Submission to the Department of Health Consultation on Home Care Services

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General questions

1. In your opinion what are the good things about home care services in Ireland?

Note: When giving your answer to this question, you may wish to think about the following - How apply for home care, how needs assessed, who can access services, what home care services are provided, how home care services provided, how home care services are monitored, how you can appeal a decision about home care

The good thing about home care services in Ireland is that when people are provided with the home care and support they need they can continue to live dignified lives in their own homes, which is their preference and right.

Carers and service users who made submissions to this consultation through Age Action pointed out how it is:

> "*very important to have this service, it gives family time to go home and have time for themselves. It can be very draining on the person looking after he or she and to have time with your family, I do appreciate this service"*

A flexible and person centred approach to the provision of home care services to meet the specific needs of the individual benefits both the person, their carer and the wider health system. For example, the provision of a dementia support worker two nights a week to allow a spouse caring for a person with dementia to have a full night's sleep, reduces carer burn-out and helps enable that person to continue to provide care, thus delaying the need for long-term residential care.

Unfortunately, this is not common practice for many older people needing support to continue to live in their own homes, as observed by a service user –"*none [good things], my experience is that services are difficult to access, poorly administered"*. This experience was reflected in research carried out by Age Action, the Alzheimer Society of Ireland (ASI), Irish Association of Social Workers (IASW) and University College of Dublin (UCD) which explored social workers' experiences of meeting older person's care needs[1], in many Community Healthcare Organisation (CHO) areas, older people can't access the home care services they need. The lack of supervisory hours and

[1] https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_lr_for_web_2.pdf

night-time support directly contributes to the premature admission of older people to nursing home care.

Application process

The Health Service Executive (HSE) publication *Home Care Package Scheme* is a good resource for people applying for a Home Care Package[2]. This publication provides clear and accessible information on the application process. It recognises the older person's agency in that they can apply directly for a Home Care Package (HCP) themselves. Alternatively a family member/ friend can apply on their behalf. However, older people face a number of barriers in making an application. Older people living alone, without close family, may have difficulties due to literacy problems, poor sight or other impairments preventing them from completing the application form. In some CHO areas, a health or social care professional can assist the person complete the application, however in others, the local Health Office does not permit this. In addition, the form requires the applicant to provide the name of a person who will help them make "arrangements for your Home Care Package[3]".

This can be problematic for people who do not have family and do not wish to involve friends or neighbours in their home care arrangements. Without a designated person to monitor the HCP, older people in some parts of the country, particularly in rural areas, may not be able to access a HCP. Instead these older people may be directed into nursing homes, not because of their care needs, but as pointed out in the research on *Meeting Older People's Preference for Care,* "because the LTC option is easier [for health care and social care professionals] in the long term"[4].

However, information on the application process for home help is not in the public domain and applicants do not know the criteria for qualifying. Generally speaking, an application for home help is made by contacting the public health nurse in an area.

Social workers, applying for home help on behalf of older people, found the process very cumbersome, requiring a lot of paperwork to access even a single hour of home help per week. A social worker who took part in the research study *Meeting Older People's Preference for Care* described the process as:

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[2] http://www.hse.ie/eng/services/list/4/olderpeople/benefitsentitlements/HCPinfobooklet.pdf
[3] http://www.hse.ie/eng/services/list/4/olderpeople/benefitsentitlements/HCPAppForm.pdf
[4] https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_lr_for_web_2.pdf

“like begging, for example, a person fell out of bed broke ribs, couldn’t dress…I asked for one hour per week...process took three phone calls to the PHN...wrote a three-page report; included personal care for dressing and washing needed...have to make case sound really bad. Home help coordinator allocated three quarters of an hour per week.” [5]

Assessment

A standardised care needs assessment process is central to ensuring older people’s needs are met in appropriate and equitable way. An assessment of the person’s needs is a legislative requirement under the Nursing Home Support Scheme Act 2009. This assessment is undertaken by the Multidisciplinary Team (MDT) using the Common Summary Assessment Report (CSAR).The good thing about this process, is that it ensures a national common equitable assessment approach in the provision of long term residential care[6].

The CSAR is also used within the acute hospital systems to determine the person’s home care needs. However, it is not a requirement and there are no national set standards relating to level of need and home care services provided.

The consequence of this, is that local community care resources and not care needs assessment determine home care provision. As a result, older people, particularly when being discharged from hospital, can undergo the MDT CSAR assessment, but also another care needs assessment by the local Community Care liaison Public Health Nurse. This assessment is undertaken within the context of resources available, both the person’s and local home care services.

