not designed as an intervention to achieve specific outcomes, but is rather seen as an essential service for people who need support to live at home. The desired outcomes for home care are often not made explicit but generally include maintaining or improving quality of life and delay or avoidance of residential care.

In their report on the legal aspects of home care, the Law Reform Commission recommended that professional home care should be defined as *"services which are required to ensure that an adult person can continue to live independently in their own home. This may include, but is not limited to the services of nurses, home care attendants, home helps, various therapies and personal care. The Commission also recommends that palliative care be included in the definition of professional home care"*²⁹.

The World Health Organisation Europe describes home care as being aimed at: *"...satisfying people's health and social needs while in their home by providing appropriate and high-quality home-based health care and social services, by formal and informal caregivers, with the use of technology when appropriate, within a balanced and affordable continuum of care"*³⁰.

2.3 Evidence on home care

Much of the research evidence on home care measures different models of intervention and different outcomes, using different methods and is therefore very heterogeneous and difficult to summarise. Research on home care also tends to focus on policy and funding arrangements. In many countries health services and social care services are funded and managed separately, and thus some international research is not readily applicable to an Irish context. There is surprisingly little research on the process of home care, i.e. what is home care comprised of and what is the experience of the recipient?

An Irish study examining the preferences of older adults receiving home care services and of home care workers in Ireland, found that while many home help recipients were generally satisfied with the service, they wanted more communication with the managers of the service and expressed a desire to become more involved in the planning of their own care³¹. Companionship was a key concern for these individuals and the carer played a vital role in fulfilling this need. The study found that both the care recipients and those providing home care felt the model of home care placed too much time pressure on home care workers, resulting in the recipients feeling rushed and the workers being dissatisfied with the amount and quality of the time they spent with clients, concluding that "task-based does not facilitate the carer working with the older person to promote independence in the home"³². A task-based model of home care with an emphasis on meeting personal care needs is recognised as far from ideal for users of home care services as well as for home care workers^{33,34}.

An Irish study evaluating intensive home care packages (IHCPs) for people with dementia also reported a focus on task-oriented care in some packages, although three approaches to configuring home support were evident in the study³⁵. One of the aims of the IHCPs was to personalise care as much as possible and to provide a greater array of services to support people with complex needs to be discharged from hospital or to remain at home. In responding to the availability of additional home support hours, IHCPs were configured in different ways depending on the needs of the person and family. A 'classic' IHCP mostly consisted of short and multiple daily visits focused on the personal care needs of the recipient. Most recipients in this group were very dependent and needed significant amounts of support with personal care. In a 'Block' IHCP, home support hours were provided in blocks in order to facilitate breaks for the carer as well as support personal care. The third type of configuration was a 'combination' IHCP, with a mix of short visits and block hours to meet the needs of the person and carer³⁶.

Given the constraints on the home care resource and in an attempt to meet increasing demands from population ageing, the focus of home care has, however, largely been on the provision of essential personal care assistance. Other countries in Europe (e.g. Denmark and the UK) have been faced with similar issues³⁷. A task-oriented approach presents two dilemmas which impact on recipients of home care generally, and have specific and significant repercussions for people with dementia.

Firstly, task-oriented care may not be the most appropriate care for a person. Home care hours providing short visits for personal care can leave little or no

²⁷ HSE (2018) Home Support Scheme for Older People. Information Booklet. <https://www.hse.ie/eng/home-support-services/home-support-services-information-booklet.pdf>

²⁸ Tarricone, R. and Tsouros, A. (2008) Home Care in Europe. World Health Organisation, Europe.

²⁹ https://www.lawreform.ie/_fileupload/Reports/r105Carers.pdf Paragraph 1.71

³⁰ Tarricone, R. and Tsouros, A. (2008) as above

³¹ Dempsey, C., Normand, C. and Timonen, V. (2016) Towards a more person-centred home care service: A study of preferences of older adults and home care workers. *Administration* 64 (2):109-136.

³² As above

³³ Daniol-Shaw, G. and Lada, E. (2011) "Work schedules of home care workers for the elderly in France: Fragmented work, deteriorating quality of care, detrimental health impact." *IOS Press* 40:531-546.

³⁴ Dempsey, C., Normand, C. and Timonen, V. (2016) as above

³⁵ Keogh et al (2018) Supporting Older People with Complex Needs at Home Report 1 Evaluation of the HSE intensive Home Care Package Initiative. Dublin : Genio. <https://cesrd.ie/wp-content/uploads/2019/11/Supporting-Older-People-with-Complex-Needs-at-Home-Report-1-Evaluation-of-the-HSE-Intensive-Home-care-Package-Initiative.pdf>

³⁶ As above

³⁷ Equality and Human Rights Commission (2011) *Close to Home: Inquiry into Older People and Human Rights in Home Care*. Manchester.

time for companionship, which has been identified as a key need in the life of an older person, and can result in home care workers carrying out the specific tasks for, rather than working with or 'doing with', the person³⁸. This can be disabling rather than enabling for the person, and may lead to a need for an even greater level of home care sooner than would otherwise be the case. For people with dementia, it is particularly important that home care, rather than simply addressing specific care tasks, enables the person to continue to use their own skills and maintain independence for as long as possible. For a person with dementia who is still physically able to do such tasks (maybe with prompting) it may be more appropriate to offer supervision, or support with social participation or with activities such as shopping. As non-task-oriented care is not typically available due to constraints, people with dementia can, as a result, receive no home care hours, leaving carers with little formal support and leaving people with dementia particularly vulnerable to exclusion and isolation.

The second dilemma is the portrayal of task-oriented care and personalised care as opposites. In a personalised approach, the quality of the care relationship, the interaction with the person and responsiveness to their wishes in terms of what is done, is central and applies to any support that is given, including personal care. For example, people can have different preferences for how their hair is washed and dried and a personalised approach would respect these and build them into the personal care for that individual. Communication is also key to establishing relationships and the public have recently indicated the value they attach to personalised communication between health care providers and people with dementia³⁹.

2.4 Personalised care

Personalised care is an *approach* to care, including home care, and not a service as such. There are four key elements (adapted from Wilberforce et al, 2017⁴⁰):

- Understanding the person
- Engaging the person in decision making around their own care
- Tailoring services based on needs and preferences (wide range of services)
- Promoting the care relationship

Personalised care '*reflects the degree to which services users/carers are involved in the processes of care planning through which support needs, care goals, preferences and available services are assessed and organised*' (p. 91), in other words, the extent to which the person's wishes shape decisions and care plans⁴¹. At the micro level, personalised care is evidenced in the direct care delivery and interpersonal exchanges between the home care workers and the person with dementia in completing tasks.

Personalised supports do not discount the range of clinical and medical services the person may need, but give equal weight to the range of supports and services required by the person in order to maintain abilities and skills thereby allowing the person to remain living well at home, connected to their families and communities⁴². Personalised community-based supports have been found to be beneficial to people across the spectrum of need^{43,44}. They have also been found to be effective in enabling people with advanced dementia and/or complex needs to remain living at home^{45,46}. International evidence has also shown that the best outcomes for people with dementia are associated with services that are timely, responsive, flexible and tailored to individual

need (Dawson et al. 2015). Although much of the research evidence is from studies on services for people with dementia, it could be argued that programmes which are effective with people with dementia are likely to be effective for people without dementia.

2.5 Scope of home care

A large number of respondents to the public consultation said that the home care service needs to be broader and not confined to a narrow range of tasks or set time allocation⁴⁷: "*The amount of time needed to support an older person to, for example, have a shower will vary depending on the individual, their physical and mental health and their cognition. The delivery of care needs to go beyond narrow definitions of the task e.g. provision of shower, to include social interaction where the home help can sit down and have a cup of tea and a chat as part of undertaking specific tasks. These types of things keep the person at home longer*" (submission from Advocacy body).

Services for possible inclusion in the statutory scheme were identified in submissions to the consultation. Other organisations, such as HCCI, have also described what could potentially be in the 'basket of services' for home care and evidence from Scotland on home based support for people with dementia suggest '8 pillars' of support. Combining suggestions from these sources results in a wide range of 'services', including:

- 'Home care' such as: home help, personal care and domestic care
- Therapies and nursing such as: public health nursing, physiotherapy, speech and language therapy, occupational therapy, social work, dietician etc.
- Social care: emotional and social support, community connections
- Other services such as: home-based palliative care, day care, respite care, support for carers, personalised support, reablement, aids and appliances, assistive

technology, transport, night-time and weekend care, meals on wheels.

- Service coordination such as: case management, dementia care coordinator
- Services related to housing such as: supported housing; housing adaptation support, energy efficiency schemes

There are two important features of this list. Firstly, the broad and somewhat incoherent mix of: clinical/health services; social supports; housing services; and modes of organising services, and secondly, the lack of specification of services to meet particular needs.

One of the striking features of this list, and of much of the evidence on home care, is the confusion of services and the lack of specificity as to which needs services can or should address. One of the emerging findings from a recently completed Irish study on resource allocation for people with dementia is the lack of specificity around describing needs and explicitly linking needs to services. Instead, health and social care professionals (HSCPs) tended to frame needs in terms of existing services⁴⁸.

