



OÉ Gaillimh  
NUI Galway



Centre for **Economic  
and Social Research  
on Dementia**

# Report of the Policy Dialogue on the New Home Care Scheme

August 2020

**Fiona Keogh and Eamon O'Shea,**  
Centre for Economic and Social Research on Dementia



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# Foreword

Successive Governments have been committed to enable people to age with confidence, security and dignity in their own homes and communities for as long as possible—a commitment articulated in the *National Positive Ageing Strategy* (2013) and the *Irish National Dementia Strategy* (2014) amongst other reports. Likewise, the *National Disability Inclusion Strategy 2017–2021* (2017) recognises the right of people with disabilities ‘to live ordinary lives in ordinary places’. The Department of Health and the Department of Housing, Planning and Local Government’s *Housing Options for our Ageing Population: Policy Statement* (2019) recognises the need to develop a wider range of housing options to enable older people with care-needs to live independently. Recent research undertaken in Ireland has shown that it is older people’s preference to continue to live at home and to receive care there when needed—a preference also voiced in the Department of Health’s public consultation on home care services, conducted in 2017.

That home-support services play a vitally important role in realising this ambition is reflected in the Department of Health’s *Sláintecare Implementation Strategy* (2018), which identifies the expansion ‘of community-based care to bring care closer to home’ as a strategic priority. Accordingly, within the broader context of the implementation of the *Sláintecare* reform of our health and social care system, the Department is currently developing a new statutory scheme for the financing and regulation of home-support services. The delivery of the right care in the right place at the right

time across the continuum of care, and the re-orientation of the model of care towards primary and community care, are central to this reform process. The new home-support scheme will make an important contribution to *Sláintecare* implementation.

Designing a new statutory scheme for the financing and regulation of the home-support services scheme which will address the challenges associated with current service-provision while also building on existing good practice represents a complex undertaking. The Department of Health is committed to developing a system which will provide responsive, integrated, person-centred care to all citizens in accordance with their assessed care-needs in the years and decades to come. While the Department’s leading role in responding to the COVID-19 pandemic, and the diversion of resources to support this, will unavoidably delay the introduction of the statutory scheme, its development remains a strategic priority. Furthermore, we will ensure that the design of the scheme is cognisant of the lessons learnt through the community response to the crisis.

Building the evidence-base for the development of the new scheme is fundamental to ensuring the success of the reforms that we implement. For the Department, this is work-in-progress to which the report commissioned from the Health Research Board, *Approaches to the Regulation and Financing of Home Care Services in Four European Countries: An Evidence Review* (2017) and the Institute of Public Health’s report, *Improving Home Care Services*

*in Ireland: An Overview of the Findings of the Department of Health’s Public Consultation* (2018), made an important contribution.

This report on the Policy Dialogue which the Centre for Economic and Social Research on Dementia (CESRD) hosted in partnership with the Department of Health in December 2019, further enhances this evidence-base. With a focus on older people, the Policy Dialogue provided an opportunity for us to gain insight into the perspectives of a range of stakeholders on key aspects of the scheme—its scope, care-planning and organisation, regulation, and funding. The rich seam of qualitative research presented in this report will help us to ensure that the scheme developed is responsive to stakeholders’ views.

I would like to thank Dr Fiona Keogh and Professor Eamon O’Shea for their invaluable assistance with the design and organisation of the Policy Dialogue and for compiling this report. I would also like to express my appreciation to the participants in the Policy Dialogue for giving of their time and expertise. We look forward to continued engagement with all stakeholders throughout the development of the new scheme.

**Dr Kathleen Mac Lellan,  
Assistant Secretary,  
Social Care Division,  
Department of Health.**



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# 1 Context



## 1 Context

### 1.1 Background to the Policy Dialogue

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 Centre has a particular focus on policy impact and contacted the Department of Health with a view to testing an approach to facilitating discussion on important policy issues, called Policy Dialogue. The Department agreed to collaborate on a Policy Dialogue to discuss some of the key issues relating to the development of a new home care scheme in Ireland, with a specific focus on older people.

Enabling older people to continue to live independently at home for as long as possible is a long-standing objective of social policy in Ireland. To advance this, the present 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 evidence, emerging good practice across the current system of health and social care delivery, the Health Service Executive's (HSE) continual enhancement of existing service-provision and the range of views from stakeholders in this area.

In preparation for the development of the new home care scheme, the Department of Health commissioned the Health Research Board to carry out a review of the home care systems in four European countries, published in April 2017<sup>1</sup>, and conducted a public consultation on home care services, on which a report was published in 2018<sup>2</sup>. 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 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, at the time of the Policy Dialogue, the Department was 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 was to be implemented in selected sites across the country in 2020. However, this work has subsequently been paused due to the diversion of resources, as part of the response to COVID-19. The Department of Health's *Sláintecare Implementation Strategy* (2018) commits to the introduction of the statutory scheme in 2021.

As a contribution to the debate, the CESRD organised a Policy Dialogue focusing on older people and people with dementia with the involvement of key stakeholders nationally. A Policy Dialogue is a structured dialogue 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. It 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"*<sup>3</sup>. Given the focus on bringing evidence to bear on policy development, the CESRD convened the Dialogue as an agency with no political or regulatory 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.

In preparation for the Policy Dialogue a discussion document was prepared for participants providing an overview of home care in Ireland and the issues to be discussed (Keogh and O'Shea, 2019)<sup>4</sup>. This document was circulated in advance of the event, along with two short films; one outlining the discussion 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' for home care and to be creative, the Policy Dialogue was held under the Chatham House Rule<sup>5</sup> to aid free discussion of sensitive issues and to provide 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.

### 1.2 Scope and aim of the Policy Dialogue

Four topics were 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 care stay largely as it is and focus predominantly on personal care needs, or should it cover a wider range of social and psychosocial needs and/or include clinical care?
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?
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?

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?

