

Improving Home Care Services in Ireland:

Have Your Say!

Your Opinion Matters

This public consultation is being carried out to help the Department of Health to develop plans for a new statutory scheme for home care services.

We would like to find out what people think about current home care services – what is working well and what needs to be improved. We would also like to hear the public's views on what the future scheme should look like. A report of the findings of this consultation process will be published. These findings will help the Department to develop the new home care scheme.

This stage of the consultation is particularly aimed at people who use home care services, their families and the general public. However, everyone with an interest, including: health and social care providers; health and social care workers; advocacy groups; those providing complementary services (such as meals-on-wheels and social activities); and representative organisations is welcome to participate.

It is important to say that this consultation paper is just the start of a broader consultation process on home care. The Department also intends to consult by:

- Meeting with individuals and groups so they can tell us directly what they think;
- Meeting with home care service provider organisations and other organisations that represent people that use home care services so they have the opportunity to put forward their views; and
- Asking everyone with an interest in home care services to tell us what they think of our plans when they are developed.

Given that the Department will be consulting again throughout the process of developing the new home care scheme, this consultation does not attempt to address every issue related to home care.

Structure of this Consultation Paper

There are four sections in this paper:

- Section 1 gives some information and background to home care in Ireland;
- Section 2 asks you to tell us a little about yourself;
- Section 3 asks you to tell us about your experiences of home care;
- Section 4 asks for your views about the current home care system and your ideas for the future.

How to take part

You can fill in the consultation online at: http://health.gov.ie/consultations/

If you prefer, you can download a copy of this document at

http://health.gov.ie/consultations/ and post it to us at:

Home Care Consultation

Room 204

Department of Health

Hawkins House

Hawkins Street

Dublin 2, D02 VW90

Alternatively, if you would like a paper copy to be sent to you, please contact the Department of Health using the contact details written above or by calling (01) 6354402 or (01) 6354732.

You can also contact the Department at these phone numbers or at our email address (homecareconsultation@health.gov.ie) if you have any questions about this document.

Easy Read Version

A shorter, "easy read" version of this consultation paper is also available on the Department's website. If you would like to receive a paper version of the easy read consultation paper, please contact the Department at the phone number, email address or postal address above.

Closing date

The closing date for submitting your views is **Thursday 31 August 2017**.

Data Protection and Privacy Provisions

The information shared by you in this consultation will be used solely for the purposes of policy development and handled in accordance with data protection legislation. An analysis of submissions received as part of the public consultation will be published online which will include a list of organisations and representative bodies that responded. Comments submitted by individuals may be used in the final consultation report but these will be anonymised. All personal data is securely stored and subject to data protection laws and policies. For more information, see http://health.gov.ie/data-protection/.

Please note that submissions received by the Department are subject to the Freedom of Information (FOI) Act 2014 and may be released in response to an FOI request.

SECTION 1 – INTRODUCTION AND BACKGROUND

Note: Before you begin to answer the questions, you might find it helpful to read this section which has information about home care in Ireland and the consultation process. An Easy Read version of this information is available from the Department of Health's website at: http://health.gov.ie/consultations/.

1. Introduction

It is widely accepted that most people want to continue to live in their own homes throughout their lives. The Government wants to improve community based services so that people can live with confidence, security and dignity in their own homes for as long as possible. In order to help make this happen, the Department of Health is developing a new scheme that will improve access to the home care services that people need, in an affordable and sustainable way. The Department will also introduce a system of regulation for home care so that the public can be confident that the services provided are of a high standard.

The Government's commitment to improving home care can be seen in its Programme for Partnership Government¹. The Programme makes several references to home care including commitments to: (i) review the management, operation and funding of national home help services; (ii) increase funding for home care services; and (iii) introduce a uniform home care service so all recipients can receive a quality support, seven days per week where possible. The recently published Report of the Oireachtas Committee on the Future of Healthcare² also shows support for improving home care from across the political system.

2. Scope of this Consultation – What is home care?

The focus of this public consultation is on home care services. However, this raises an important question – what is home care?

The meaning of home care can differ significantly between countries and, as such, there is no standardised definition. However, a recent evidence review by the Health Research Board titled "Approaches to the regulation and financing of home care services in four European countries" states that:

¹ http://www.merrionstreet.ie/MerrionStreet/en/ImageLibrary/Programme for Partnership Government.pdf

² http://www.oireachtas.ie/parliament/media/committees/futureofhealthcare/Oireachtas-Committee-on-the-Future-of-Healthcare-Slaintecare-Report-300517.pdf

http://www.hrb.ie/publications/hrb-publication/publications//731/

"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".