In this context, one of the key issues to be considered in the new Home Care Scheme is what specific services are to be included within the remit of the scheme. A very wide range of services could have significant cost implications, but a very narrow range of services, might fail to meet important needs of home care users, such as the need for companionship and social connection. An additional question to be considered is what organisations are best placed to provide and fund specific services, to a quality standard and in a cost-effective way. A balance also needs to be struck between, on the one hand, addressing the immediate imperative to improve existing home care services and to establish the new scheme by 2021, and, on the other hand, to support the delivery of person-centred, integrated community care on a sustainable basis. Recognising that the improved coordination of health

³⁸ Dempsey, C., Normand, C. and Timonen, V. (2016) as above

³⁹ Walsh et al above

⁴⁰ Wilberforce, M, Challis, D., Davies, L., Kelly, MP., Roberts, C. and Clarkson, P. (2017) "Person-centredness in the community care of older people: A literature-based concept synthesis" *International Journal of Social Welfare* 26:86-98.

⁴¹ Wilberforce as above

⁴² Keogh, F. and Pierce, M. (2017) *Personalised care for people with dementia in Ireland*. In: O'Shea, E., Cahill, S. and Pierce, M. (2017) *Developing and Implementing Dementia Policy*. CESRD: Galway

⁴³ Cahill, S, Pierce, M. and Bobersky, A. (2014) *An Evaluation of Flexible Respite Options of the Living Well with Dementia Project in Stillorgan and Blackrock*. Dublin: Trinity College Dublin.

⁴⁴ Cahill, S, Pierce, M. and Bobersky, A. (2014b). *An Evaluation of the Dementia Support Worker Initiative of the 5 Steps to Living Well with Dementia in South Tipperary Project*. Dublin: Trinity College Dublin.

⁴⁵ Keogh et al (2018) as above

⁴⁶ Brady, A., Ciblis, A., Hynes, G., Keogh, B., Daly, L., Kennelly, B., Bracken-Scally, M. & McCarron, M. b. (2017). *Evaluation of the Memory Matters Carlow/Kilkenny Community Dementia Project*. Dublin: Trinity Centre for Practice and Healthcare Innovation, School of Nursing and Midwifery, Trinity College Dublin

⁴⁷ Institute of Public Health in Ireland (2018).

⁴⁸ Keogh, F., Pierce, T. and O'Shea, E. in preparation

and social care through ‘an integrated care system’ will be ‘needed to meet the needs of our older population, with its more complex set of clinical and social care needs’, the *Sláintecare Report* also calls for ‘a new model of integrated care’ that ‘puts the person at the centre of system design and delivery’.⁴⁹

2.6 Thinking of needs rather than services

In order to introduce clarity and specificity into a consideration of the scope of home care, Figure 2 below sets out the range of needs which are relevant when supporting an older person at home. These are then linked to services and supports which typically meet that need. We deliberately do not subsume needs into a service such as ‘home help’ (which anyway has different meanings depending on who the provider is and where in the country it’s being provided). However, before needs are considered, the setting has to be fit for purpose. In this case, the setting is the person’s home - where the person typically resides, which may need to be adapted so the person can continue living there. ‘Home’, may also include a supported or assisted living setting. If the person’s home is not suitable, no amount of home supports will enable the person to remain at home. A number of enablers of the home setting are also described, such as universal design, adaptations and technology. The health system currently has little role in the provision of these supports (beyond the provision of referrals and OT assessments), although they have a crucial role in enabling home care.

Needs are described under six headings:

1. Support with Activities of Daily Living (ADLs) – these activities typically include eating, bathing, dressing, toileting, mobility, and grooming.
2. Support with Instrumental Activities of Daily Living (IADLs) - including managing finances, handling transportation, shopping, preparing meals, using the telephone or other communication devices, managing medications and doing housework.
3. Support for living well – such as Information, Advice, Peer support, Social contact, Meaningful activity, exercise, day care etc.
4. Support with clinical/health needs – e.g. physiotherapy to maintain mobility, dietician to address swallowing difficulty, PHN for wound care, etc.
5. Services that support carers e.g. support with ADLs and IADLs for the care recipient, information, advice, a break, peer support, support to continue working, emotional, psychological support, etc.
6. Specialist support: e.g. palliative care, dementia care, mental health, diabetes care.

The provision of one service, such as home support hours for ADLs, may meet the needs of more than one person (i.e. the care recipient and the family carer); and one ‘service’ may meet more than one need. For example, a visit from a PHN or other HSCP may meet a clinical need but might also meet an information/advice need and may provide emotional support to the carer. Other essential features of home care such as quality and care coordination are considered in other sections of this document.

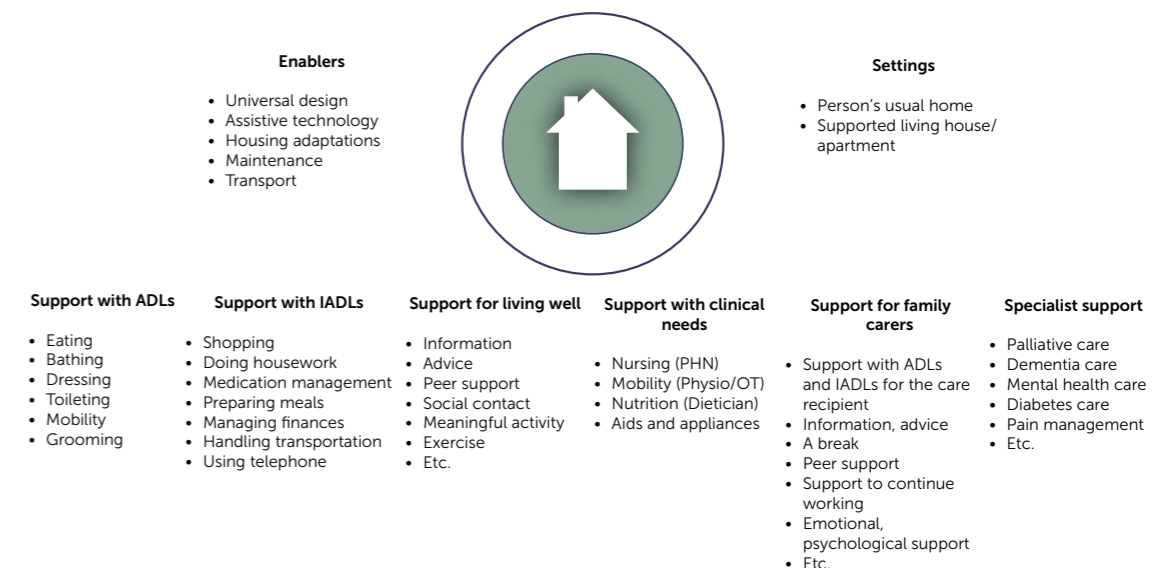
2.7 The home setting

Home care is normally provided to an older person in their own home. Sometimes, however, it may make sense for older people with support needs, to move from their current home to live in more supported accommodation. This is sometimes called supported living, housing with supports, housing with care, or independent living with care facilities. Housing with supports can play a huge role in supporting dependent older people to live independently, offering a practical response to many people who can no longer live in their own homes, but who do not require nursing home care. The availability of high support sheltered housing may also have potential to provide alternative accommodation for some people with dementia, as recently outlined in a report for the National Dementia Office⁵⁰. The issues in this discussion document refer to traditional home care mainly, but apply equally to all parts of the housing with supports continuum.

2.8 Questions for discussion

1. What needs should be covered in the home care scheme?
2. The Department of Health’s commitment to the introduction of the new home care scheme in 2021 reflects the urgent need to address the problems with current service provision (including the short-fall in service provision, the ‘postcode lottery’ and the lack of regulation). Recognising the challenge this represents, how can we best ensure that people with care needs receive integrated, person-centred health and social care services across the continuum of care.

Figure 2: Enablers, needs and services to support home care



⁴⁹ Oireachtas Committee on the Future of Healthcare, *Sláintecare Report (2017)*. Dublin: Houses of the Oireachtas.

⁵⁰ O’Shea et al (2019) *The Continuum of Care for people with dementia in Ireland*. Tullamore: National Dementia Office. <https://cesrd.ie/wp-content/uploads/2019/11/The-Continuum-of-Care-for-People-with-Dementia-in-Ireland.pdf>

3

Care planning and
organisation of
care delivery3. Care planning and
organisation of care
delivery

3.1 Introduction

One of the central elements for the effective delivery of home care is a needs assessment process which determines needs in an objective and standardised way. The Single Assessment Tool is being rolled out in Ireland and it is the intention that this will provide the assessment for home care provision. While a standardised assessment of need is essential, equally important is the process which translates needs into an individualised care plan⁵¹. The care planning process presents an important opportunity for the person and family (if appropriate) to have a central role in co-designing a care plan based on the professional needs assessment.

This section of the discussion document focuses on elements of the care planning process and the organisation of care delivery that were highlighted in the public consultation. These processes are largely operational and so are relevant to the development of the service-delivery model for the statutory scheme, as well as to the development of the funding options presented to service-users. In addition, the principles underpinning individualised care-planning are of relevance to the design of the scheme, to the development of quality standards for home care, and to optimising outcomes for service-users.