These four topics were selected for the following reasons. Firstly, they are key features of home care which emerged from the public consultation on home care undertaken by the Department of Health<sup>6</sup>. Secondly, some of the issues emerged in related events organised by the CESRD and are described in the discussion document for the Policy Dialogue: a policy symposium, a dementia Policy Café and a Carer's Assembly. Thirdly, many of the issues are the subject of research in the CESRD, for example, issues which emerged in a report by CESRD on the continuum of care for people with dementia in Ireland<sup>7</sup>. Fourthly, they are issues which are being considered by 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 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.

Participants for the Policy Dialogue were selected to include a range of perspectives: service users; advocacy groups; academics; service providers; and government departments. Considering this range of perspectives, the goal of the dialogue was to obtain participants' views on the four topics referenced above (with a particular focus on older people and people with dementia) and, through open discussion, provide further insight into what consensus might look like in these areas. These discussions in the dialogue were recorded in notes and are summarised here as the main output from the event. It is intended that this report will inform the development of the new scheme as well as enriching the evidence-base for research in this area in Ireland.

<sup>1</sup> Kiersey, R.A and Coleman, A. (2017) [https://www.hrb.ie/fileadmin/publications\\_files/Approaches\\_to\\_the\\_regulation\\_and\\_financing\\_of\\_home\\_care\\_services\\_in\\_four\\_European\\_countries.pdf](https://www.hrb.ie/fileadmin/publications_files/Approaches_to_the_regulation_and_financing_of_home_care_services_in_four_European_countries.pdf)

<sup>2</sup> 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. <https://www.gov.ie/en/publication/601dbf-report-on-the-findings-of-the-public-consultation-on-home-care-servi/>.

<sup>3</sup> 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>

<sup>4</sup> Keogh, F. & O'Shea, E. (2019) *Policy Dialogue on the New Home Care Scheme: Discussion Document*. Galway: NUI Galway. [https://cesrd.ie/?page\\_id=141](https://cesrd.ie/?page_id=141)

<sup>5</sup> <https://www.chathamhouse.org/chatham-house-rule>

<sup>6</sup> See Reference 2 above - Institute of Public Health Report

<sup>7</sup> O'Shea, E., Keogh, F. & Cooney, A. (2019). *The Continuum of Care for People with dementia in Ireland*. Tullamore: National Dementia Office.

# 2

## Description of the Policy Dialogue

### 2. Description of the Policy Dialogue

The Policy Dialogue was held on 12th December 2019 in the National University of Ireland building in Dublin. In order to have in-depth discussions on the topics and to ensure a variety of voices were included, 32 people were invited to participate from across a number of sectors. Twenty five attended from the following areas: policy making (10), people using services (4), HSE and service providers (5), NGOs (4) and researchers (2). The participants were divided into four groups with a mix of different stakeholders in each group. There was a facilitator and a note-taker from NUI Galway at each table. All the facilitators were researchers with experience in research with older people and/or people with dementia. During the course of the day members of the groups switched around so that different perspectives could be shared in different groups.

All invitees were sent documents and films in advance to help them to prepare to participate as fully as possible. Materials included:

- A short film describing what a Policy Dialogue is and what is involved [Policy Dialogue Introduction](#)
- A discussion document which set out the context of home care in Ireland and summarised material relevant for discussion of the four topic areas <https://www.gov.ie/en/publications-and-resources/publication/2019-12-12-policy-dialogue-on-the-new-home-care-scheme/> (Keogh and O'Shea, 2019)
- A short animated film describing the topics to be discussed [Policy Dialogue Animation](#)

In order to include the voice of people using home care services as much as possible throughout the event, two short films featuring people with dementia and their views on home care were shown on the day and can be seen here: [Kathy and Marguerite](#) and [Kevin's story](#).

The Policy Dialogue began with brief presentations by the Department of Health and the CESRD. The day was divided into four sessions to discuss each of the four

areas; the home care continuum; the planning, organisation and delivery of home care; quality and regulation; and the financing of home care. The discussions from each session are summarised here.

“A Policy Dialogue is a structured dialogue 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”



# 3

## Home care continuum

### 3. Home care continuum

The main questions discussed at this session were (i) a consideration of the potential scope of the new home care scheme in terms of the needs to be covered and (ii) how can we best ensure that people with care needs receive integrated, person-centred health and social care services across the continuum of care. While the discussion in this session was very wide ranging, the fundamental aim of the scheme, to provide a statutory basis for the financing and regulation of home care, was welcomed by all. There was also good consensus on the need to ensure that the new scheme should reflect our values and principles as a society and to gain clarity on the purpose of home care so that this is clearly communicated.

#### 3.1 The scope of the new home care scheme

This question generated much discussion and many different views. The discussions can generally be grouped into the *what*, as in what needs should be covered by home care, and the *how*, as understandably, much discussion under this heading strayed into the area of quality. In terms of what needs should be covered in a new home care scheme, some discussion centred on the need to distinguish between fundamental needs and additional needs. There was agreement that it is essential to meet fundamental needs - however there were differing opinions on what fundamental needs actually are. For some fundamental needs involved assisting people with activities of daily living (ADLs), for others they included social aspects such as going for coffee or being assisted in social activities which were previously enjoyed (such as leisure or sporting activities). While there was general agreement that addressing ADLs is important, there was also a strong emphasis on the need for the system to take a broader view on what needs should

be supported. Some people took the view that the new home care scheme provides an opportunity for social care to take centre stage as an alternative, not only to admission to residential care, but to unnecessary acute care admission. As one participant put it: *To move from the current residual nature of community-based care to one where it would be centre-stage in the resource allocation process.*

'Fundamental needs' do not exist in isolation, they are part of a range of needs a person may have, all of which are inter-related, such as psychological wellbeing or psychosocial wellbeing. Therefore, addressing one set of needs (such as assistance with ADLs), could be instrumental in addressing or reducing other needs. Social isolation was also discussed and how it might be addressed, as evidence suggests loneliness is a growing issue which can have important health implications. Encouraging people to remain connected and to be part of their community was important but the challenge is how to prescribe that in a scheme. There was no clear consensus on whether 'social needs' should be included in the home care scheme but there was agreement that responses to address social isolation should be closely integrated to the home care scheme. There was a general consensus on the importance of including both medical and psychosocial needs, with the necessity to ensure balance and that the 'essential things' are done.