While the home care service in Ireland is mainly used by older people, it is also provided, in a limited way, to some people with disabilities and other identified care needs. This includes services for people leaving hospitals who need support.

The key home care services provided by or funded by the HSE are home help, home care packages and intensive home care packages. These services are explained below.

<u>Home Help Service</u>

The HSE home help service visits people to help with:

- Personal care (washing, changing, oral hygiene, help at mealtimes);
- Essential domestic duties related only to the individual client (lighting a fire / bringing in fuel, essential cleaning of the person's personal living space).

Home Care Packages

HSE Home Care Packages aim to help people with medium-to-high support needs to continue to live at home independently. Home Care Packages consist of community services and supports which may be provided to assist a person, depending on their individual assessed care needs, to return home from hospital or residential care or to remain at home where mainstream or normal levels of services are insufficient.

The services provided in a Home Care Package include more home help hours in addition to the average level available locally. Packages may also include nursing and therapies (for example - physiotherapy, speech and language therapy, occupational therapy), respite care and aids or appliances. The services delivered are based upon the assessed client needs and the level of other supports already provided such as home help services or informal care by family, friends or neighbours to the client.

Intensive Home Care Packages

Intensive Home Care Packages allow people who require a very high level of assistance to be discharged home from hospital or avoid admission. It is a limited service that includes supports over and above those provided as part of a standard Home Care Package or current community services.

3. Other Services and Supports

In addition to home care as described above, it is recognised that many other services may be necessary to support people in their own homes. These include primary and community care services (GP; public health nursing; physiotherapy; speech and language therapy; occupational therapy; day centres; and respite care) and specialist services including geriatrician-led teams. Personal Assistants also play an important role in helping some people with disabilities to live independent lives. Home Support provides personal and/or essential domestic care and support for some disabled people to facilitate participation in social and leisure activities. Aids and appliances or house adaptation grants also help individuals make changes to their homes that are required to meet their particular needs.

Furthermore, many people are looked after by carers, family and friends. Care provided by family and friends can be called informal care. These carers make a vital contribution to the health, well-being and quality of life of those that they care for.

While all of these other services and supports are important to enable people to live independently in their own homes for as long as possible, **this public** consultation is focussed primarily on home care services, that is home help services, home care packages and intensive home care packages.

The Department recognises the need for those providing home care services to work effectively with other community and primary care service providers. This will help to ensure that services delivered best meet the needs of the service user.

4. Who provides home care in Ireland and how is it funded?

Formal home care is professional care paid for by recipients, family members or the State. In Ireland, formal home care services are provided by the Health Service Executive (HSE), private providers and not-for-profit voluntary providers.

The HSE directly employs a range of staff to provide home care services. The HSE also contracts not-for-profit providers and private providers to supply services on its behalf.

The HSE will spend approximately €370 million on home care services in 2017. This funding will enable the HSE to provide 10.57 million home help hours to support about 49,000 people. In addition, the HSE expects to provide 16,750 Home Care Packages and 190 Intensive Home Care Packages for clients with complex needs in 2017.

5. How is home care accessed?

When individuals need home care, they or someone on their behalf, can apply to the HSE for services. HSE staff then carry out assessments of the individuals' need for home care services. The HSE staff then prioritise and allocate the services based on the assessed need.

There is currently no charging or means testing for HSE funded home care services. However, there is more demand for home care services than there are resources available to deliver them.

Many people also purchase home care services directly from private providers. These services can act as a top-up to services funded by the HSE or can be instead of HSE funded services. Tax relief may be available for the purchase of private care in certain circumstances which may encourage those with the means to do so to pay for services.

6. Why we need a new Home Care Scheme

The National Positive Ageing Strategy⁴ recognises that population ageing is a success story. It goes on to state that "later life can and should be a time for active citizenship, for continued contribution and participation in local community affairs, for engaging in the kinds of activities that enhance physical and mental health, and a time for involvement with family, friends, neighbours and the wider community". Home care is an important part of the services that some people will need in order to help them do this. It can also help to reduce the need for long-term nursing home care. However, the reality is that the vast majority of older people lead active lives in their communities without the assistance of formal home care.