3.2 Findings from the
public consultation

The public consultation highlighted several key features of home care delivery which respondents wished to see. These relate to (i) methods by which the person 'has a say' such as co-design, choice and so on; and (ii) ways in which home care should be organised and delivered such as being integrated, coordinated, holistic and individualised. These features are echoed in national and international evidence.

A theme running through the consultation responses was that people need to be at the heart of the design, delivery and evaluation of services: "...home care services require a more participatory co-design approach to involve all stakeholders, build trust between the carer and those being cared for, and not solely rely on a standardised, off-the-shelf package⁵²:"

The home care should be assessed with the family and the client included, most times the client doesn't have a say. [former home care assistant]". (p.38)

There was overwhelming support (over 90%) for recipients of home care having a say in the range of services that are provided and having a choice in the provider of their care (87%).

The lack of integration of services was also noted in the consultation:

"Overall, while there are individual stories where home care services work well, the experience of home care services in general point to the reality that they are ad hoc, piecemeal, fragmented, limited and lacking in flexibility..." [submission from advocacy body]

⁵¹ OECD and European Commission (2013) *A Good Life in Old Age? Monitoring and Improving Quality in Long-term Care*: OECD Health Policy Studies, OECD Publishing.

⁵² Institute of Public Health Report ref 4 above

One of the challenges is the range of services and agencies which may be involved in addressing the variety of needs described in Section 2.6. Many respondents to the public consultation wanted to see services better integrated through a multidisciplinary approach that brings the necessary services together at the point of delivery. Different coordination and liaison functions were proposed to link assessment, through to the type of care mix provided and to incorporate necessary services in housing, community-based programmes (especially around companionship and social connectedness) and transport. The need for a case management /key-working approach, whereby an individual would have a single, named point of contact in their primary care team co-ordinating multidisciplinary care planning and service delivery, is envisaged in the National Dementia Strategy⁵³, the Integrated Care Programme for Older People⁵⁴ and also in the Slaintecare Action Plan⁵⁵. The application of this type of function is dependent on the care needs of the individual and is typically used for more complex cases.

3.3 Evidence and guidelines on care planning and organisation of care

The National Institute of Clinical Excellence (NICE) has a detailed guideline on home care: *Delivering personal care and practical support to older people living in their own homes*⁵⁶. This guidance provides recommendations on several areas including: ensuring care is person-centred; providing information about care and support options; planning and reviewing home care and support.

Guidance on ensuring the provision of person-centred care includes, for example:

- 1.1.1 Ensure services support the aspirations, goals and priorities of each person, rather than providing 'one size fits all' services.
- 1.1.2 Ensure support focuses on what people can or would like to do to maintain their independence, not only on what they cannot do. Recognise: that people have preferences, aspirations and potential throughout their lives, and that people with cognitive impairment and those living alone might be at higher risk of having unmet social care-related quality of life needs or worse psychological outcomes.

The challenge of delivering services that support the goals and priorities of the recipient is recognised in the guidance, and practical resources are provided to assist. A practical issue is where the care recipient has communication difficulties or difficulties with decision-making capacity which present challenges to their participation in the care planning process. Communication tools and guidance on assisted decision making will be important to assist individuals. The full implementation of the Assisted Decision Making (Capacity) Act (2015)⁵⁷ will be important to provide guidance and practical assistance in this regard.

A recent comprehensive systematic review of 31 research studies⁵⁸ synthesised the evidence for the effectiveness of community-based interventions for older people in delaying or avoiding admission to residential care with a focus on identifying elements of interventions that were effective or not. Their main finding was that to reduce the risk of admission to residential care for older people requires multifactorial complex interventions rather than minimal, single-focus interventions. The review also helpfully identified the most common elements in the complex intervention studies which included:

- the use of a comprehensive assessment process with good communication and liaison with GPs.
- individualised care plans and interventions with frequent client contact if required.
- regular reviews.
- careful case management that included referrals to services not provided within the study intervention was also a common feature.
- developing skills and capacities within clients and/ or carers through education and training was a part of many complex intervention studies.

The review concluded that there was less clear evidence on who is best placed to deliver the assessment and case management, or whether there needs to be a multidisciplinary approach to service delivery.

There was a surprising low level of involvement of clients and/or carers in decision making given the emphasis in many policies and the preference for involvement demonstrated in other literature. Lukar et al (2019) note that it is likely that shared decision making will be required by future generations of older people as more informed consumers with higher expectations of services become care recipients. Shared decision making fits with consumer driven models and optimises autonomy for clients and their support network.

A review of the evidence on care planning for people with dementia identified similar elements to those identified in the Lukar et al (2019) review and identified practical aspects including the importance of everyone inputting into a single care plan and having one person responsible for coordinating and documenting assessments and planning⁵⁹. This review also identified the importance of gathering information from the person and family on the strategies and everyday activities of the person and including them in the care planning process. Several care planning tools were also identified; some are developed for people with dementia; some for people with disabilities; some for older people and it is important to use the most appropriate tool.

⁵³ Department of Health (2014) National Dementia Strategy. <https://assets.gov.ie/10870/3276adf5273f4a9aa67e7f3a970d9cb1.pdf>

⁵⁴ <https://www.hse.ie/eng/about/who/cspd/icp/older-persons/>

⁵⁵ <https://assets.gov.ie/22606/4e13c790cf31463491c2e878212e3c29.pdf>

⁵⁶ <https://www.nice.org.uk/guidance/ng21>

⁵⁷ <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>

⁵⁸ Luker, et al. (2019) The evidence for services to avoid or delay residential aged care admission: a systematic review. *BMC Geriatrics*. <https://doi.org/10.1186/s12877-019-1210-3>

⁵⁹ Moloney, et al (2018) Person centred assessment and care planning. *Gerontologist*, 2018, Vol. 58, No. S1, S32–S47 doi:10.1093/geront/gnx173

The review of Moloney et al (2018) noted that: *many persons living with dementia do not receive person-centred assessment and care planning because of programmatic, organisational, and regulatory requirements and professional and provider practices that reflect the needs of staff and settings, more than the needs of the person with dementia* (p. S43). This observation can be said to apply equally to older people and not just people with dementia. Five recommendations were made on assessment and care planning:

1. Perform regular, comprehensive person-centred assessments and timely interim assessments.
2. Use assessment as an opportunity for information gathering, relationship-building, education, and support.
3. Approach assessment and care planning with a collaborative, team approach.
4. Use documentation and communication systems to facilitate the delivery of person-centered information between all care providers.
5. Encourage advance planning to optimise physical, psychosocial and fiscal wellbeing and to increase awareness of all care options, including palliative care and hospice.

3.4 Organisation of care delivery – integration and coordination

Figure 1 in Section 2 of this document, illustrates the range of potential needs that may need to be addressed when supporting a person at home. These needs are met by a range of health services delivered through different divisions of the HSE; services provided through private and voluntary organisations which are funded by the HSE; other non-health services (such as transport); supports provided through community and voluntary organisations; and informal support from family, friends and neighbours. Depending on the complexity of need and the range of services required, coordinating services can be a significant undertaking.

Poor care integration is a main cause of dissatisfaction, leading to harmful events such as avoidable hospital re-admissions. Several initiatives from other jurisdictions were identified by the OECD as showing potential for improving care co-ordination in LTC, such as: i) good case management or primary-care co-ordinators in Japan and Sweden; ii) interdisciplinary care in Belgium, France and Portugal; iii) availability of integrated information system linking data through the continuum of care and portable across health and care settings as in Portugal; iv) multidisciplinary assessments teams, single-entry points as in the Netherlands and Sweden⁶⁰.

It is helpful to distinguish between 'integration' and 'care coordination'. There are at least 175 definitions of integrated care. The consensus is that successful integrated care is primarily about patient experience, although integration can occur across six dimensions⁶¹:

1. **Systemic** – the co-ordinating and aligning policies, rules and regulatory frameworks.
2. **Organisational** – the coordinating structures, governance systems and relationships across different organisations.
3. **Clinical/service** – how care services are coordinated.
4. **Informational** – the clinical and managerial information systems to support practice across different care settings.
5. **Financial** – the budgetary and payment systems in place across the participating organisations.
6. **Normative** – the extent to which mission, work values etc. are shared within a system.

Micro-level integration is about coordinating care for individual patients. The coordination of care needs to be explicitly addressed to avoid fragmentation or break-down in communication. Responsibility for micro-level care co-ordination is generally assigned to a specific individual or team, who may be a primary care provider, although, as much

care coordination activity is not medical, responsibility may be assigned to a specific care coordinator, such as a case manager. A shared care plan, to ensure everyone is working towards the same goals, may be used to facilitate coordination.

A key development in Ireland has been the Integrated Care Programme for Older People (ICPOP)⁶². The programme uses a 10-Step Framework at the core of which is a case management approach to integrated care. The aim of the programme is to develop and implement integrated services and pathways for older people with complex health and social care needs, shifting the delivery of care away from acute hospitals towards community based, planned and coordinated care. The objective of the programme is to improve the quality of life for older people by providing access to integrated care and support that is planned around their needs and choices, supporting them to live well in their own homes and communities.