Hence, despite huge resources going into the assessment process, level of need does not determine home care hours allocated. Other factors including age, living situation, delayed hospital discharge, level of risk and family support are also taken into consideration. This deficit based approach means that where a person has family members providing care, they are less likely to be assessed as needing home care services[7]. The process of assessment is therefore subjectively based and locally determined criteria for prioritisation are used in each CHO area. The

[5] https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_lr_for_web_2.pdf
[6] http://www.hse.ie/eng/services/list/4/olderpeople/nhss/CSARGuidanceDocument.pdf
[7] ibid

CSAR is very much focused on the person’s physical care needs. The lack of attention to social care needs often exclude those with mental health issues and/or cognitive impairment/dementia from qualifying for services.

Older people in the community face additional problems getting an assessment. Waiting lists for assessment are in place resulting in older people not having their needs recognised or addressed in a timely manner, which could cause their health needs to deteriorate to a point at which they need hospital care and only then become eligible for home help.[8]

Provision of home care

For many older people, their home help is their only support and is invaluable in helping them maintain their independence to live at home. Flexible, person-centred home care provision enables the building of relationships between the older person and the carer, and can offer support for essential tasks such as shopping.

However, the lack of statutory framework in the allocation of home care services means that older people’s experiences in accessing services differ throughout the country.

“The home help service that is available is discretionary and there is no clarity about how or on what basis the service is allocated. Not knowing what to expect in terms of home help provision is a very unsettling factor for older people and contributes to a sense of vulnerability and a depletion of self-confidence in daily living.” (Age Action Glór Galway[9])

In some CHO areas there are long waiting lists for home help services, e.g. there were 554 people waiting in CHO 9 at the end of December 2016, compared to nobody in CHO 7[10]. People often must wait until the death of a client or their move into nursing home for hours to become available as attested to by a social worker interviewed for the research study *Meeting Older People’s Preference for Care* who said: “Often the situation is that you are waiting for someone to die to access hours.”[11]

[8] ibid
[9] We are grateful to the members of the Age Action Glór group in Galway who helped to inform this submission.
[10] Response to PQ 6494/17
[11] https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_lr_for_web_2.pdf

Home help hours available are minimal and ranges from less than an hour to a maximum of five hours per week, usually Monday to Friday, between 9am and 5pm. In some areas, very short, task oriented visits of less than an hour are the norm; this approach leaves no time for person-centred care that ensures care provision upholds the older person's dignity.

The types of services provided also vary between CHO areas. In many CHO areas, home care services only provide personal care. Assistance with Instrumental Activities of Daily Living (IADL) to support independent living such as shopping and meal preparation are rarely included as services. Determining needs within the narrow context of physical care needs and measurable tasks has consequences for people with dementia and mental health issues. Their psycho-social needs are not being met within the current definition of 'care needs'. For example, a person with dementia will be unlikely to be allocated supervisory hours, unless they live in a CHO area where this service was provided under the GENIO programme.

A further issue is the failure of home care services to offer consistency in staffing. Frequent changes to staff providing care can be confusing and upsetting for the older person, particular for those with dementia. This was raised by this carer who told us *"lack of consistency between carers should be minimised … too many strange faces is unsettling".*

The monitoring of home care being provided to an older person is inadequate. Many older people receiving home care services are in vulnerable positions; they live alone and are dependent on the home care worker to remain living at home. They are therefore reluctant to make a complaint and are more at risk of abuse, particularly financial abuse. There is no one body, no regulator overseeing home care provision, so concerns or complaints must be made directly to the provider These carers highlight issues that should be addressed through monitoring: *"my brother receives home care, [it is] poorly regulated, services can decline over time, [it] should be monitored*"; *"poor coordinating – hit or miss if service provider is competent or interested"*

In general, demand for all home care services far outstrips what is available so it is difficult for older people to get the level of service that their care needs' assessment indicates. The current selective approach to home care provision, the narrow criteria used to determine need, and therefore eligibility for home care supports, excludes many older people from having their needs adequately met in the community:

"*Our express wish to remain in our own home, as we age, with adequate home care provision is not currently being supported."* (Age Action Glór Galway*).*

Appealing decisions

The lack of transparency on the criteria to qualify for home care services makes it difficult to appeal decisions. Informal prioritisation occurs within CHO areas, but these 'rules' or criteria are not disclosed to the general public or other health and social care professionals. Social workers participating in the research, *Meeting Older People's Preference for Care*, reported that 40 per cent of those requiring home care hours did not get the hours they were assessed as needing. To ensure older people get the home care they need, social workers in some CHO areas, apply for more hours than required as explained by this participant in the research study *Meeting Older People's Preference for Care* - "*generally whatever is asked for would be reduced regardless of the older person's circumstances".*

Question 2, 3 and 4 ask whether the different services that are needed to help people stay at home work well together. This information will help to inform how services can work better together in the future.