⁴ http://health.gov.ie/wp-content/uploads/2014/03/National Positive Ageing Strategy English.pdf

Equally, a person's disability should never dictate the path that they are able to take in life. What should count is the person's abilities, their talents and their determination and aspiration to succeed. People with disabilities are writers, artists, entrepreneurs, everyday people who work in offices and shops, who pay taxes and contribute to society and who personify the core principles of community inclusion and active citizenship. Home care can be a support to help those with disabilities who need it in order to live ordinary lives in ordinary places and participate in and contribute to the life of the community.

Formal home care services can also be a crucial support for carers.

These services can also help people to avoid having to be admitted to hospital as well as help them to return home sooner after a hospital stay.

Although the Government is committed to increasing funding for home care services, the supply of such services is unlikely to keep up with the increasing demands without reform of the home care system. This means that the Department of Health needs to develop a new scheme that operates in a consistent and fair manner for all those who require it. Two of the main reasons why we need a new home care scheme are outlined below.

(i) <u>Unmet Need and Population Changes</u>

Despite the significant level of spending on home care referenced in Section 4 above, there is unmet need. This means that that the level of services cannot keep up with demand, resulting in approximately 4,600 people now on waiting lists for home care. This number includes new applicants and those who are receiving services but are seeking additional resources or care hours.

The level of unmet need is likely to increase in the years to come because demand is growing for the HSE's home care services. A key reason for this additional demand is the expected increase in the number of older people in the country. The number of people over the age of 65 will double in the coming years while the number over the age of 85 will treble. Further detail on this issue can be seen in the figure below which shows the substantial growth in the number of adults aged 60 and older that will be seen between 2011 and 2046.

95+ 95+ Males **Females** 90 - 94 90 - 94 **2046** 85 - 89 85 - 89 ■ 2011 80 - 84 80 - 84 75 - 79 75 - 79 70 - 74 70 - 74 65 - 69 65 - 69 60 - 64 60 - 64 55 - 59 55 - 59 50 - 54 50 - 54 45 - 49 45 - 49 40 - 44 40 - 44 35 - 39 35 - 39 30 - 34 30 - 34 25 - 29 25 - 29 20 - 24 20 - 24 15 - 19 15 - 19 10 - 14 10 - 14 5 - 9 5 - 9 0 -4 250 200 250 200 150 100 50 0 50 100 150 Thousands ('000)

Figure 1: Pyramid for males and females, 2011-2046 (estimated)

Note: estimates based on M1F3 combined assumptions for migration and fertility.

Information from the TILDA⁵ study shows that older people are more likely to have difficulty with basic activities of daily living such as: dressing; walking across a room; bathing/showering; eating; getting in or out of bed; and using the toilet. Older people are also more likely to have difficulty preparing a hot meal; doing household chores; shopping for groceries; making telephone calls; taking medications; and managing money. Some people with disabilities may also face difficulties with some of these tasks. In light of this, home care will continue to be an increasingly important part of the supports we offer into the future.

(ii) Consistency in Service Provision

The provision of home help and home care packages has a basis in law but there is no statutory entitlement to these services. Services are not means tested or 'limited' in any other way. For instance, services are not restricted to medical card holders and no charges apply for these services (unless a person procures these services privately).

⁵ This information is from The Irish Longitudinal Study on Ageing - TILDA (wave 2, 2012). **T**he Irish **L**ongitu**D**inal Study on **A**geing (TILDA) is a large-scale, nationally representative, longitudinal study on ageing in Ireland, the overarching aim of which is to make Ireland the best place in the world to grow old.

This absence of a statutory underpinning for home care provision has led to inconsistencies in how State funded home care is delivered across the country. This means that the availability of services can vary from place to place and at different times of the year. This contrasts with the Nursing Homes Support Scheme – "A Fair Deal" which is consistently applied throughout the country.

A statutory scheme for home care would help to introduce clear rules in relation to what services individuals are eligible for and how decisions are made on allocating services. For that reason, developing a new statutory scheme will be an important step in ensuring that the system operates in a consistent and fair manner for all those who need home care services.

7. Why we need Regulation of Home Care Services

There is also a need to ensure that home care services, whether funded by the HSE or privately funded by individuals, are regulated appropriately.

Unlike other health and social care services, such as long term residential care (for example, nursing homes or residential centres for people with disabilities), there is currently no statutory regulation of home care services. A recent national opinion poll commissioned by the Health Information and Quality Authority⁶ (HIQA) found that 76% of people that responded mistakenly thought that home care services are independently regulated or monitored.