3.5 Elements of the home care system

In summary, a number of desired features or elements of the home care system were highlighted in the public consultation. These are largely supported by research evidence and are summarised in the text box below. Some may be part of the home care scheme (such as standardised assessment of need) and others are enablers of good quality care – such as integrated systems of care.

Care organisation and delivery

- Standardised assessment of need
- Individualised care plan
- Case management/care coordination
- Integrated systems of care
- Regular review leading to changes in care plan as required

3.6 Questions for discussion

1. What methods can be used to ensure that the home care recipient and family carer (as appropriate) 'have a say' and are central to the care planning process?
2. Given that the funding provided by the state for home care, and the care-workers available to deliver it, are limited, how can we ensure that service-users' basic needs are met at the same time as providing choice (for example, in relation to the services provided or in relation to the provider)?
3. Recognising the breadth of the health and social care services on which people with care needs depend to live independently at home, how can we balance the standardisation of services with the need for flexibility and responsiveness to the needs of individuals and of individual communities?

⁶⁰ OECD and European Commission (2013) see footnote 51

⁶¹ Pike, B. and Mongan, D. (2014) *Integration of Health and Social Care services*. Health Research Board.

⁶² <https://www.hse.ie/eng/about/who/cspd/icp/older-persons/>

“how can we balance the standardisation of services with the importance of flexibility and tailored responsiveness to the needs of individuals and communities?”

4

Quality and regulation in home care



4. Quality and regulation in home care

4.1 Introduction

Quality in home care is important for several reasons—to protect vulnerable people from potential abuse; to ensure accountability for public spending; and to ensure that the service is responsive to the needs and wishes of care recipients⁶³. There is currently no statutory regulation to quality assure home care in Ireland and a consistent message from the consultation process on home care services was that a new system of regulation of home care needs to be developed⁶⁴. The components of a regulatory system described by respondents to the consultation and further identified in a HRB evidence review⁶⁵ included:

- developing a registration and licensing system for providers;
- developing standards;
- compliance processes to monitor and accredit provider performance;
- monitoring of outcomes for people using services;
- inspection and outcomes reports made publicly available;
- guidance/standards on training and qualifications for professional carers;
- developing a Code of Conduct for providers;
- taking enforcement action where service providers do not meet required standards;
- developing good practice for carers, families and home care providers.

It is essential that regulatory oversight of any service, including home care, is carried out by an independent authority. Many respondents to the consultation felt that the Health Information and Quality Authority (HIQA) had the necessary expertise and experience to carry out this function.

4.2 The Irish context

At present in Ireland there is no statutory regulation of home care services. However, as part of a suite of measures taken by the HSE's Older Persons' Services to quality-assure Exchequer-funded home care services, the National Guidelines and Procedures for the Standardised Implementation of the Home Care Package Scheme and the current national procurement framework⁶⁶ have made an important contribution to standardising service provision and to enhancing the accountability of home care providers. In addition, the providers of home care which are members of Home and Community Care Ireland (HCCI) are required to meet HCCI standards and are regularly audited by an independent inspector to ensure compliance.

Nevertheless, there is no regulatory oversight of many providers of home care, with no safeguards in place for people who procure home care independently from such providers. This absence of statutory regulation has contributed to the variation in service provision that can be seen across the country—both in terms of the services provided and the quality of these services. It is also reflected in the lack of quality standards and of mandatory training / qualifications for care-workers.

A key challenge that emerges in relation to the regulation of home care services in Ireland is the need to sustain the 'mixed economy of welfare' of public, private and voluntary providers on which the system depends, as well as to support family carers and to ensure that 'bottom-up' innovative approaches to home care provision are not stymied.

⁶³ OECD and European Commission (2013) see footnote 51

⁶⁴ Institute of Public Health in Ireland (2018) *Improving Home Care Services in Ireland: An Overview of the Findings of the Department of Health's Public Consultation*. Dublin: Institute of Public Health in Ireland.

⁶⁵ Kiersey, A., and Coleman, A. (2017). *Approaches to the Regulation and Financing of Home Care Services in Four European Countries: An Evidence Review*. Dublin: Health Research Board.

⁶⁶ <https://www.hse.ie/eng/services/list/4/olderpeople/national-guidelines-and-procedures-for-the-standardised-implementation-of-the-home-support-service-hss-guidelines.pdf>

4.3 Challenges

However, there are particular challenges in designing a regulatory system to support the provision of quality home care services, not

least the fact that there is no single 'location' of care, which is the basis of many regulatory systems. These challenges are described in the text box below.

Challenges in designing regulatory systems to support quality home care services

The home as a unique setting

Regulating home care presents unique challenges due to the nature of the setting as the clients' personal space - with the attendant vulnerabilities and boundaries - and the use of the home as a workplace for carers.

Standardisation vs. individualisation

Incentives designed to create desired behaviours among providers must be considered for the possibility of unintended consequences. There may be a tension between a drive for standardisation of practice and the need for flexibility to respond to an individual's needs^{67,68}. Many countries using standardised assessment distinguish clearly between the (standardised) process of assessment, and the (tailored) process of drawing up a care plan. This makes it possible to strike the right balance between standardisation of assessment and tailoring of care to individual needs and circumstances⁶⁹.

Measuring the right things

The literature indicates a need to consider the use of outcome based measures of quality (such as users' quality of life, choice and dignity) rather than input based measures

(such as labour and infrastructure) and processes such as care planning and safety measures^{70,71,72}.

Supporting quality

Researchers examining systems across Europe report that there can be a disconnect between legally mandated quality systems and supports and enabling measures – such as staff training, organisational development and funding of projects to promote continuous improvement within and between organisations⁷³.

Provision of consumer information

Consideration should be given to the translation of inspection reports into useful consumer information. In England, the Care Quality Commission provides consumer information - rating services across the following categories: safe, effective, caring, responsive and well-led⁷⁴.

Dynamic field

Quality in long-term care provision is a field under development and subject to challenge in other jurisdictions. In the UK both regulatory bodies⁷⁵ and respective quality and registration regulations / powers⁷⁶ have been changed several times in recent years.

Reproduced from: Timoney, A. (2018). *Spotlight: Home Care for Older People - Seven Policy Challenges*. Dublin: Oireachtas Library & Research Service. With additional material from OECD and European Commission (2013) *A Good Life in Old Age? Monitoring and Improving Quality in Long-term Care*; OECD Health Policy Studies, OECD Publishing.

⁶⁷ OECD and European Commission (2013) see footnote 51

⁶⁸ Leichsenring, K, Billings, J and Niews, H (Eds.) (2013) *Long-term care in Europe – Improving Policy and Practice*. Basingstoke: Palgrave Macmillan.

⁶⁹ OECD as above

⁷⁰ OECD as above

⁷¹ Leichsenring as above

⁷² Rodrigues, R., Leichsenring, K and Winkelmann, J. (2014) *The 'Make or Buy' Decision in Long Term Care: Lessons for Policy*. Vienna: European Centre for Social Welfare Policy and Research.

⁷³ Leichsenring as above

⁷⁴ See: <http://www.cqc.org.uk/content/ratings>

⁷⁵ See: House of Commons Library (2007) *Briefing Paper on the Health and Social Care Bill 2007-08; Research Paper 07/81*, 23 November 2007.

⁷⁶ See: House of Commons Library (2013) *Briefing paper on the Social Care Bill 2013 -14*, Research Paper 13/71, 11 December 2013. Also UK Department of Health (2014) *Care Bill becomes Care Act 2014; and Care Quality Commission (2009) Tough new powers for adult social care watchdog*.

The Department of Health would need to consider what service or activities it wishes to see regulated with careful definitions of the activities, for example, home care, respite care and so on. A definition of 'care' is also required, ideally one which is framed in such a way as to allow for future developments in care models. Legislation and regulation in this area should be 'future proofed' as far as possible, such that developments in technology and monitoring systems, for example, could be accommodated. The importance of avoiding a regulatory 'big bang' has also been highlighted by providers, who recommend a transitional period of 12 months to the enactment of new regulations⁷⁷. With a model of service provider inspection it will be challenging to monitor the direct views and experiences of care recipients. Germany, The Netherlands and Sweden use annual customer surveys and/or responses to specific complaints to supplement inspections of home care providers.

HIQA's view

Cognisant of the 'need to review and expand regulation to have oversight and provide public assurance on the different models of care and service delivery' (p.2), the Health Information and Quality Authority (HIQA) published a discussion paper exploring the regulation of health and social care services for older people⁷⁸. This paper reviewed models of care, regulatory models from a number of jurisdictions and held a number of discussion groups and was in favour of a regulatory model based around the registration of the service provider (rather than a location), with an accompanying suite of regulations tailored for different service types. The paper also suggested a model of primary registration with no need for re-registration. The advantages of this approach are summarised in the text box above.