2. Do you think that home care services work well alongside primary care and other community services to meet the needs of people who receive home care?

Note: Primary and community services include GP services, public health nursing, physiotherapy, speech and language therapy, occupational therapy, and respite care.

Yes _____ No___X__ Don't know _____

3. Do you think that home care services work well alongside hospitals to meet the needs of people who receive home care?

Yes _____ No___X__ Don't know _____

4. Do you think that home care services work well alongside informal carers to meet the needs of people who receive home care?

Note: informal carers are family and friends that provide care and support

Yes _____ No___X__ Don't know _____

If you have any comments in relation to how well home care services work with other providers of care, please include them below:

Home care services need to be better integrated into primary care and community services and not viewed as standalone services. For older people with complex needs, case management is required to monitor and ensure that the home care services continue to meet the person's need,

but also that the person is receiving interventions such as physiotherapy and occupational therapy to maintain functionality as part of their HCP. The implementation of the proposed Integrated Care Programme for Older Persons should support this more holistic approach

The current primary care model determines eligibility for services on the basis of a medical card. Older people without a medical card are poorly integrated into the system. In some CHO areas, they will not qualify for a visit from a PHN, hence cannot have their needs assessed so will not qualify for home care services. Nor can they access appliances/ equipment or primary care counselling.

Older people have to wait months to have their homes assessed for adaptation by an occupational therapist. Many are forced to pay privately to ensure they can live safely in their own homes. Changes are needed in the operation of the home adaptation scheme to enable it to deliver adaptations in a proactive manner before the older person is in crisis. For example Cluid's report, *A Home for Life,* highlights how minor adaptations such as grab rails in the bathroom can reduce the number of falls that older people experience and in this maintain independence[12].

The current policy of prioritising the provision of HCPs to facilitate discharge from acute hospital means older people in hospital can access HCPs more easily than those in the community. The average hours provided to those being discharged from acute hospital are often higher than that provided to community applicants[13]. However, in some instances, the package provided is time limited, in that the funding comes from the hospital and after a certain period of time, community care becomes responsible for the funding and home care hours are reduced. Resourcing and targeting HCPs for the acute hospital system discriminates against older people in the community in having their care needs met. At the end of April 2017, there were 2,204 older people waiting for HCPs[14].

There is a heavy reliance on family members to provide the majority of community-based care with an estimated 89.5 per cent of both personal care and household tasks provided by family

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[12] https://www.cluid.ie/wp-content/uploads/2015/10/A-HOME-FOR-LIFE-FINAL-28-10-15.pdf
[13] https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_lr_for_web_2.pdf
[14] Response to PQ: 26789/17

carers[15]. Instead of working alongside family carers, home care services are used as a substitute for family care. Older people receiving informal care may find it difficult to access home care hours, as they are not seen as a priority in some CHO areas. The types of supports informal carers need such as supervisory hours for people with dementia are not provided for in many CHO areas. Informal carers can be frustrated by the task-to-time approach (e.g. 30 minute time slots) and staff turnover (with carers regularly changing) and question the benefit of the care that is provided because of the upset caused to the person for whom they are responsible by these approaches.

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 ___X__ 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 __X___ No_____ Don't know _____
If you have any comments in relation to choice of home care services and providers, please include them below:

If you have any comments in relation to how home care services work with other providers of care, please include below:

The current system is very much premised on the provision of services based on a charity model rather than a rights-based statutory model. Article 8 of the European Convention on Human Rights makes clear that older people are entitled to right to respect for private and family life, home and correspondence. The enactment of the Assisted Decision Making (Capacity) Act (ADM) (2015), as part of the process to ratify the Convention on the Rights of Persons with Disability (CRPD), requires health and social care professionals to ensure all older people are involved in decision-making and care planning regardless of their disability.

[15] Care Alliance Ireland (2015) Family Caregiving in Ireland. Available at: http://www.carealliance.ie/userfiles/file/Family%20Caring%20in%20Ireland%20Pdf.pdf.