The potential of good quality home care to maintain health generally and to have a preventative focus was also discussed. It was felt that this approach has great potential to address downstream issues (e.g. falls) but is not possible in the current highly reactive approach to home care. There was strong emphasis on this concept of a holistic response to care needs to address the wellness of the individual.

There was a wide ranging discussion on the role of health and social care professionals (HSCPs) such as public health nurses (PHNs),



occupational therapists and physiotherapists under any new scheme. These services have a crucial role when someone is receiving home care and need to be closely integrated so that the person experiences an overall 'package' of supports regardless of what sectors they come from or their level of dependency. There was likely to be a variety of needs in the community, with different implications for resource allocation and provision. One suggestion which had some support was that home support should be divided into care bands, such as low dependency, medium dependency and high dependency. Different levels of care would be available for each band. The number of support hours available in each band would reflect the associated level of dependency. Prevention and re-ablement would be important principles underpinning resource allocation within each of the bands, with a strong focus on independence and autonomy for care recipients, irrespective of their level of dependency.

There was strong support for the recalibration of home care towards a more person-centred allocation system based on personhood for people with dementia. Participants wanted an increase in support hours for people with dementia, mainly because of concerns about the adequacy of current levels of provision. But, there was also a view that any additional hours should reflect a broader and more holistic view of dependency linked to cognitive impairment and its implications for social participation and social inclusion. Participants also emphasised flexibility of provision and the need for improved communication between formal care providers and people with dementia to ensure that cognitive impairment is not a barrier to the delivery of good quality care.

There was strong consensus that the new home care system should include consideration of the needs of family carers - potentially linking family carers in with services if needed. A related issue was the possible disadvantage that can occur in terms of home care provision because of the presence of family carers, with the likelihood that a reduced package of home care is allocated in these circumstances. Participants at the dialogue favoured complementary provision rather than substitution, implying that family carers should be central to the decision-making process. While the presence of family carers should be taken into account in the resource allocation process, the consensus was that this should be done in a way that supported the caring process rather than undermined it. In practice this means the provision of a different package of care, rather than the removal of any public support due to the existence of informal care within the household.

### 3.2 How should home care be delivered?

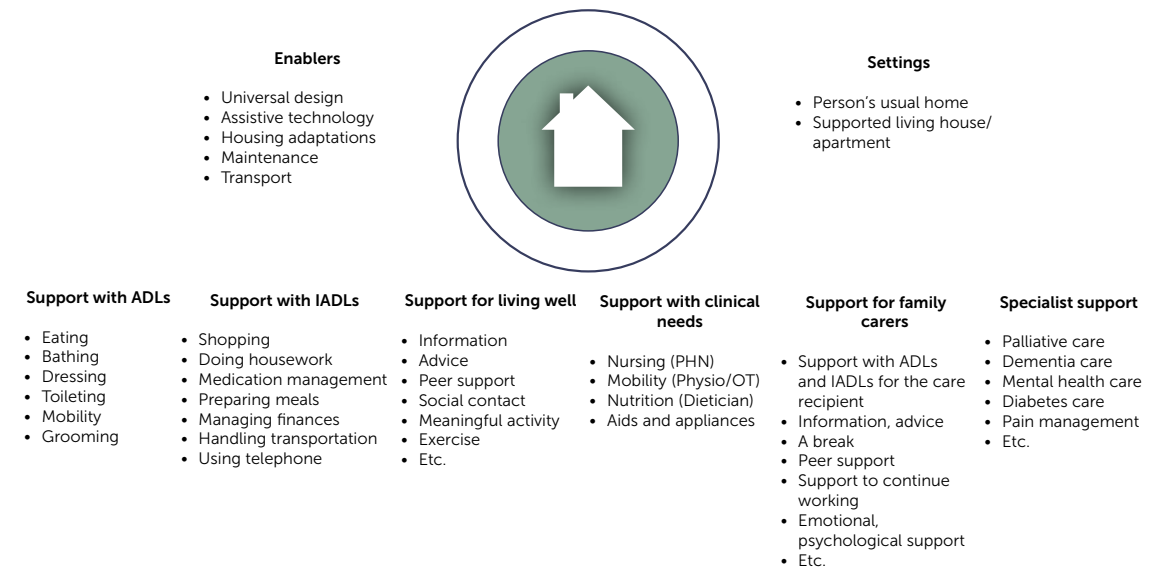
The second question to be addressed was to consider how can we best ensure that people with care needs receive integrated, person-centred health and social care services across the continuum of care, given the current challenges within the home care system? In terms of how home care should be delivered, there were several discussions on the need to personalise or individualise care so that we move beyond the 'one size fits all' approach. Flexibility is also needed and there was general consensus that a good home care system should be more flexible in how time is allocated (i.e. could be social time rather than ADL assistance), and be better linked and integrated with primary care and community services. A system allowing for flexibility to review and scale up home care as dementia or other conditions progress, was seen as important.

There was general acknowledgement that the current home care service is designed to focus on ADLs and some instrumental activities of daily living (IADLs) and there are several things to be considered if the scope is to be broadened, including:

- Having staff trained to provide specialty and dementia specific services - currently only trained to provide ADLs;
- Family carer supports to be considered in the design of home care packages;
- Ensuring dynamic change from week to week and flexibility of service response as need evolves.

There was general agreement that various enablers and supports need to be in place in order for the home support system to work well (see Figure 1). There was discussion around the need for greater use of technology into the future and also the need for integrated and timely action to upgrade and adapt homes that may not be currently suitable for the delivery of home care. Different types of housing were referenced, including the potential for the development of new integrated housing with care schemes that link social housing with scaled up home care services and supports. There was also discussion of the need to change our approach to risk so that, for example, paid formal care providers can be allowed to carry out some tasks that family carers do, such as administer medications.