The examples of how regulators in other jurisdictions define services show that most follow a model of registering or certifying the service provider as opposed to the physical location at which the service is provided. This approach offers a number of advantages:

1. It provides clarity to service users, providers and regulators.
2. Separate regulations can be tailored to the service model.
3. Service providers can be more flexible and innovative. For example, they could accommodate service users with different support needs in the same settings.
4. Administration would be reduced, both for the service provider and the regulator.

Reproduced from Health Information and Quality Authority. (2017b). Exploring the Regulation of Health and Social Care Services: Older People's Services. Dublin: HIQA.

4.5 Regulatory options

4.5.1 The Patient Safety Licensing Bill

One option for the regulation of home care services in Ireland is to incorporate them into the Patient Safety Licensing Bill. The general scheme of this Bill has been approved by Government and the Bill is currently being drafted. The Bill provides for the licensing of public and private hospitals, and the licensing of public and private designated health activities. Under this option, home-support services would be designated a "designated activity" and home support providers would be required to apply to HIQA for a licence to undertake home support activities. A person

could not carry on a home-support activity unless he or she was licensed to do so.

HIQA will be the licensing authority under the Patient Safety (Licensing) Bill, granting or refusing licence applications and enforcing the legislation. Requirements to be met by applicants for a licence and holders of a licence will be set out in the Bill and the Minister will make regulations setting out the standards of care which must be met.

4.5.2 Extend the remit of HIQA under the Health Act 2007

In its December 2011 Report on Legal Aspects of Professional Home Care, the Law Reform Commission recommended that section 8(1)(b) of the Health Act 2007 be amended to extend the functions of HIQA to include the setting of standards in relation to services provided by professional home care providers.

Under this option, the functions of HIQA could be extended to include the setting of standards in relation to services provided by professional home care providers. The definition of "designated centre" would be amended and the power of the Chief Inspector under section 41 of the Health Act would be extended to register and monitor all home care providers.

4.5.3 Regulate home care workers under the Health and Social Care (Professionals) Act (2005)

CORU is a multi-profession health regulator whose role is to protect the public by promoting high standards of professional conduct, education, training and competence through statutory registration of health and social care professionals. Protection of Title is an essential part of CORU's function to protect the public. Registrants are entitled to use the title

that is designated to their profession. It is a criminal offence for a non-registrant to use a protected title. Under this option for regulation, the inclusion of "home support worker" as a regulated profession under the Act would be explored.

4.6 Outcomes-based standards

There are limitations of regulation and monitoring of standards⁷⁹, specifically in the ways in which these processes can stifle innovation and encourage providers to focus only on what is regulated rather than on quality improvement. Scenarios can arise where care staff and providers might be complying with the technical terms of a contract but this does not necessarily mean that someone is experiencing high quality care⁸⁰. For example, the principle of personhood is the cornerstone of the Irish National Dementia Strategy, but it has been very difficult to operationalise the concept through new regulation and standards in relation to autonomy, communication and social inclusion. The move towards outcomes-based standards is the latest development in the ever-evolving quality and regulation landscape. The Scottish Health and Social Care Standards, published in 2017⁸¹, mark a fundamental shift in Scotland's policy and practice for care as they represent one set of standards to cover the whole care system⁸². These outcomes-based standards adopt a person-led approach and set out in some detail what human rights and wellbeing look and feel like for someone, irrespective of which part of the health and social care system they are using. The standards are described as "turning the traditional regulatory framework on its head by looking at standards from the perspective of a citizen experiencing care, rather than minimum requirements for a professional provider to meet"⁸³.

⁷⁷ Home and Community Care Ireland (2019) Providing More Citizens the Freedom to Live at Home: A road map to the statutory scheme for home care in Ireland. Dublin: HCCI

⁷⁸ Health Information and Quality Authority. (2017b). Exploring the Regulation of Health and Social Care Services: Older People's Services. Dublin: HIQA.

⁷⁹ OECD and Rodrigues as above

⁸⁰ Mathias, H. (2018) Scotland's Health and Social Care Standards. Care Inspectorate. Scotland. [https://www.careinspectorate.com/images/documents/4479/Scotlands's%20Health%20and%20Social%20Care%20Standards%20Journal%20-%20final.pdf](https://www.careinspectorate.com/images/documents/4479/Scotlands%20Health%20and%20Social%20Care%20Standards%20Journal%20-%20final.pdf)

⁸¹ Scottish Government (2017) Health and Social Care Standards. My support My Life. Scotland: The Scottish Government.

⁸² Mathias, H. (2018) as above

⁸³ pp. 1, Mathias, H. (2018) as above

4.7 Costs of regulation

An important challenge in designing a regulatory system is to successfully balance the benefits of regulation against the related costs. Regulatory systems involve considerable direct costs to the state in terms of maintaining a regulatory regime, costs falling on providers in terms of preparing for inspections and meeting the required standards, and the costs of outcome measurement and data collection systems⁸⁴. However, less visible costs of regulation include a loss of choice on the part of those cared for (for instance where only those with particular qualifications may be permitted to provide care) and the potential loss of small not-for-profit providers or paid relatives/friends as a source of care where the regulatory burden may cause them to cease providing care. While many jurisdictions, including Ireland, raise part of the cost of regulation and inspection from service providers, and some is paid for via insurers (e.g. in Germany), the bulk of the cost of a regulatory system falls on central or local government.

4.8 Stakeholder perspectives

Finally, any discussion of regulatory systems and quality in home care needs to be aware of the different focus on quality among different stakeholders as described in the text box above.

- People using services (and their families) would like to know what type of services, mix of services and what level of quality they can expect, in particular if there are several providers to choose from;
- Purchasers (regulators) are concerned to know what they pay for, in particular with rising public expenditures in long-term care;
- Providers are interested in how they perform against their competitors and/or to improve their bargaining position in relation to purchasers;
- Larger provider groups also use quality management for internal comparisons and improvements,
- Care workers might want to choose their workplace according to performance indicators of their employer.

Reproduced from: Rodrigues, R., Leichsenring, K and Winkelmann, J. (2014) The 'Make or Buy' Decision in Long Term Care: Lessons for Policy. Vienna: European Centre for Social Welfare Policy and Research.

These valid but varied perspectives underline the complexity of designing a regulatory system for home care.

“A key question is what should be regulated in home care services—providers (public, private, voluntary), care-workers, people’s homes, family-members providing care?”

4.9 Questions for discussion

1. Should home care services in Ireland be regulated?
2. What should be regulated in home care services—providers (public, private, voluntary), care-workers, people’s homes, family-members providing care?
3. What form should regulation take? Should it encompass quality standards, a register of care-workers, audits, user-satisfaction surveys, other quality-assurance mechanisms?
4. What should be measured – inputs, process and outcomes?
5. Who should pay for regulation—the taxpayer, service-users, providers, care-workers?
6. Should minimum standards of training/ qualifications for care-workers be introduced?
7. There are risks associated with the introduction of regulation—it could drive up the cost of services, reduce the pool of care-workers, or stifle innovative approaches to meeting care needs. How can these risks be minimised?

5

The financing of home care services

5. The financing of home care services

5.1 Introduction

With an ageing population, the financing of home care services represents a challenge internationally. The principal models through which home-support is financed are general taxation and social insurance.

General taxation has many advantages in that it is democratically accountable, universal, yields large amounts of money and it tends to be progressive, which means that the rich pay proportionately more than the less well off in society. However, older people seem to continually lose out in the allocation of scarce public resources collected through general taxation, particularly when it comes to funding community-based care. And even when resources do trickle down to older people, automatic entitlement is unusual and cost sharing in the form of co-payment rates for long-term care is the rule rather than the exception in many countries. In Australia, Denmark, England and Sweden, home care services are funded through taxation with means-tested co-payments for service-users. In Norway and Scotland, services are fully Exchequer funded but charges are levied for home help (assistance with domestic tasks).

An alternative option is long-term care social insurance, which is used in Germany and the Netherlands. Under a social insurance system, individuals pay into a fund over the life cycle, in return for automatic entitlement should they need benefits at some time in the future. Government can pay the premiums of those not in the labour market and inability to pay would not deny access to any new national scheme. A designated social insurance fund would allow for a more protected, community-based funding model than currently exists. It would also encourage transparency in priority-setting and service delivery. It would likely be more consumer oriented and consumer responsive than a

general taxation system. Social insurance organised through the labour market would, however, draw from a smaller contributory pool than the general taxation system. Back in 2002, when this was last examined in detail for Ireland, Mercer favoured a social insurance approach to funding long-stay care in Ireland arguing that it would generate additional resources and would establish a clear link between contribution and benefit⁸⁵. Their calculations suggested a one percentage point increase in both employer and employee PRSI contributions would, for example, yield approximately €725 million, not an inconsiderable amount, then or now. The key advantages of introducing a long-term care social insurance contribution noted by Mercer were: the ability of social insurance to support a standardised needs assessment; the creation of a bias in favour of home care; the separation of financing and service delivery; the end to the welfare stigma associated with means tests; and the provision of long-term stability to the financing regime. Cost would obviously be an issue and they acknowledged that there could be potential adverse effects on competitiveness from raising PRSI rates. The inter-departmental Report of the Long-term Care Working Group (2006)⁸⁶ concluded that a co-payment scheme by nursing home residents based on ability to pay, taking both income and assets into account, was the optimal approach to funding residential care. This model was subsequently adopted in the Fair Deal scheme.