Older people therefore have a right to make choices about their daily life and should be able to have a fulfilling and active life. Hence their views on the types of supports and care they want and need should guide decision-making about services. Currently, older people and families feel 'lucky' to get 30 minutes home care at 8am in the morning. They therefore accept whatever home care they are offered, even if the service and timing of delivery does not fit within the older person's lifestyle (e.g. they were never early risers).

Self-reliance is important to older people; they want to keep their independence. The current range of home care services available offers little in the way of restoring maintaining or improving mental and physical functionality. The services provided focus on 'doing for' the older person tasks in the shortest time possible.

If older people are to be afforded choice and maintain independence, care and supports services need to expand beyond the current focus on personal care. Through consultation with older people in local communities, such as the County Council Public Participatory Networks, local communities should be encouraged and assisted to develop a range of supports like befriending, 'give a lift' and social eating programmes. Linking older people in with these supports should be part of community care provision.

Older people should have a choice of providers. However, it is critical that the State does not seek to abdicate its responsibility in this regard. Under human rights law the State is still the duty-bearer, responsible for ensuring that all providers, public and private, meet certain minimum standards.

We would also expect the State to continue to be the main provider of home help and home care services, functioning as the bedrock of the home care system. The introduction of a consumer model through the use of private sector mechanisms (introduction of competition into the provision of services) into the provision of home care with the aim of reducing the role of the State and increasing efficiency will not benefit older people.

Users of home care are not true consumers as, in practice, people have little opportunity to exercise real choice due to insufficient knowledge, physical and cognitive impairment and lack of

alternatives for those with more complex needs. It is also essential to guard against service providers 'cherry-picking' those clients with less serious needs.

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 apply for home care, how needs assessed, who can access services, what home care services are provided, how home care services provided, how home care services are monitored, how you can appeal a decision about home care

If older people are to enjoy the highest attainable standard of physical and mental health, as is their right under the International Covenant on Economic, Social and Cultural Rights, home care provision must move from a selective model, where the allocation of services are at the discretion and 'rules' of local management in each CHO, area to a universal model underpinned by rights. Older people whose care needs are such that they require support should be able to access this support to enable them maintain their independence and lead fulfilled lives.

Application process
The Health Service Executive (HSE) should be required to publish information leaflets/booklets on home help service, similar to those on HCPS. The information provided should outline the application process, what home help covers, the assessment process, and the process for appeal. These booklets should be available in local post offices, social welfare offices, citizen information centres and other community hubs etc.

Through their GP or other health and social care professional, older people experiencing difficulties with IADLS and/or personal care should be able to apply for home care services.

Assessment
The Single Assessment Tool (SAT), when implemented, should provide a national standard for the comprehensive health and social care needs assessment for older persons.

The SAT provides a more person centred approach to assessment as it gives a 'voice' to the older person and promotes independence by focusing not just on the person's disabilities but also on her abilities and capabilities. It takes into account physical and psychosocial needs and things older persons need assistance with.

The data generated should avoid the need for multiple assessments and support decision-making in care planning and service provision in a consistent manner across CHO areas, ensuring fairness of access to resources.

Provision of home care

1. Transparency in entitlement to care

There needs to be transparency in entitlement to care. Whilst the European Convention on Human Rights and the Convention on the Rights of Persons with Disability (CRPD) recognise and confirm the right to care, legislation at a national level is needed to strengthen the formal rights of older people to care.

A statutory entitlement to care allows older people to claim their rights and steers policy and resources to the State's legal responsibilities. Home care services underpinned by legislation can also address the absence of any rigorous monitoring, regulation or quality standards. Clarifying entitlement and service provision through legislation increases transparency and strengthens older people's rights. It should also make the appeal of decisions more straight forward.

2. Reorientation of thinking

The WHO Report on Ageing and Health 2015 points to how long-term care will have to evolve in radical ways if growing need, driven by rising life expectancy, is to be met in a fair and sustainable manner. This requires changing the way we think about long-term care. At a societal and political level, long-term care should be recognised as a public good, not as an individual responsibility. It must be understood in a more positive and proactive way, not as a minimal and basic safety net that provides supports to those who can no longer look after themselves and are at risk[16].