While a statutory regulatory regime is not in place, a significant step towards quality assurance for home care services was taken in 2012 when the HSE introduced a single procurement framework for external providers. This included quality standards in terms of governance and accountability, personcentred care, complaints management, training and qualifications. Providers are monitored through Service Level Agreements with the HSE and are required to provide a range of information in relation to the services they provide.

Some of the reasons why a system to regulate home care services, whether HSE funded or privately funded, is required, include:

- to ensure that all users are treated with dignity and respect while promoting their independence and choice;
- to promote client safety;
- to promote equity and freedom of choice for service users;

_

⁶ https://www.hiqa.ie/sites/default/files/2017-05/HIQA%20National%20Poll.pdf

- to improve performance and quality;
- to provide assurance that core standards are achieved;
- to provide accountability both for levels of performance and value for money; and
- to bring Ireland in line with best international practice.

8. Home Care working with other Services and Policies

It is important to recognise that the new statutory home care scheme will not be developed in isolation. It will be designed to complement and integrate effectively with other health and social care services such as long term residential care (including the Nursing Homes Support Scheme), primary and community services as well as hospital services.

The new scheme will also be developed in the context of relevant existing policies such as the Report of the Oireachtas Committee on the Future of Healthcare, National Carers Strategy⁷, the Positive Ageing Strategy and National Dementia Strategy⁸, among others. Work currently underway such as the development of new community nursing services and the Task Force on Personalised Budgets in the disability sector will also be considered.

8 http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf

http://health.gov.ie/wp-content/uploads/2016/02/National-Carers-Strategy.pdf

SECTION 2 – YOUR DETAILS

In this section, we ask you to tell us a little about yourself so we can look at the responses received from different points of view. This is the only reason for collecting this information.

(Note: If you are making a submission on behalf of an organisation or representative body, please complete Part B.)

Part A – to be completed by individuals.

Your name (optional): If you would prefer to not give your name, please skip to the next question.

Title					
First Name					
Surname					
What is your gend Male □	der: Female □	Prefer not to	say 🗖		
Your age: Under 40 70 – 79 Prefer not t	□ □ o say □	40 – 59 80 – 89		60 – 69 90 +	
What county do y	ou live in?				

Of the list below, which best describes yo	ou: (you can select more than one)
Someone who receives or has received ho	ome care
Family member or friend of someone who	no receives home care \square
Member of the public	
An informal carer (not paid to provide care	re)
Home care worker	
A health professional providing home care	re services
A health professional working in another s	sector
Prefer not to say Other, please provide details	
(If you are NOT a home care worker or he the following two questions)	nealthcare professional, please ignore
If you are a home care worker or a health what type of organisation you work in: HSE Private Sector	thcare professional, please indicate
Voluntary/Not for Profit Sector	
If you are a home care worker or a health what service you work in:	thcare professional, please indicate
Home care/home help	
Primary/community care and therapies	
Meals on Wheels	
Respite care	
None	
Other, please specify:	

PART B – This section only needs to be completed by organisations or representative bodies (you do not need to fill in the section below if you are responding as an individual)

Please state name and address	of orga	nisation:	
Title			
First Name			
Surname			
Job Title			
Please state category of organisation	on:		
Union/ staff representative body		Representative Body	
Regulatory Body		Patient Interest Group	
Public Interest Group		Academic institution	
Advocacy Body		Private Home Care Provider	
Voluntary/Not for Profit Home Care	e Provid	ler 🔲	
Other, please specify:			

(Note: If you are responding on behalf of an organisation, you do not need to complete Section 3)

SECTION 3 – YOUR EXPERIENCES

select more than one):	owing nome care services? (You can
Home Help]
Home Care Packages	_]
Intensive Home Care Packages	
None of the above]
Have you ever received any of the follo	owing services? (You can select more
than one):	
Meals on wheels	
Day centre	
Residential respite care	
Respite care in your home	
Therapies such as Occupational Therapy	y, Rehabilitation \Box
Public Health Nursing	
GP services	
Help from family, friends or neighbours	
None	
Other, please provide details	
Are you currently paying for private ho	ome care services?
If you are currently paying for private he do you receive from the private provid	•
hours	
Have you paid for private home care so	ervices in the past?