5.2 The funding of home care in Ireland

A significant number of submissions to the Department of Health's public consultation process emphasised the need for increased investment in home care services⁸⁷. At present publicly-funded home care is provided free of charge on a fixed budget allocation. It is what is termed a 'supply-led' service – there is a certain amount of supply (determined by funding allocated each year) and it is rationed out (e.g. by using waiting lists or stretching the number of hours across

⁸⁵ Mercer (2002), *Study to Examine the Future Financing of Long-Term Care in Ireland*, Dublin: Mercer.

⁸⁶ <https://www.lenus.ie/bitstream/handle/10147/45733/8780.pdf?sequence=1&isAllowed=y>

⁸⁷ Institute of Public Health Report ref 4 above

clients). The report of the public consultation noted several requests for the introduction of a 'demand-led' scheme. This would mean that no matter how many people applied, assuming they met the entitlement criteria, their needs (however defined) would have to be met. Thus, the service must be provided notwithstanding any budgetary constraints.

Changes to the home care scheme, particularly around statutory entitlement, will require significant additional funding. The question of funding models for long-term care is beyond the scope of this paper and would require a Policy Dialogue of its own. Several papers and discussions have already been undertaken on potential funding models, for example, the Forum on Long-Term Care organised by Sage Advocacy and a document on financing long-term care in Ireland⁸⁸. The specific focus of this chapter is cost-sharing and co-payments for home care.

5.3 Context for co-payments – the Fair Deal scheme

In contrast to home care, Ireland has a well-established funding system for residential care, of which co-payments is a feature. The Nursing Home Support Scheme (Fair Deal) was introduced in 2009 to address care and funding issues in residential care in the country. The current Fair Deal budget is close to €1 billion annually. For those who choose to avail of the Scheme, there is significant assessment of care needs and economic means as part of the qualification process. Under Fair Deal, older people in residential care pay up to 80 per cent of their disposable income towards the cost of their care. They also pay up to 22.5 per cent of the value of their home, if their assets are over a certain limit, for the first three years of their care – 7.5 per cent annual contribution. The payment can be deferred and collected posthumously.

Cost sharing plays a significant role in the Fair Deal funding system for residential care. This is not surprising given the long-term budgetary implications of universal provision for long-stay care. A review of the NHSS found that increased public funding will be necessary to sustain the system, even with significant co-payments⁸⁹.

There are clear benefits associated with the Fair Deal scheme, even if all issues have not been resolved. Certainty and transparency are important advantages, relative to what existed before the introduction of the Scheme. Individuals know they will receive care until they die and that they have to contribute 80% of assessable income on an ongoing basis, which for most people is four fifths of their old age pension. Asset-related cost sharing can be deferred until after the death of the resident and further if there is a partner or certain dependents living in the principal residence. In general, people know that the State will cover approximately two thirds of the cost of long-stay care should they need it. The pressure on older people and their families to come up with the money to pay weekly payment rates of up to €1,000 has been considerably reduced. People do not face the prospect of having to sell their home to pay for care. The new arrangements has also reduced the potential of bad debts for private nursing homes, as there is now much less risk of default on payment, or of people being denied appropriate care as a result of default.

Criticisms of the Fair Deal scheme have been both practical and philosophical. The burdensome nature of the application process and the need for considerable information on both dependency and assets has been criticised and administrative changes have been recommended⁹⁰. There have also been philosophical objections to the Fair Deal scheme. At its simplest, this case rests on the view that care for older people should be free and universal, notwithstanding economic arguments that population ageing will impose significant

pressures on the public finances. The core argument is that older people in residential care are being discriminated against since health care for the general population in acute care is paid for out of general taxation, with minimal cost sharing. Critics question why should people be treated differently simply because of their age, condition or care setting? Opponents of this view point to the significantly longer length of stays in residential care and the difficulty of sustaining public funding for chronic conditions across many different patient groups in the longer-term.

5.4 Views on co-payments

5.4.1 Evidence from a discrete choice experiment

Researchers at NUI Galway have recently undertaken a discrete choice experiment (DCE) on personhood within home care for people with dementia in Ireland⁹¹. Over 500 members of the general public were interviewed as part of this research and five attributes of home care were examined. Personhood was incorporated into the experiment through two practical attributes, flexibility (two levels: high and low) and communication (two levels: personalised and standard), both of which were identified as essential and measurable elements of person-centred care. The third attribute was the number of publicly funded care hours provided to the person with dementia per week, ranging between 10, 15 and 20 hours of care, where usual care was set at 10 hours.

The fourth attribute related to co-payments by the person with dementia. Though co-payments for home care services are not currently in place in Ireland, they have been identified by policy-makers as a potential source of funding in the future reform of home care⁹². The co-payment attribute was defined based on approaches adopted internationally, whereby they can be either means-tested or compulsory⁹³. Finally,

a tax-based cost attribute incorporating both direct and indirect taxes was used to generate willingness to pay (WTP) values. Respondents indicated their support for attributes and levels through their willingness to pay additional taxation of between zero and €250 per annum.

The results indicate that members of the general public were willing to pay €109 per year in additional taxation for a home care system that provides highly personalised communication relative to standardised business-like communication, and €117 for a system that offers high flexibility relative to low flexibility. Regarding the number of home care hours per week, the public are willing to pay additional annual taxation of €77 for 15 hours, and an additional €116 for 20 hours of home care relative to 10 hours.

The WTP value showed that members of the general public were opposed to a compulsory co-payment for home care and they had no preferences between a means tested co-payment and no co-payment.

Overall the DCE study has shown that while welfare gains can be achieved by just increasing home care hours for people with dementia, higher gains are achievable by incorporating changes to the home care system that reflect a move towards person-centred care based on the principle of personhood, and these welfare gains persist even when a means-tested co-payment is introduced. It seems that the public are not against means tested co-payments as part of any new system of care that seeks to improve person-centred care for people with dementia⁹⁴.

5.4.2 Evidence from the Department of Health's Public Consultation on Home Care

The public consultation sought views on the introduction of means tested user-contributions for home care services; along

⁸⁸ https://www.sageadvocacy.ie/media/1538/sage-advocacy_summary-financing-long-term-care-in-ireland_2002019.pdf

⁸⁹ Department of Health (2015) Review of Nursing Homes Support Scheme. <https://assets.gov.ie/14095/f39a443d0a054c78a548d5fad8711df4.pdf>

⁹⁰ Deloitte and Touche Consultants (2015). Review of the nursing home support scheme: a fair deal. Dublin: Deloitte and Touche. <https://www.gov.ie/en/publication/6f512a-review-of-the-nursing-homes-support-scheme-a-fair-deal/>

⁹¹ Walsh, S., O'Shea, E., et al (2019) Public preferences for home care services for people with dementia: A discrete choice experiment on personhood. *Social Science and Medicine*, 245. <https://doi.org/10.1016/j.socscimed.2019.112675>

⁹² O'Shea et al., 2017 as above

⁹³ Kiersey and Coleman, 2017 as above

⁹⁴ Walsh et al, 2019 as above

with willingness to purchase additional hours of care if state-funded services were limited. The following question was asked:

Taking account of limited state resources, do you think that people who receive home care services should make a financial contribution to the cost based on their ability to pay? The majority of respondents to this question (57%, n=786) felt that older people should make a financial contribution, with 32% (n=444) rejecting the proposition, and the remaining 11% (n=149) indicating that they did not know.

Amongst those respondents who indicated their support for the introduction of user contributions, there was broad consensus that such a funding model would be more equitable than the current system, ensuring that those without the financial means to contribute would receive the care that they required.

A wide range of views were expressed about how means testing should be implemented, including:

- the introduction of a minimum income threshold, beneath which service users would not have to contribute;
- the introduction of a maximum expenditure threshold above which no contribution would be required;
- user contributions required to be assessed on a case-by-case basis;
- user contributions only to be sought from those in the highest tax bracket;
- user contributions to be cognisant of the contributions (through taxation and national insurance) made by a service user throughout their life.

Interestingly, and in support of the DCE results referenced above, there were also suggestions that means tested user contributions could only be legitimately introduced if the service provided was comprehensive and of a high quality, and if service users were given a choice of carer and influence over the services provided.

There was also support among respondents for the position that home care should be freely available to everyone at the point of use. A number of respondents argued that since older people have paid taxes throughout their lives to support others, they should, in turn, be cared for by the State. Others indicated that the introduction of user contributions would increase the incidence of poverty; or would create a risk that a person with limited resources may forgo services, and as a consequence, cost the State more for acute-care provision. There is a large health policy literature showing that cost sharing decreases use⁹⁵, most notably the RAND Health Insurance Experiment which found that increased cost sharing reduced aggregate health care spending and use⁹⁶. However, a more recent study in the impact of cost sharing on the use of home health services among older adults in a specific Medicare plan in the USA did not lead to significantly lower use, but may have added to the burden of out-of-pocket spending among frail older adults⁹⁷.