The focus needs to move towards optimising intrinsic capacity and compensating for a lack of capacity at a level that maintains an older person's functional ability and ensures dignity and well-being[17]. For example, in Denmark, municipalities are required by law to assess if a person in need of home care services could benefit from a reablement programme. A specific aim of home care services therefore is restoring, maintaining and improving functionality so services are combined

[16] http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf?ua=1
[17] http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf?ua=1

with a strong emphasis on rehabilitation and reablement[18]. Similarly in Scotland, reablement enables the freeing up of traditional home care resources[19].

There are positive indicators that identifying older people at risk for becoming frail and providing them with reablement and rehabilitation programmes results in improvements in health-related quality of life and well-being and reduced personal home care costs. A HSE Report carried out by Mazars highlighted that reablement programmes in England were cost-effctive and reduced the need for homecare.[20].

This requires moving away from restricting home care services to those with higher support needs or who are more vulnerable, and instead developing and providing services for older people aimed at promoting their health, well-being and independence and to prevent or delay their need for higher intensity care. Providing home care support for older people with low to moderate needs has been shown to be effective in avoiding the need for more intensive home care, residential and hospital care in the future[21].

3. The provision of high-quality home care that is more responsive to older people's needs and choices

The lack of flexibility in the provision of hours and the limited types of support available must be addressed. Of particular concern is the trend towards time-to-task home care visits of 30 minutes or less. The findings from a survey, *Care is not a commodity*, published by the UK Home Care Alliance in 2012, present a worrying picture of the way in which home care services are commissioned by local councils.

In Northern Ireland 87 per cent of visits commissioned were for between 15 and 30 minutes resulting in the dignity of service users being put at risk, raising the question whether inappropriate commissioning of short visits amounts to institutional abuse; Continued downward-

[18] http://www.sum.dk/~/media/Filer%20-%20Publikationer_i_pdf/2016/Healthcare-in-dk-16-dec/Healthcare-english-V16-dec.ashx

[19] http://www.audit-scotland.gov.uk/uploads/docs/report/2016/nr_160310_changing_models_care_supp1.pdf

[20] http://www.hse.ie/eng/services/publications/olderpeople/Activity-Resource-Review-Home-Care-Services-May-2016.pdf

[21] https://www.nice.org.uk/guidance/ng21/resources/costing-statement-488862829

pressure on the prices paid for care, where lowest price has overtaken quality of service in commissioning decisions[22].

Older people have a right to expect dignified, quality, home care services that keep them safe in their home and able to remain in their local community. Home care is not a commodity to be purchased like walking aids, it requires the building of trust between the care recipient and giver. That can create problems when carers are obliged to stick to a rigid set of minutes to accomplish a task. The amount of time needed to support an older person to, for example, have a shower will vary depending on the individual, their physical and mental health and their cognition.

The delivery of care needs to be go beyond narrow definitions of the task e.g. provision of shower, to include social interaction where the home help can sit down and have a cup of tea and a chat as part of undertaking specific tasks. These types of things keep the person at home longer. Service users want home care services that are "*tailored to the individual (more so than at present) and adapted to suit changing need, i.e. proper monitoring*".

Home care services focused almost exclusively on the provision of personal care are not meeting the specific needs of this cohort of older people. For example, many older people live alone and their families now live in urban areas or abroad. For these older people, not being able to access support with domestic tasks or night time supervision, can mean their only choice is to move into a nursing home. The wider needs of older people could be met through the development and provision of supports, particularly a range of domestic supports that are flexible enough to meet the older person's needs; supervisory support to people with dementia; basic services such as access to aids and appliances, home adaptations, social clubs, day centres, meals-on-wheels, befriending services, public transport, home care support services and supported housing.

Consideration should be given to how other countries address the lack of an individualised, needs-led approach. For example, in Denmark, standardised lists of available services related to four levels of functional ability have been developed. To ensure flexibility in home care services and to empower service users to direct and facilitate the daily negotiation of needs, service users can exchange services within the same category as long as the home help can provide them within the

[22] https://www.ukhca.co.uk/pdfs/UKHCACommissioningSurvey2012.pdf

same time span[23]. In Scotland and Germany, service users can receive a payment/voucher which enables them hire their own care provider or purchase services[24].

4. Access to home care services based on need not on local resources and geography

Currently, older people's access to home care services are determined by the resources available in the particular CHO area in which the older person resides. Eligibility is decided locally within the context of resources available, demand and subjective judgments as to the most vulnerable. Hence, geography and not need determines the number of care hours allocated and the types of services provided, which in turn determine whether the older person can remain living at home.