If you have or are currently paying for priva	ate home care, please state why:
Did not know about HSE services	
Applied to the HSE but was not approved	
On a waiting list	
Top up to HSE services/needed more hours	
Prefer not to apply to the HSE	
This question does not apply to me Other, please specify:	

SECTION 4 – TELL US WHAT YOU THINK

This section asks for your views about how home care currently works and your ideas for the future.

Here we are asking about <u>formal home care services</u>. By this we mean care that is provided by a professional and is paid for by the HSE, the person receiving home care or by family members.

In this section you will be asked to give your opinion on the different home care services, the strengths of the current home care system and what could be improved. This information will help the Department to decide what should stay the same and what needs to be done differently.

Ge	General Questions		
1.	In your opinion, what are the good things about home care services in Ireland?		
	hen giving your answer to this question, you may wish to think about the llowing: How you apply for home care How your need for home care services is assessed Who can access services What home care services are provided How home care services are provided How home care services are monitored How you can appeal a decision about your home care		

Questions 5 and 6 ask for your views in relation to choice of home care services and providers.
5. Do you think that people who receive home care should have more of a say in the range of services that are provided to them?
Yes No Don't know
6. Do you think that people who receive home care should have a choice in who provides their care?
Note: Home care can be provided by the HSE, not-for-profit providers and private providers.
Yes No Don't know
If you have any comments in relation to choice of home care services and providers, please include them below:

7. In your opinion, how could home care services in Ireland be improved?
,
Note: When giving your answer to this question, you may wish to think about
the following:
How you apply for home care
 How your need for home care services is assessed
Who can access services
What home care services are provided
 How home care services are provided
 How home care services are monitored
How you can appeal a decision about your home care
Questions on Information in relation to Home Care Services
This section asks who you would contact if you needed information on home care services. It also asks whether you are aware of the tax relief that is available for privately purchased home care.
8. If you, a relative or friend needed home care services, who would you ask for information first?

If you have any comments on this issue, please include them below:
9. Are you aware that tax relief is available to people that pay for home care services?
Note: tax relief reduces the amount of tax that an individual has to pay.
Yes No
If you have any comments on this issue, please include them below:

Question on Standardisation

At the moment, home care services operate in different ways across the country. This means that the amount and type of home care available can vary depending on where you live or the time of the year. Many other countries have home care systems that make sure that home care is provided in the same way across the country.

10.Do you think that the same approaches	should a	pply acro	oss the country in
relation to the following?			
 How you apply for services 	Yes	No	Don't know
 How your need for services is assessed 	Yes	No	Don't know
 Who can access services 	Yes	No	Don't know
 What home care services are provided 	Yes	No	Don't know
 How home care services are provided 	Yes	No	Don't know
• How home care services are monitored	Yes	No	Don't know
 How you can appeal a decision about yo 	ur home	care	
	Yes	No	Don't know
If you have any comments on this issue, ple	ase includ	de them I	pelow:
Question on Quality Standards			
At the moment, there are no national stand that the quality of home care can differ amore countries have introduced national standar views on whether or not you think national the future to home care providers in Ireland Note: National standards would mean that have to meet a minimum standard of qualit home care services.	ong homeds. We was quality steed.	e care pro rould like randards me care p	oviders. Other to know your should apply in provider would

11.Do you think that the same national quality standards should apply to all (public, private and not-for-profit voluntary) providers of home care?
Yes No Don't know
If you have any comments on this issue, please include them below:
Question on Training for Care Workers
Currently, there is no minimum level of training required in order to be a home care worker in Ireland, though many have completed relevant training. Other countries have introduced minimum training levels in order to help ensure a better quality of service. We would like to know whether or not you think this would be a good idea for Ireland.
12.Do you think that formal home care workers should have to complete a minimum level of training that would be set by the Government?
Note: formal home care workers are people who are either self-employed or work for a home care service provider organisation
Yes No Don't know
If you have any comments on this issue, please include them below:

Questions on Funding
In Ireland, there is no means test for home care services that are funded by the HSE. People who receive these services do not have to pay for them. This is different to many other countries which have some form of charging or means test.
13. 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?
Yes No Don't know
If you have any comments on this issue, please include them below:
14.If the State could only provide a certain amount of home care services based on health need, would you be prepared to purchase additional hours with your own money, if you needed them?
Yes No Don't know
If you have any comments on this issue, please include them below:

Other issues
15. If there are any other comments that you would like to make, please
include them below.
Thoules on for completing this consultation
Thank you for completing this consultation.
If you would like to receive a copy of the results of this consultation, please
provide your postal or email address
provide your postaror email address