Figure 1: Enablers, needs and services to support home care





## 4

## Care planning and organisation of care delivery

**4. Care planning and organisation of care delivery**

The main issues to be considered in this session were how to ensure that the home care recipient and family carer (as appropriate) 'have a say' and are central to the care planning process; how can we ensure that service-users' basic needs are met at the same time as providing choice; and how can we balance the standardisation of services with the need for flexibility and responsiveness to the needs of individuals and of individual communities?

There was considerable overlap in the discussion in this session and the content of the first session on the scope of home care. Several processes were identified by participants that need to be part of the planning and organisation of home care: assessment; developing a care plan; delivering care; and coordinating care. Figure 2 which was in the discussion document provides some context for these processes (see below).

**4.1 Assessment**

In terms of assessment for care – this was seen as the first step in the process and crucial in the overall home care scheme and will determine much of what happens, or doesn't happen, for the person and family. The single assessment tool (SAT) was viewed by many as the method for identifying needs and developing a care plan. The SAT was seen as critical to the introduction of the scheme and is the way the individual's needs will be identified. However, there were some concerns or caveats. Access shouldn't be purely based on the SAT and it's important to acknowledge that there are aspects of need that cannot always be identified through a health or clinically focused assessment. Insight should be provided by family members also, especially on social needs.

There were concerns expressed that the use of very rigid thresholds for care derived from the SAT may exclude people just below the threshold from accessing care. There was a sense from several discussions that assessments are very clinically led and that a better balance between clinical needs and more holistic wellness indicators is required. Some participants recommended that the family carer should be communicated with clearly in relation to the outcome of the SAT, so that they are aware of the required care needs. Some people felt that the health needs of the family carer should also be included in the assessment process if appropriate. There was also agreement that given the different groups who might need home care, any new system should be needs-based rather than age-based.

The setting in which an assessment takes place is important. Many take place in a hospital setting at the moment and this can have a real impact on what is allocated and the desired outcomes. It is important that older people receive the right care at the right time in the right place. The assessment of people before they end up in a hospital setting is really important. This would lead to resources being put in place to prevent unnecessary admissions in the first instance. It was also acknowledged that allocated home care hours generated through hospital assessment tend not to be revised downwards, even though need may reduce as the person regains function following a hospital admission. Some participants suggested that for people with dementia, a conversation around the challenges experienced by the person and their family could happen around the time of diagnosis. Alternatively, people with dementia and families could be referred onto a designated single point of contact after diagnosis to begin the process of care planning.

## 4.2 Having a say

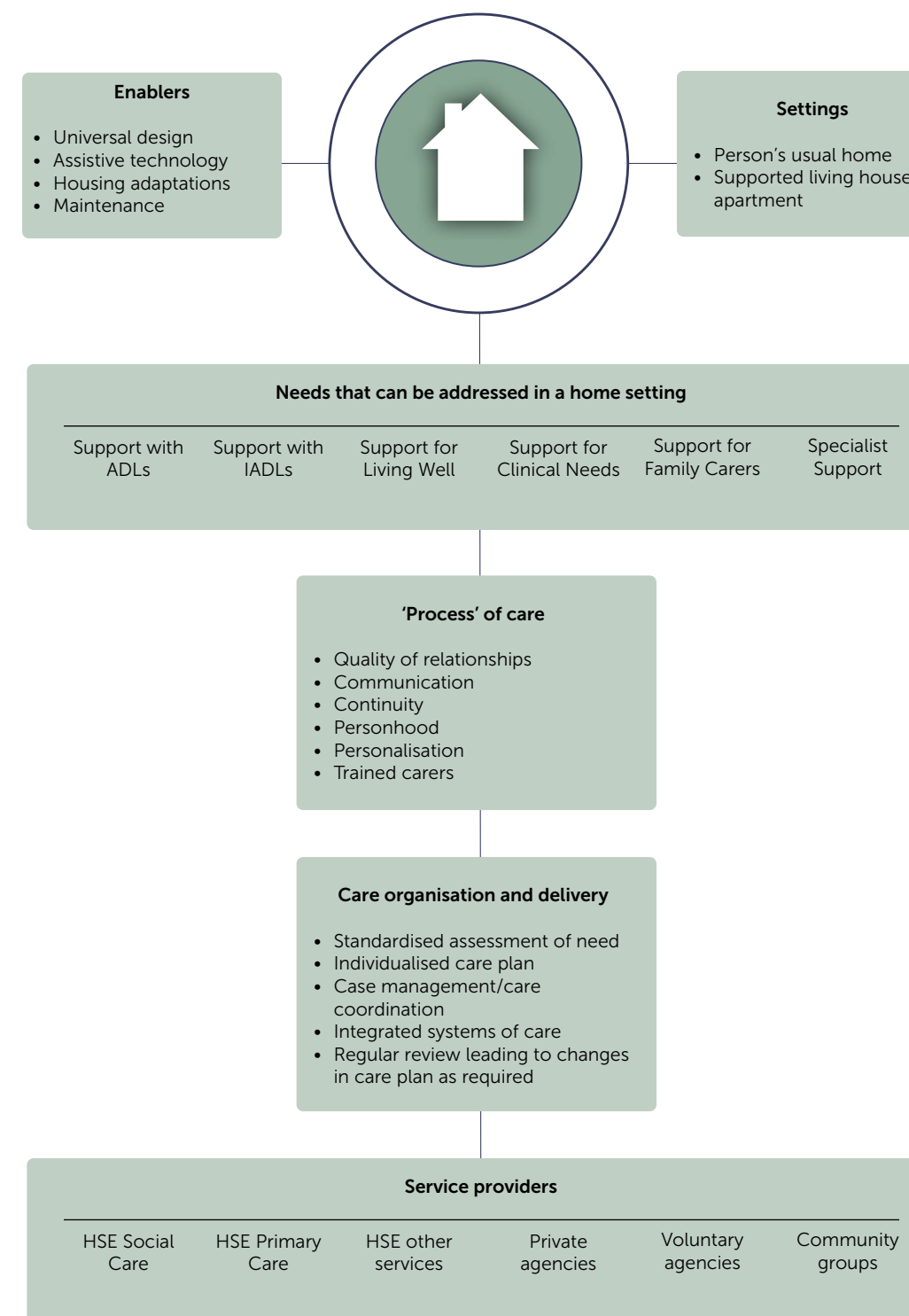
In terms of ensuring the person and family using home care services 'have a say', the overall sense was that in the current system there is little real input by the family or the person in terms of care planning. People generally 'take what they are allocated' as there is such a scarcity of resources currently. There was a view that care recipients accept whatever is offered, irrespective of whether the service provided actually meets their needs. People with dementia and family carers may be unsure of the range of services available in the community and therefore unaware of what their options are - a deficit in communication that needs to be addressed by the new scheme.