To provide home care services in an equitable way based on need, each CHO area should be allocated ring-fenced funding based on their demographic profile and other health indicators. Each CHO area should be obliged, in consultation with older people, to provide a wide range and level of community and home care services, sensitive to local conditions, that meets the needs of their older population. To ensure equitable access and consistency in relation to eligibility for community and home care services, there should be a universal entitlement.

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:

As outlined previously, information on the application, qualifying criteria and home care provision is not readily available to the public. Older people requiring home care services are often in a vulnerable situation due to their care needs and face many barriers in accessing information. For example, they maybe unable to visit or call information lines due to their physical or cognitive condition; they may not use/have access to the internet; they may have no close family or friends. Family members and service users point to how *"very dependent on who you get to speak to, [information] not consistent*" and "[*there is] little knowledge or awareness of what is available*"

[23] Rosgaard, T (2012) Quality Reforms in Danish home care – balancing between standardisation and individualism. Health and Social Care in the Community (2012) 20(3), 247-254. https://www.ncbi.nlm.nih.gov/pubmed/22512317

[24] Kiersey, R.A and Coleman, A (2017) Approaches to the regulation and financing of home care services in four European countries. Dublin, Health Research Board. http://health.gov.ie/wp-content/uploads/2017/04/FINAL-HRB-Evidence-Review-7-4-17.pdf

Older people need information to make decisions about their future care. Hence, all CHO areas should be required to make information about home care services, eligibility criteria and the application process available to older people. With policy now focused on delivering health and social care through local primary care centres, GPs and other health and care professionals who interact regularly with older people should provide them with information and assist them with accessing the services they need. For example, one older person who completed their survey through Age Action suggested that there "*should be a nominated person [in HSE] with guaranteed reply time".*

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 ___X__ No_____
If you have any comments on this issue, please include them below:

Information on tax relief is not widely disseminated within the public arena. As a family member pointed out, "*info [on tax relief] only came from Private Home Care Provider- not HSE*".

People are unsure of how to apply for this relief as outlined by this family member- *"in the case of shared expenses, me and my Dad, who claims tax exemption".*

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 apply across the country in relation to the following?

- How you apply for services Yes __X_ No___ Don't know___
- How your need for services is assessed Yes __X_ No___ Don't know ___
- Who can access services Yes __X_ No___ Don't know ___
- What home care services are provided Yes __X_ No___ Don't know ___
- How home care services are provided Yes _X__ No___ Don't know ___
- How home care services are monitored Yes __X_ No___ Don't know ___
- How you can appeal a decision about your home care Yes __X_ No___ Don't know ___

If you have any comments on this issue, please include them below

As discussed under previous questions and illustrated in the research *Meeting Older People's Preference for Care*, there is a huge geographic variations in the assessment, qualifying criteria and allocation of home care services. In areas with higher proportions of older people, services have to be spread more thinly to ensure those most vulnerable can get some kind of service.

As already highlighted, the SAT should ensure consistency in assessment, however currently there does not see to be any process in place to ensure consistency in the allocation of home care services. Other countries use categories of services linked to care levels e.g. Common Language system in Denmark. In Ontario, a level of care framework is used to ensure services are consistent across the province[25]. Level of care frameworks are typically divided into three or more levels. The specific focus of care interventions at the different levels, e.g. support for activities of daily living (ADL), instrumental activities of daily living (IADL), therapies and professional services ensure that the diverse needs of older people can be met and the person can transition across levels if their needs change. Benefits include enabling more consistent and transparent service levels by focusing care needs and services into similar layers[26].

Question on Quality Standards

At the moment, there are no national standards for home care. This means that the quality of home care can differ among home care providers. Other countries have introduced national standards. We would like to know your views on whether or not you think national quality standards should apply in the future to home care providers in Ireland.

Note: National standards would mean that every home care provider would have to meet a minimum standard of quality in order to continue providing home care services.

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 ___X__ No_____ Don't know _____

If you have any comments on this issue, please include them below

If older people are to be provided with quality home care all providers must be required to adhere to the same standards to ensure care is delivered by trained and qualified care workers. We must

[25]http://healthcareathome.ca/ww/en/news/Documents/Roadmap%20to%20Strengthen%20Home%20and%20Community%20Care%20-%20Overview%20May%2013%202015.pdf

[26] http://oaccac.com/Policy/Documents/LOC-Jurisdictional-Review-final.pdf

avoid a race to the bottom where cost, and not quality, determines standard. The Migrant Rights Centre of Ireland's (MRCI) analysis of the home care sector revealed low pay rates and conditions experienced by care workers. These included zero hour contracts, workers not being paid for travel between clients, and being assigned duties without adequate training[27].