5.4.3 Evidence from survey by Home and Community Care Ireland (HCCI)

HCCI commissioned iReach Insights to carry out an online survey of a nationally representative sample of the Irish adult population⁹⁸. Among the questions asked was: How much would you be prepared to contribute to a Homecare package at home? If it costs the government €30 per hour in total to provide homecare – i.e. for a carer to come to your home assisting you with personal care needs and household chores, etc. – what percentage of this total cost would you be willing to contribute? Respondents were prepared to contribute, on average, 19% of the cost – equivalent to roughly €5.70 an hour. Nevertheless, many respondents responded that they would pay less than 19%.

5.4.4 Recommendations of the Citizen's Assembly

The second topic considered by the Citizens' Assembly in 2017 was *How We Best Respond to the Challenges and Opportunities of an Ageing Population*⁹⁹. A total of 16 wide-ranging recommendations were made by the Assembly; eight related to long-term care and seven to pensions. The results of the voting on the long-term care ballots are shown in **Table 3**. All of the votes are interesting in the context of the topics being covered at the Policy Dialogue, but it is worth pointing out the strong support for prioritising home care (Rec 4) through additional funding generated through a new compulsory social insurance payment (Rec 5).

5.5 Questions for discussion

1. What funding model should be used to underpin Ireland's new home care scheme?
2. Should the state take full responsibility for the provision of the home care required by people with care needs, or should those with means above a threshold assume responsibility for their own care?
3. Should co-payments form part of the funding model for home care?
4. If co-payments are introduced should they be means-tested or not?
5. Should the care provided by families be taken into account in this model?

“There was strong support from the Citizen's Assembly in 2017 for prioritising home care using additional funding generated through a new compulsory social insurance payment”

⁹⁵ Grabowski, D. (2017). Cost Sharing and Home Health Care. *JAMA Internal Medicine. Health Care Policy and Law*.177 (7):1018-1019. doi: 10.1001/jamainternmed.2017.1077.

⁹⁶ Newhouse, J. (1981) *The Demand for Medical Care Services: A Retrospect and Prospect*, in van der Gaag, J. and Perlman, M. (eds.) (1981) *Health, Economics, and Health Economics*, eds. Amsterdam: North-Holland.

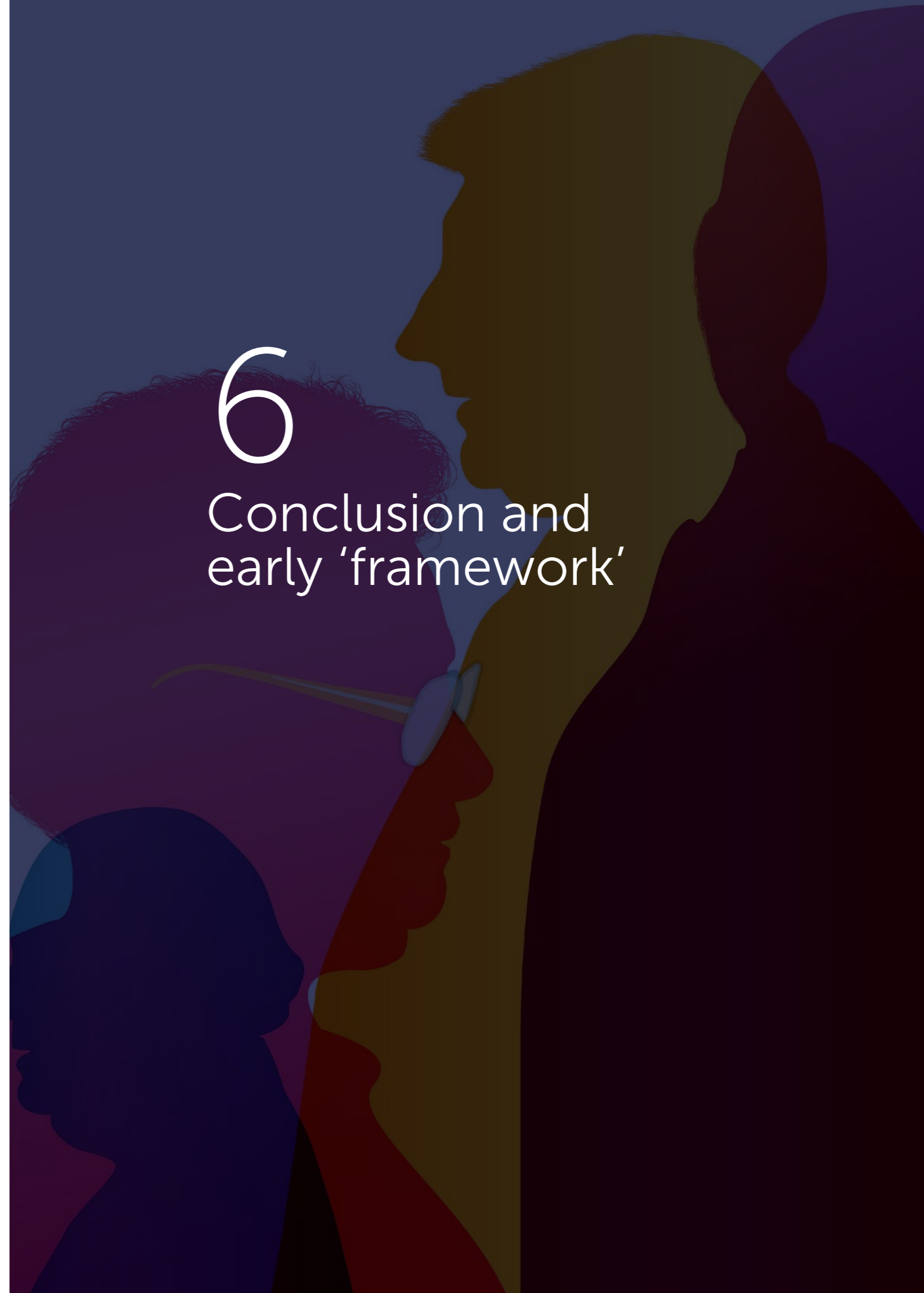
⁹⁷ Li, Q. et al (2017). Association of cost sharing with use of home health services among Medicare advantage enrollees. *JAMA Internal Medicine. Health Care Policy and Law*.177 (7):1012-1018. doi:10.1001/jamainternmed.2017.1058.

⁹⁸ Home and Community Care Ireland (2019) *Providing More Citizens the Freedom to Live at Home: A road map to the statutory scheme for home care in Ireland*. Dublin: HCCI

⁹⁹ <https://www.citizensassembly.ie/en/How-we-best-respond-to-challenges-and-opportunities-of-an-ageing-population/Final-Report-on-how-we-best-respond-to-the-challenges-and-opportunities-of-an-ageing-population/Final-Report-on-Older-People-Incl-Appendix-A-D.pdf>

Table 3: Votes of the Citizen’s Assembly on Long-Term Care

Recommendation	Ballot Proposition	% of Assembly Voting in Favour
Recommendation 1	That Government should urgently prioritise and implement existing policies and strategies in relation to older people including, for example, the National Positive Ageing Strategy, the Carers Strategy and the National Dementia Strategy	100%
Recommendation 2	That the family/older person should be principally responsible for providing required care for older people, but that the State should have at least some responsibility.	60%
Recommendation 3	That there should be an increase in public resources allocated for the care of older people.	87%
Recommendation 4	That additional funding for care of older people should primarily be spent on home care services and supports.	Ranked 1st
Recommendation 5	That overall funding for the care of older people should come from a compulsory social insurance payment – an earmarked tax for all workers linked to labour market participation – not unlike the current PRSI mechanism to fund long-term/social care for older people.	Ranked 1st of 4 options
Recommendation 6	That the Government should expedite the current commitment to place homecare for older persons on a statutory footing.	99%
Recommendation 7	That regulation, such as that currently in place for residential centres, should be extended to afford better protection to older people in receipt of all health and care services.	99%
Recommendation 8	That, if the Government were to decide to extend regulation to other health and care services for older people, the following services should be regulated:- <ul style="list-style-type: none"> • Respite services (90%) • Day care services (87%) • Care and support services delivered by service providers in a person’s own home (92%) • Care and support services provided through a supported housing scheme (91%). 	