Currently people receiving home care tend not to complain in case their home care is taken away, although there was no evidence that this has happened. There was some consideration as to how consultation could be built into the new Home Care scheme. The need for specific mechanisms and actions to facilitate effective consultation with people using home care was identified. There was agreement in at least one group that consultation infrastructures needed to be developed to facilitate wide scale engagement from people using home care services. Overall the view was that the new system needs to be demand-led rather than supply-driven. This will be the real test of the new legislation according to one participant.

## 4.3 Care planning

There was little focused discussion on the process of care planning itself, although it was implicit in many of the discussions on the other topics. It was noted that care plans are largely task based currently. The term 'care' is very narrow and implies dependency and lack of agency. The term support plan is preferred as it implies that control remains with the person and much more is encompassed than simply care, especially in relation to the social context of need. The importance of addressing wellness in a care plan was noted, as well as preventive aspects of care and support. One participant noted that while care planning in residential care has changed dramatically over the last decade, the same could not be applied to home care. That needs to change to give greater voice to the consumer and to ensure that social needs are given equal weight to personal care needs. Community will have to become much more prominent in any new legislation to allow care recipients to age in place surrounded by family and friends.

Figure 2: Potential Home Care Framework



#### 4.4 Co-ordinating care

The task of coordinating care was seen as crucial, particularly where a person is accessing several services as well as home care. While this function may not necessarily be included in a home care scheme, it is essential that it is recognised as an important function. There was considerable discussion and some suggestions as to how care management and coordination might happen. The need for a clear point of contact was supported as currently, it is unclear who to contact for different issues. It was noted that families can spend a lot of time trying to find the correct point of contact. Private care providers also need a contact person, especially for crisis situations.

A community connector was suggested as a 'middle person' between the home care providers and people with dementia and family carers receiving the service. Case managers were identified as a formalised type of community connector with the capacity to act as a pragmatic advocate for home care users. A case manager who has a holistic overview and understanding of the home care service could act as a community connector.

One of the questions to be considered was, how we might balance the standardisation of services with the need for flexibility and responsiveness to the needs of individuals and of individual communities? There was limited discussion on this question. There were general statements about the need for clearer communication between the client, the family and home care providers, both HSE and private. There was a recognition of the need for discretion within a standardised service in order to be able to respond to exceptional needs or circumstances. There was strong consensus throughout other discussions on the need for greater flexibility in terms of responding to the needs of home care recipients, but little discussion as to how that might conflict with standardisation or how flexibility might be achieved within a service that has certain parameters in order to promote standardisation.

While there were some areas of agreement within the overall topic area, it was difficult to identify consensus on what needs to be done in relation to care planning and delivery. A recognised challenge is the complexity of the current system, and discussions were strongly focused on improving the current system rather than envisaging new ways in which a home care scheme might work. Participants found it difficult to understand why co-ordinating care represents a long-standing challenge, questioning why integrated care is so difficult to achieve in Ireland. There was concern about the complexity of provision for some elderly households, especially those where multiple providers were providing different aspects of care. There was also an awareness of the increasing role played by a variety of private companies in the provision of care, mainly as providers paid for by the HSE. Participants expressed the view that, while very welcome, this care was not always timely or consistent and, according to some participants, pointed to the need for improved co-ordination. It was also pointed out that an increasing number of older people and their families are paying privately for care, which may lead to equity issues in the future unless addressed under new legislation.

# 5

## Quality and regulation in home care



## 5. Quality and regulation in home care

### 5.1 What should be regulated?

There was a strong consensus that home care services should be regulated. In terms of what should be regulated, there was also consensus that regulation should be the same for public, private and voluntary providers and that regulation should focus on the *service* and not the *setting* i.e. the person's home. There was discussion that home care regulations need to be simpler than those for residential care and that 'the nursing home model should not be applied to home care'. It was seen as not feasible or desirable that family carers and family homes could, or should, be regulated, although there were important caveats. For example, it was suggested that there needs to be a mechanism to identify when a person's home may not be a suitable care environment, and that some assessment is also needed in terms of the safety for home care professionals providing care within it. Overall, the prevailing view was that while home care should be subject to some regulation, it should 'not become big brother' type monitoring.

### 5.2 Regulating care workers

In terms of the regulation of care workers there was general agreement that formal, paid care workers should be regulated and licensed and that a register of home care workers should be established.

There was also general agreement on the need for training, for example training in how to handle certain behaviours, and a requirement that staff be educated up to a certain level (e.g. QQI level 5 or 6). However, it was stressed that we need to guard against losing competent carers

due to an inability to gain educational qualifications. Many unregulated home care professionals were highly skilled but did not have formal training, and training may dissuade people from formally registering. Suggestions were made that different levels of training can be used to attract people to the profession or to introduce a banded requirement of homecare with different levels of carer training levels. This seems to be the model in England where training levels are matched to remuneration. It was emphasised that there is a need to make sure that family carers are not accidentally included under the regulation umbrella.

### 5.3 What to measure?

Some suggestions were made as to what should be measured:

- We should measure inputs, processes and outcomes, although, it should be noted, that some participants felt this was too much;
- The outcome for the person receiving the care is most important - the outcome should be determined by what the individual terms as being a good outcome; this can include social outcomes, for example social networks;
- Fundamental care including assessments and care plans
- Communication with family members and regular reviews;
- Whether home care is connected into pre-existing social services;
- Whether regulation makes a difference for the care recipient or not;
- That the requirements to meet regulations should not upset the care recipient;
- Up-to-date training for home care professionals – including dementia-specific training.