From an older person's perspective, Age Action Glór group in Galway explains how "*it is really important that we can have confidence in home help workers. We need to know that they are honest and discreet when entering our personal special space that is our home. The monitoring, accountability, evaluation and transparency aspects of the service therefore need to be addressed by a dedicated regulatory body similar to the HIQA model*".

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 ___X__ No_____ Don't know _____

If you have any comments on this issue, please include them below:

The greatest demand on services now and in the future is to meet the care and support needs of people with multi-morbidities requiring health and social care. The present skill-mix does not meet these needs. As pointed out in a report by the MRCI, carers are expected to meet the intimate needs of older people such as catheter insertion, without any formal training[28].

An NHS briefing paper[29]identified the need to realign training budgets and career pathways. Approximately 60 per cent of the NHS training budget is spent on the most highly paid health professionals (doctors, nurses and allied health professionals), with no national funding for

[27] Migrant Workers in the Home Care Sector: Preparing for the Elder Boom in Ireland'http://www.mrci.ie/wp-content/uploads/2015/09/Migrant-Workers-in-the-Home-Care-Sector-Preparing-for-the-Elder-Boom-in-Ireland.pdf
[28] http://www.mrci.ie/wp-content/uploads/2015/09/Migrant-Workers-in-the-Home-Care-Sector-Preparing-for-the-Elder-Boom-in-Ireland.pdf
[29] http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/perspectives-nhs-social-care-workforce-jul13.pdf

training less qualified workers such as healthcare assistants, despite the fact that biggest growth in need will be in hands-on, out-of-hospital, and social care[30].

To ensure care workers are competent to provide good quality care to older people, training is essential. Training will foster high standards of professional conduct and competence, For example, if people with more complex needs are to be cared for in the community, care workers with more specialist training will be required.

From a service user perspective, "*delivering good quality educational training courses will provide opportunities for subsequent employment that is integral to proper ethical home care service provision"* (Age Action Glór Galway).

However, achieving a minimum level of training should not be over burdensome, in terms of cost and time commitment, particularly for current home car workers. Hence State funded blended learning courses, which uses both on-line and face-to-face modules, with accredit third level institutes should be developed to ensure staff with years of experiences are retained within the sector. Service users stress the importance of practical training: "*training should be practical rather than academic"*

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:

It is important to be clear, before responding to this question, that the concept of 'limited State resources' is often an artificial one.

[30] ibid

The amount of resources available for spending on public services, like home help, is – to a large extent – a political choice made by the Government of the day. Other choices, such as increased spending in other areas or cutting taxes, reduce what is available for spending.

A human-rights based approach to budgeting is based on the principle of identifying the maximum available resources to the State and then making decisions on priorities based on need.

At the core of funding is, first, a philosophical question as to whether we, as a society, see the provision of home care for older people as a collective, social, responsibility or one that is the responsibility of the individual and his or her family.

The WHO Report on Ageing and Health 2015 points to how we need to rethink long term care. We all need care and support at some stage in our lives so long-term care (which includes home care) should be recognised as a public good[31].

As a public good, a universal home care scheme should be provided to all those who can benefit. Collective responsibility implies collective funding through general taxation, social insurance or a combination of these streams.

In other European countries, such as the Nordic countries, Germany and Scotland, home care services are viewed as a public good, with full or near full universal entitlement to basic services. These schemes are funded from a combination of general taxation, social insurance and co-payments.

Secondly, is meeting the care needs of older people a State priority? Ireland is spending less per capita on older people as a group than eight years ago. In 2009, it was €3,514, by 2015, it had reduced to €2,612 per capita[32]. Just over 40 per cent of potentially dependent population receive long-term care support (either at home or in institutional setting) compared to EU average of 48

[31] http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf

[32] All Party Oireachtas Group on Dementia, 'Report Two: A Statutory Scheme for Home Care Round Table Event' (Houses of the Oireachtas, March 2017

per cent. The coverage rate in Denmark, Norway, Sweden and the Netherlands is over 60 per cent[33]. It could be said that the State has not prioritised the needs of older people.

Thirdly, as the number of older people in Ireland grows, and with it demand for home care, so funding has fallen. For nearly a decade there has been no increase in the funding for home care services, with €331 million allocated for home care services in 2008 and €320 million in 2015[34], despite a 25 per cent increase in the population of those aged 65 and over and a near 30 percent increase in those aged 80 years in the same period.