6

Conclusion and early 'framework'

6. Conclusion and early 'framework'

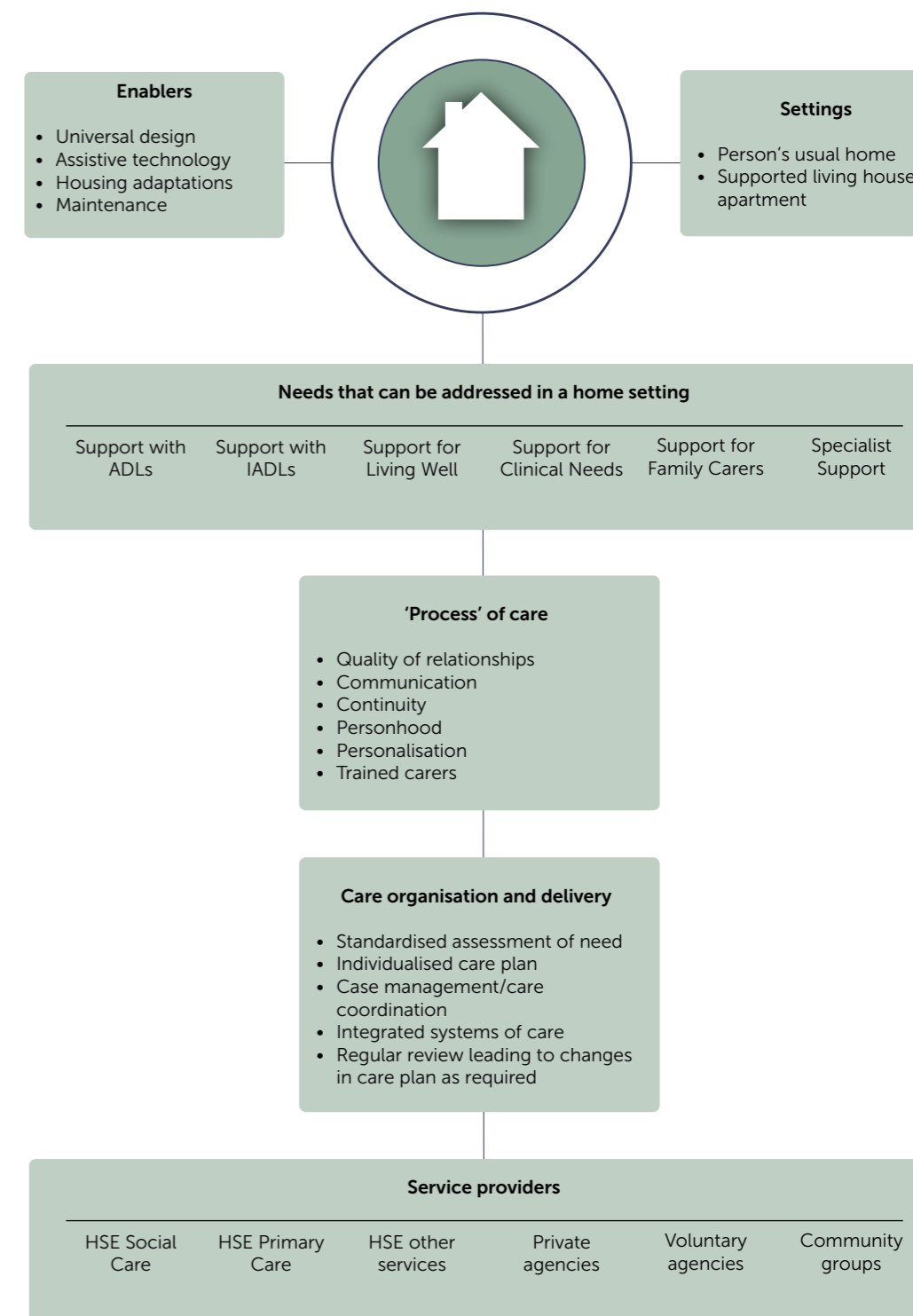
Our understanding of home care has moved on quite significantly since the *Care of the Aged Report* in 1968 when home help services were offered "by a small number of pioneering voluntary organisations"¹⁰⁰. Our understanding of home support is continually evolving, as new services and innovations test the limits of what can be achieved in enabling people, sometimes with complex support needs, to remain at home. The commitment in the Department of Health to develop a new home care scheme, is a recognition of the significant transformation of home support that has occurred and the need to create a funding and regulatory system which can address current challenges, along with the need to create a platform which will support further development into the future.

Although this discussion document only addresses some areas of home care, it is apparent that the home care/home support landscape is a complex one. The framework in Figure 3 is an attempt to provide an overview, in one diagram, of the elements, processes and providers of different types of care for older people in a home setting. We hesitate to call it a framework, as it is not a comprehensive representation of every aspect of home care, and crucially, it does not capture the dynamic nature of home care/home support.

Nevertheless, it is a beginning in terms of capturing and describing in a systematic way, an understanding of what 'home care' or 'home support' in Ireland might encompass. The framework describes what needs may be addressed in a home setting; what enablers may be physically required in order to make the home setting amenable to the support of dependent older people; what the process of care might be; how home support can be organised and the main providers in the landscape. These, and other, issues will be further elaborated and discussed at the Policy Dialogue.

100 Robins, J. (1988) *The Years Ahead: a policy for the elderly*. Dublin: Report of the Working Party on Services of the Elderly. <https://www.lenus.ie/handle/10147/46365>

Figure 2: Potential Home Care Framework



Appendix 1

Dementia Policy Café “A voice for people with dementia”

The *Dementia Policy Café* brought together a group of people with dementia to discuss research findings from the Centre for Economic and Social Research on Dementia (CESRD) and to develop their own key messages for policy makers. The Policy Café took place on Tuesday the 9th of March in the Ashling Hotel in Dublin.

The CESRD worked with the Alzheimer Society of Ireland and the Irish Dementia Working Group to bring ten people with dementia together. The idea for the Policy Café and the topics discussed came from regular interactions with people with dementia over the past number of years. The topics that were discussed focused on diagnosis and support after diagnosis, and experience of home or community-based supports.

An adapted World Café format ensured the Café was highly participative and an illustrator captured the key messages in a visual format which was very accessible. The proceedings were also filmed so that the voice of the participants could be disseminated directly. Following the discussion of each topic, participants selected the themes and messages they wanted to be recorded:

Home care

- Model of home care: social health
 - Help with activities and community involvement
 - Tailored to the person, look beyond symptoms, provides the assistance the person wants and needs
 - Flexible and responsive
 - Support to keep healthy, connected, active and social
 - Support ‘in time and at the right time’
 - Our voices and our choices
 - Vital role of the community for the continuum of care

- Pathway of care to be clear
- Carers to be trained/skilled (e.g. empathetic, confidential, sensitive, understand dementia and comorbidities)
- Information and support for family carers
- Adapting the house for the person
- Transport is essential
- Ring-fenced funding – allocate resources to need
- Strong policy and Bill of Rights for dementia
 - NB for under 65

Diagnosis

- Public Awareness
 - Reduce stigma (and fear-based stigma)
 - Increase training
- Personalised Diagnosis
 - Trained personnel to make and impart diagnosis
 - Ask person and family what their challenges are
 - Give hope, use appropriate language
 - Enable and empower person
- Proactively link person to services after diagnosis
 - Personalised and appropriate information
 - Age appropriate information/services
- Social Supports
 - (appropriate) peer-support
 - Normalised living
- Interdisciplinary team (including person themselves) and dementia diagnosis support team
- Timely diagnosis
- Right to know diagnosis
 - Not knowing prevents obtaining services
- Citizenship
 - Part of society
 - Inclusive
 - Being part of our community
 - Conflict between dementia focused and being inclusive

Appendix 2

The Carers’ Assembly was organised by the Centre for Economic and Social Research on Dementia (CESRD) at NUI Galway on 19th October 2019 in the Connacht Hotel. The aim of the Carers’ Assembly was to hear the views of family carers of people with dementia in relation to dementia care in Ireland.

During the Carers’ Assembly, 30 family carers, drawn from a variety of sources, listened to four presentations on the following themes: homecare services, respite care, social support and economic support. Family carers discussed the evidence highlighted in the presentations and then completed a ranking exercise within and across the four themes.

A ballot on the topics contained within each theme was put to carers attending on the day for a private vote. The topics considered under each theme were generated from evidence-based research and suggestions made by family carers on the day. Carers were also asked to rank the four themes addressed on the day in order of importance to them.

The ballot exercise was overseen by an Advisory Panel consisting of representatives from a number of carer and dementia organisations including: Care Alliance Ireland, The Alzheimer Society of Ireland, Family Carers Ireland and Western Alzheimers.

The four themes addressed on the day were ranked in order of priority and policy relevance by carers through a private ballot. The result of this ballot was as follows:

Ranking	Theme
1	Homecare services
2	Economic support
3	Respite care
4	Social support

Within the homecare services theme, the priority topic, as voted by carers, was: dementia-specific training for both family carers and professional carers providing homecare support within the home.

Under the economic theme, the priority topic, as voted by carers, was non-means tested Carer’s Allowance, defined as automatic entitlement to financial support for anyone providing full-time care to a person with dementia.

For the respite care theme, the priority topic, as voted by carers, was in-home respite, defined as short term respite, two or three hours, where a person comes into the home to sit with the person with dementia to give the carer a break, or the opportunity to run errands outside the home.

For the social support theme, the priority topic, as voted by carers, was information for carers, provided at the right time, in the right place, using the right medium (this includes media campaigns and digital technology).

The main ballot results from the Carer’s Assembly will be presented at a Policy Dialogue of key stakeholders in December 2019. A full report on the Assembly will be published by the CESRD in the Spring of 2020.

Year: 2019
Publisher: NUI Galway.
ISBN: 978-1-908358-82-0

This research was funded by the Health Research Board.