## 5.4 Minimising risks of regulation

Several risks of regulation were noted and some suggestions were made as to how these could be minimised:

### Risks

- When you have regulation, price is affected - likely to drive up the cost of services;
- There is a risk of home care becoming over-regulated and technocratic;
- People may not report regulation issues to avoid conflict;
- Ensure the framing of regulations does not result in family carers accidentally being included under the regulation umbrella;
- Introducing regulations will decrease the pool of home care professionals initially. Consequently a sufficient timeframe to implement new regulations would be necessary.

### Suggestions

- Legislation should be well thought out, based on wide-ranging consultation;
- A carefully managed scheme that is introduced on a phased basis;
- Regulation may help with making home care a more attractive career, thereby raising standards;
- Future potential for nursing home providers to provide home care also – they are familiar with regulation and there are likely to be transferable skills.

There was general agreement that providers should pay for regulation, along with recognition that the regulation system also needs to be funded by taxation. People using the services should not pay for regulation and this cost should not filter down to them.

## 5.5 Workforce issues

Participants expressed the view that the entire scheme was dependent on staff availability and therefore several measures were necessary to make home care an attractive work option. There was agreement of the need to place more value on home care workers and the work they do. This will ultimately mean higher remuneration for home care workers. If minimum standards for training and qualifications are introduced then reciprocal action on pay will be required. Introducing enhanced pay, contracts and career progression for home care worker should be incorporated in any regulatory framework. The introduction of a staffing framework, two years in advance of a regulatory framework, was recommended. Introducing home care 'types' (e.g. dementia-specific) may facilitate career levels and the 'streaming' of home care workers. Regulation can be used as a tool to attract people to the service and greater use could be made of regulation to achieve this goal.



## 6

## The financing of home care services

## 6. The financing of home care services

## 6.1 Potential funding models

The consensus of the discussion of potential funding models was that a mixture of funding models should be considered and might offer more scope to respond to different elements of the scheme in different ways. The view was that the most pragmatic model was likely to be some combination of general taxation and co-payment. While the social insurance model was appealing to many participants, there was some concern as to its practicality in the short-term. Any change to social insurance would need a very long lead time. One participant also raised the question as to whether social insurance contributions could be successfully earmarked for home care or whether they might be used for something else. There was some support for the view that social insurance could be viable in the long-run and that it should be investigated further.

There was general consensus that co-payments were a viable and workable option in terms of funding, with a strong preference for means tested co-payments. For co-payments to work there would have to be a supporting context, i.e. a statutory home care scheme with clear rights and entitlements and guaranteed funding for home care to be provided. Graded rather than binary levels of co-payment based on income were preferred, so that, for example, individuals with higher incomes would have a higher co-payment. This issue has been considered by Walsh et al (2020)<sup>8</sup> with significant public support exhibited for means-tested co-payments to help fund additional resource allocation for people with dementia in Ireland.

There was general agreement that the funding element of the Nursing Home Support Scheme (Fair Deal) model was not a suitable model for home care. There was much discussion in some groups on this, particularly regarding the use of the family home as collateral in any new scheme. There was a strong view that the value of a person's home should not be included in any way in the new legislation, not even posthumously. Participants also referenced the difference in potential cost between the two schemes. Homecare is likely to cost a lot less than nursing home care, at least until later in the care pathway. It will be important, therefore, to reassure people that they will not have to give up their homes or have any perception of their homes being under threat as part of the funding arrangements for the new scheme.

There was some discussion of the need to learn from other sectors, particularly disability, in the way people are supported through potential funding models. Personal budgets and/or individualised funding has long been part of policy and practice in the disability sector. It was mentioned in several groups as a mechanism to enhance autonomy in any new home care funding model for older people. It was suggested that, while a recent pilot initiative<sup>9</sup> by the HSE on individualised funding for older people was not entirely successful, it should not be seen as definitive in relation to innovative approaches in the future. People felt that there may still be merit in this approach, especially as a way of promoting the social model, although it needs to be implemented carefully.

<sup>8</sup> Walsh, S., O'Shea, E., Piersie, T., Kennelly, B., Keogh, F., & Doherty, E. (2020). 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>

<sup>9</sup> Phelan et al (2018) <https://www.hse.ie/eng/services/list/4/olderpeople/consumer-directed-home-support-evaluation-report.pdf>

## 6.2 Taking family care into account

Whatever new scheme is introduced, the benefits for family carers will need to be clear and be articulated. The economic well-being of family carers particularly spousal carers, was discussed in relation to the Fair Deal scheme. It was observed that family carers' own means are taken into account when applying for Fair Deal, thus undermining their earning capacity following admission of their relative to long term care. There was a strong feeling that family carers should not be penalised in the new home care scheme. This also applied to co-payments, with one participant suggesting that family carers might be willing to make a co-payment only if they receive remuneration for being a family carer.

Discussion of how the care provided by family carers might be taken into account in terms of funding models was tied up with earlier discussions of support for family carers. It was emphasised that we need to value what family carers do and to see them as a vital part of the 'care ecosystem', while recognising the uniqueness of their contribution. This might include paying current family carers more, providing practical supports for them to take time off work (flexible and other leave, maintenance of pension contributions etc.) and providing more and guaranteed supports for family carers, such as breaks from care.



# 7

## Discussion and conclusion

## 7. Discussion and conclusion

The discussion provides an opportunity for the authors to reflect on the content of the Policy Dialogue presented here, to provide some context and to draw some tentative conclusions, although it is acknowledged that we are at the very early stages of the recalibration of social care in Ireland. Nevertheless, the development of the new home care scheme represents an unprecedented opportunity to influence the shape of home care services in Ireland for the coming decades. Home care is an essential service for many thousands of people in Ireland and is envisaged, under *Sláintecare*, to play a central role in future health care provision. The development of the new scheme and the move to put the financing and regulation of home care on a statutory footing were universally welcomed in the Policy Dialogue. The participants were less expansive than anticipated in terms of the potential for home care into the future and much of the discussion focused on marginal improvements in the current system rather than a bold new vision. This is perhaps not surprising given the challenges within the current system where there is an acknowledged undersupply of home care, resulting in waiting lists and a model of care that is less than optimal<sup>10,11</sup>. However, the discussions in the Dialogue produced many important insights on how home care might be shaped into the future and these are highlighted below.