For some time the State has been spending below what is needed to maintain, let alone expand, home care services. Hence the level of unmet need has grown, which results in the need for more intensive supports and increased need for health services. The funding of home care services in Ireland is therefore starting from a low base.

In 2013, public expenditure on long-term care as a share of GDP ranged by more than a factor 14 in the EU, with France, Belgium, Demark, Sweden and the Netherlands spending between 2 and 4.1 per cent; Ireland, Romania, Portugal, Poland spend less than 1 per cent[35]. This variation in public spending on long term care reflects population structures and coverage. Ireland spends a third less on the provision of home care compared to institutional care spending, compared to EU average of 50 per cent on home care and institutional care[36]. The State therefore needs to increase spending on home care services to a level equal to other European countries.

General taxation offers a broader tax base, maximises risk pooling, and is democratically accountable, however accessing funding on a yearly budgetary basis is problematic due to competing priorities, particularly when services for older people in Ireland is low on the political agenda.

However, general taxation funds comprehensive home care services in Scotland and Denmark and Sláinte Care Report (2017) propose a universal home care scheme as part of its 10 year plan[37] .

[33] http://ec.europa.eu/economy_finance/publications/european_economy/2015/pdf/ee3_en.pdf
[34] https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_lr_for_web_2.pdf
[35] https://ec.europa.eu/info/sites/info/files/file_import/ip037_vol1_en_2.pdf
[36] https://ec.europa.eu/info/sites/info/files/file_import/ip037_vol1_en_2.pdf
[37] https://www.oireachtas.ie/parliament/media/committees/futureofhealthcare/Oireachtas-Committee-on-the-Future-of-Healthcare-Slaintecare-Report-300517.pdf

With the number of people 65 and over expected to double over the next 30 years, with the greatest increase occurring in the over 80s[38], the funding base for long-term care (including home care) will probably need to be widened to ensure sustainability.

A social insurance model would increase the visibility of long-term care, pool risk, provide contributions over a lifetime and funding would be ring-fenced. For example, Korea introduced a social insurance model ten years ago paid for through income related premiums and administered by the national health insurance scheme.

However, like any public service, to ensure sustainability costs need to be controlled. In most countries, demand for home care services has increased and sustainability has become a policy issue. To meet demand and sustain the services, countries have come up with different policy frameworks. These include co-payments, increased thresholds for qualifying, focus on reablement, reorientation of social resources found in the voluntary sector and wider civic society, including increased reliance on family care.

For example, co-payments have been introduced in a number of countries, such as Scotland, where service users may be charged for help with housework, however there is no charge for personal care. In Sweden, the threshold for accessing home care services has been raised. In Denmark and Scotland, reablement programmes are in place to reduce the need for home care services. In other countries, voluntary programmes like befriending are being used to supplement formal care.

Sustainability therefore can be achieved in a number of ways. It should not just involve charging home care service users for services.

- Firstly, the thinking/objectives of home care services need to change (as discussed already) with the State meeting it's duty of care to protect the right of people in Ireland to enjoy the highest attainable standard of health. Hence the State must resource and provide preventive and restorative interventions e.g. chronic disease management, rehabilitation and reablement.
- Set a basic, universal, standard set of care that covers nursing, rehahilitation, reablement, therapies, counselling and personal care and which is provided free of charge to all those

[38] https://tilda.tcd.ie/assets/pdf/glossy/Chapter1.pdf

assessed as in need. A level of care framework is developed using data from SAT. This data should indicate the types of services and supports a person with a particular level of care requires to live well. Services should include practical help e.g. laundry, cleaning, shopping. People cost share for services (outside those covered for all) subject to income thresholds, with exemption or social assistance mechanism for people on low incomes. A maximum limit for co-payments is set at national level (this will control cost to those with highest care needs).

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:

If we as a society want a system that ensures equitable access to comprehensive services, we must be prepared to fund a universal scheme for home care. As pointed out under question six, older people in need of homecare services, particularly those with more complex needs, should not be expected to negotiate with providers around care hours, nor do they have the resources to 'purchase additional hours' within the market place. Home care services are part of the health and social care system, a public good and as such non-excludable (people who can not pay should not be prevented from accessing). The State needs to increase its role in home care provision, not reduce it, to ensure the protection of older people's right to live safe and fulfilled lives.

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