### 7.1 Continuum of home care

As with many long-standing elements of health services, home care developed organically in response to perceived local needs and, over time, became more formalised. Thus there are differences in the funding, practice and delivery of home care

around the country. More importantly, there is ambiguity surrounding the sometimes conflicting policy objectives underpinning current home care service provision. For example, is the purpose of home care primarily social, to support older people to age well at home – a long-standing policy aim in Ireland? Or, as sometimes represented, does home care exist primarily as an adjunct to inpatient acute care, available when required to support discharge from hospital? Moreover, is home care a service primarily for the recipient, for the carer or for both? The discussions in the Policy Dialogue noted this lack of clarity of purpose for home care and highlighted the importance of using this opportunity to provide more precision, and to go further and describe the outcomes that we want from a home care service. There was also good consensus on the need to ensure that the new scheme should reflect our values and principles as a society. The sense from many participants was that home care is currently largely focused on enabling discharge from acute hospitals, hence it's reactive, 'crisis' focused and narrowly focused on ADLs and clinical needs. There was an emerging consensus of the need for a wider purpose, with a focus on 'health production', providing a service to maintain health and prevent the emergence of other health problems. Home care is very well placed to provide this model and there has been little focus on this potential of home care to date.

In terms of how home care should be delivered, there were several discussions on the need to personalise or individualise care so that we move beyond the 'one size fits all' approach. Flexibility is also needed and there was general consensus that a good home care system should be more flexible in how time is allocated (i.e. could be social time rather than ADL assistance), and be better linked and integrated with primary care and community services. A system allowing for flexibility to review and scale up home care

as dementia or other conditions progress, was seen as important, as was the need to support important transitions along the care continuum.

There was also consensus on the need for home care to have a wider focus than the current focus on assisting with ADLs and some IADLs. However, there was a diversity of views as to what other needs should be incorporated into a new home care scheme and how this might be done. There was a lot of discussion of 'fundamental needs' versus other needs, also characterised as medical vs social needs. It was agreed that this is not always a helpful distinction and it is not useful to have these as opposites, meaning that you can have one of these but not the other. That said, there was concern that basic needs should always be met in order to ensure the health of the person, and that these cannot be neglected if the scope of home care is expanded. The person, and family if appropriate, should be involved in identifying and prioritising needs and what they think should be met and how within the overall parameters of the scheme. The challenge for those designing the scheme is to ensure that essential needs are met, but to have sufficient flexibility to incorporate both personal and social elements within the core set of needs.

### 7.2 Family carers

There was general consensus that the needs of carers need to be recognised more explicitly within the provision of home care. There is an implicit assumption underpinning the delivery of the current home care model that as well as meeting the needs of the recipient, home care also directly assists family carers. There is evidence that home care meets the needs of family carers in relation to the practical and sometimes physically demanding tasks of providing care, specifically providing assistance with ADL tasks<sup>12</sup>. However, family carers have other needs, many associated with the emotional

dimension of caring. Some of these needs could potentially be addressed through providing home care in a different way – such as providing a break from care if hours are provided in a 'block'<sup>13</sup>. Other needs are typically not met by home care, regardless of how many hours are provided. Referral to formal health services such as counselling, or other supports such as peer support groups, or the provision of information and some training, may be required. The high level of care provision by family carers in Ireland means that family carers' needs should be considered in the new home care scheme.

As with other areas discussed in the Policy Dialogue, there was consensus on the central importance of an issue, but less agreement on the 'how' and it was suggested that a societal conversation relating to realistic social expectations of family carers is needed.

### 7.3 Care planning organisation and delivery

While there were rich and wide-ranging discussions on the planning, organisation and delivery of home care, no clear consensus emerged on priority-setting in this area. The primary response among participants was to call for an enhancement of traditional home support for dependent older people. People wanted an increase in home care hours above everything else. This is not surprising given the current fragmented nature of existing care and prevailing inequities in the provision of community-based care<sup>14,15</sup>. When resources are scarce people want core clinical and physical needs to be met in the first instance. When pressed, participants recognised the importance of social needs among older people, but were less sure of how those needs could be met, given the current architecture of care. This was particularly the case in regard to the psychosocial needs of people with dementia. Therefore,

<sup>10</sup> Donnelly, S., O'Brien, M., Begley, E. and Brennan, J. (2016). "I'd prefer to stay at home but I don't have a choice" Meeting Older People's Preference for Care: Policy, but what about practice? Dublin: University College Dublin.

<sup>11</sup> O'Shea, E., Cahill, S. & Pierce, M. (eds.) (2017). *Developing and Implementing Dementia Policy in Ireland*. Galway: Centre for Economic and Social Research on Dementia.

<sup>12</sup> Keogh et al. (2018). *Supporting People with Complex Needs at Home Report 1: Evaluation of the HSE Intensive Home Care Package Initiative*. Dublin: Genio.

<sup>13</sup> Keogh et al (2018). *Supporting Older People with Complex Needs at Home Report 2: What Works for People with Dementia?* Dublin: Genio.

<sup>14</sup> <https://www.gov.ie/en/press-release/6f9c95-improving-access-to-home-support-statement-from-minister-daly/>

<sup>15</sup> Keogh, F., Pierce, T. & O'Shea, E. (2020) *Dementia services in Ireland 2018: Audit of community-based health and social care services used by people with dementia*. NUI Galway.



if the social model is to take hold in the planning and organisation of home care services, more work will have to be done to develop an understanding of what social needs look like and how current resources can be recalibrated to meet those needs. Similarly, people recognised the importance of prevention among older people, but again were unsure of how this might be improved. If prevention is to take hold, it will have to be formally recognised and supported in a much more proactive manner in the new scheme. Keeping older people active, mobile and independent should be a major goal of the new system of home care to support a more pro-active approach to disease prevention and independent living.

Part of the problem relates to an ageist attitude in society that tends to infiltrate many discussions on community-based care for dependent older people<sup>16</sup>. Giving dependent older people more responsibility and providing opportunities for them to exercise choice in regard to services and supports is not central to current thinking and provision. Things are done *for* older people rather than *by* older people or *with* older people<sup>17</sup>. The model supporting services for older people is very different to the model underpinning services for people with disabilities. Participants at the Policy Dialogue recognised that this is a limiting aspect of current policy, but were less forthcoming on how to give more autonomy to older people. The use of the Single Assessment Tool (SAT) as the means of assessing need for home care was largely welcomed, although some participants observed there may be some shortcomings still in relation to the potential for holistic assessment. The findings from the Genio community-based interventions, showing the importance of engaging directly with older people<sup>18,19</sup> and the role of enhanced and targeted home care in keeping people out of residential care were reflected in the Dialogue. There were also examples

provided on how consultation could and should be built into the new Home Care scheme. The need for specific mechanisms and actions to facilitate effective consultation with people using home care was identified, mainly through enhanced public and patient involvement (PPI) at every stage, including any future research and evaluation work<sup>20</sup>.

## 7.4 Quality, regulation and financing home care

Compared to the discussions on the continuum of home care and the planning and organisation of home care, there were more areas of clear consensus in the discussions around quality and regulation and the financing of home care. Thus there was strong consensus on the need to regulate home care and home care workers, with a focus on the service rather than the setting. There was strong agreement on the need to value home care workers and to create conditions and payment scales that make care work an attractive career option. The importance of measuring outcomes as well as processes in a regulatory system was emphasised. It was recognised that regulation also carries risks, particularly in driving up costs, and some suggestions were made as to how to mitigate these risks.

The consensus of the discussion of potential funding models was that a mixture of funding models should be considered and might offer more scope to respond to different elements of the scheme in different ways. In practice, the most likely combination in the short to medium term was a continuation of the current general taxation system supported by a new co-payment mechanism. Participants saw merit in a new social insurance scheme, but were pragmatic in their view that any such system could only be considered in the longer-term, after careful consideration of the costs and benefits. There was general consensus that

co-payments were a viable and workable option in terms of funding, with a strong preference for means tested co-payments. However, participants also noted that for co-payments to work there would have to be a supporting context, i.e. a statutory home care scheme with clear rights and entitlements and guaranteed funding for home care to be provided. There was also consensus that cost sharing was necessary whatever model of financing existed, given the demands on the resources available.

## 7.5 Terminology

Finally, we need to remember that language matters. It shapes our thinking, often in unconscious ways, thus the words we use are important in shaping what is provided in the form of a service. Thus, home support emerged as a preferred term among many participants, as it denotes a recipient who is actively involved in deciding what it is they want and need and how they want a service to be delivered as opposed to a passive recipient of care. The term 'support' infers the existence of strengths and abilities in the service recipient who needs help and assistance in some ways, which may include the provision of care and implies 'doing with rather than doing for'. These are all desired attributes of the way in which support should be delivered into the future. The recent re-organisation by the HSE of two elements of the home care service into the home support service reflects this thinking and was welcomed by participants.

<sup>16</sup> O'Shea, D. (2020) *Mind your Language! Some words of advice for print and broadcast media from Dr. Diarmuid O'Shea, President of the Irish Gerontological Society* <https://www.irishgerontology.com/news/latest-news/mind-your-language>

<sup>17</sup> O'Shea, E. (2020) *Remembering people with dementia during the COVID-19 crisis.* <https://hrbopenresearch.org/articles/3-15> accessed 07/05/2020

<sup>18</sup> Cahill, S., Pierce, M. & Bobersky, A. (2014) *An Evaluation Report on Flexible Respite Options of the Living Well with Dementia Project in Stillorgan and Blackrock.* Genio, Dublin.

<sup>19</sup> Cullen, K and Keogh, F (2018) *Individualised and Person-Centred Supports in Community-Based Dementia Services: The value case.* Genio, Dublin.

<sup>20</sup> Murphy, E., et al (2020) *Public patient involvement, now more than ever.* HRB Open Research

<sup>21</sup> (Daly 2019), <https://www.oireachtas.ie/en/debates/debate/dail/2019-06-12/46/>.



## 7.6 Conclusion

The Policy Dialogue is a contribution to the conversation and deliberations that are currently taking place in Ireland on home care for older people now and in the future. The most important point, agreed by all participants, is that the new legislation should, for the first time, facilitate a genuine community-based, rights-driven approach to home care in Ireland. Some participants expressed the hope that home care can finally be part of mainstream health and social care policy, rather than a residual appendage, determined more by hospital discharge needs than any inherent worth of its own. There was, however, also a recognition that negotiating a way through the new scheme was not likely to be easy, given the ground to be made up in terms of services and supports for older people, as well as the certainty of enduring budget constraints. While additional funding for home care has been made available in recent years with the budget growing from €306 million in 2015 to almost €446 million in 2019<sup>21</sup> spending is still below 50% of public expenditure on residential care, through the nursing home subvention scheme (NHHS).

There was support for different bands of care provision, based on increasing levels of need and dependency among care recipients. Providing additional hours will be hugely important as dependency increases, but so too will the actual services available to people within various bands. There was a recognition that some form of cost sharing was inevitable, given the cost of care, and that the most realistic approach was to initiate a means-tested co-payment strategy. Participants also recognised the importance of a more social model of home care production, even if they could not always articulate what that would mean in practice. There was more agreement on the need for greater choice and autonomy for older people, leading to consensus on the importance of replacing generic care approaches with personalised care provision. People also wanted more co-ordinated care, linked to a greater emphasis on information generally, especially for

people with dementia. Finally, there was an enduring commitment within the Dialogue to equity with many contributors emphasising the importance of justice and fairness in the treatment of dependent older people, irrespective of age, income or geography.

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