Discussion Document on the Consultation Process for the Establishment of a Statutory Homecare Scheme

19 April 2017

Introduction

Organisations from across the NGO sector welcome the Minister for Mental Health and Older People's announcement of a consultation process on establishing a new statutory homecare scheme. The Minister told the Dáil that she wishes to run a consultation process that "will allow all those who have views on this topic to have their say, including older people themselves, their families and health care workers". This discussion document has been prepared to assist with that process.

It is a stated objective of successive governments that people would, where possible, continue to age within their own homes and communities. As acknowledged by the Minister, this process is about ensuring that this objective could be supported with a statutory scheme, thereby keeping more people at home.

The NGOs that have contributed to this paper (listed at the end) wish to support the Minister and the Department in creating a robust consultation process that will provide a context for any policy or legislative work and will also encourage people who receive care, as well as those who deliver care, to have their voices heard.

The issues which should be addressed by submissions are as follows:

A Definition of Homecare

The consultation process must tackle the issue of what constitutes homecare, identifying what services are within the remit of the scheme. It needs to find agreement on what structures need to be in place to ensure that homecare can provide a range of services so that what is appropriate to the person is covered and, at the same time, is sustainable and can be delivered in the person's home.

Current inconsistency of homecare delivery

Homecare, as it is delivered across the country, is not consistent. For example, different systems and eligibility criteria are in place to access home help services in different parts of the country, while homecare as a whole is not regulated.

There is a need to define the parameters of what can be constituted homecare under any legal and regulatory frameworks and the consultation should include identifying the appropriate body or mechanism to regulate homecare in Ireland. A definition of homecare must capture the diverse range of needs that are being met by homecare workers.

For example, people with dementia may require social supports; for people with mobility issues, their needs may include support with everyday activities but not with what is defined as 'activities of daily living'.

There is also a need to clarify how homecare interacts with Personal Assistant Services, a service available to those receiving *Disability Services* but not *Older Persons' Services.*

The place of technology in homecare
Technological supports in homecare also need consideration. Technology cannot replace careworkers. The potential for a strong complementary relationship, however, means that it must be considered both in terms of medical technology such as diagnostics and medical monitoring as well as assistive technology which can support people with various activities, particularly people who have mobility difficulties. These could include, for example, telecare and telehealth, environmental controls, voice prompts etc.

Core Principles Underpinning Homecare
The scheme, as proposed by the Minister, will put homecare on a statutory footing. Clarity is needed about the principles that underpin the delivery of the scheme. Potentially, the topics that could be discussed within these core principles are:

Person-centred care
As with all other care services, a person-centred approach should form the basis of homecare. This is about recognising the needs and preferences of individuals who make up the diverse population known as ‘people in receipt of homecare’. Consultation can tease out appropriate equivalent processes for encouraging the discovery of people’s needs and wants in a homecare setting, akin to what is promoted under Theme 1 of the HIQA National Standards for Residential Care Settings for Older People in Ireland.

There is also a need to support the mechanisms around assisted decision-making / co-decision making under the 2015 legislation and for redress and advocacy mechanisms that are properly resourced for those times when care does not meet the recipient’s own wishes.

Regularising carework
In order for a homecare scheme to work effectively, it will need to tackle employment within the sector and value the workers who deliver care. The issues within this sector include: the lack of a homecare workers register, working hours, zero-hours contracts, lack of career development structures and labour inspections.

If someone is receiving care from family members, either on a regular or irregular basis, this should not exclude the recipient from homecare packages. The 2012 National Carers Strategy identifies Family Carers as key care partners. Both Family Carers and the providers of paid homecare need to invest time in building relationships with each other that are characterised by consultation, respect and ongoing communication.

There are also a number of issues faced by migrant workers in carework which also require consideration, such as discrimination, legal status and communication barriers.

Security of the person
For those receiving care at home, there is a need to promote the security of the person in receipt of care. By the very nature that someone is receiving care, they are restricted in some way which may mean that they have difficulty ensuring their right to security, leaving them open to violence, abuse or neglect. While the vetting of careworkers is vital, it is also about ensuring that an advocacy mechanism is available for anyone using homecare. Careworkers also need to be able to work safely.

Homecare across the life-course
The consultation process needs to consider how homecare is delivered across the life-course rather than there being material differences between homecare delivered under *Disability Services* and *Older People’s Services*.

Quality of Care, Inspection and Supervision

The consultation must consider how best to provide a robust set of processes that will assure quality of care for those who receive homecare. For example, homecare is not amenable to the same inspection processes which prevail in residential and day care settings. Inspection models used internationally need to be reviewed.

Assuring quality in careworkers

The consultation can explore how quality can be assured. Quality of care requires properly trained and certified careworkers who have received appropriate training to provide care in the home, rather than exclusively in acute or institutional settings. Workers also need to be supported and supervised to operate knowledgably in a person-centred context where they understand the recipients of care. Careworkers also need to have sufficient time to deliver agreed care in a context of trust and have the skills to be able to deliver different types of care, e.g. end of life care.

Inspection and complaints

The consultation can also helpfully explore the mechanisms whereby homecare can be inspected and a formal complaints procedure is put in place.

Integration with Public Policy and Social Supports

The consultation can usefully explore how a robust homecare scheme should interact with pre-existing policy around: health and wellbeing, the National Dementia Strategy, the National Carers' Strategy, the National Positive Ageing Strategy, ratification of the CRPD and the National Neurorehabilitation Strategy. As the health sector reorients itself with a focus on maintaining and building health and resilience, homecare can provide reablement and rehabilitation. Responsive and flexible homecare can support with reducing admissions to both residential care and to acute care, with associated savings in expenditure.

The consultation can also consider how the scheme will interact with other schemes such as the NHSS, home adaptation grants and with various other services and supports such as acute services, primary care, Section 38 and 39 NGOs providing direct services, as well as age friendly initiatives in local authorities. It should also consider other consultations and strategies such, for example, the Personalised Budgets Taskforce.

Access and Availability

By placing the scheme on a statutory footing, it should provide people with care as needed, regardless of age, geography or economic circumstances.

The consultation process is well-placed to explore how access and availability currently works in practice. It can consider how homecare hours are currently allocated and what changes people would like to see. It would also provide an opportunity to explore types of assessments which could be used (both medical and social) to understand how best to allocate services in a timely and equitable way. There does not appear to be clarity about how this currently happens.

A discussion about how recipients are prioritised and the potential to provide low-level supports as a preventative or a reablement measure for those at risk of needing much higher levels of support would also provide useful information to a consultation. It is also helpful to discuss timeliness of care, particularly in the context of palliative care.

There should also be consideration about how people become aware of care options. Information must not simply be available; it is critical that is accessible and easily understood, and that people are facilitated to make choices in that regard.

Funding Mechanisms

The consultation process must explore funding mechanisms that will ensure that a robust homecare scheme can be delivered year-on-year, accessible to those who would most benefit from it. It may also prove useful to consider, in the context of defining homecare services and the principles underpinning it, to seek opinion on how it can best be funded and, where tendering mechanisms are in use, what criteria might be prioritised in order to fund better rather than merely cheaper services.

Creating a Wide and Inclusive Consultation Process

While best practice around consultation processes will be in place, such as a published terms of reference, a timescale and clarity about what will not be addressed, the consultation process needs, according to the Minister, to "allow all those who have views on this topic to have their say".

In order to facilitate this, it is important to engage the following groups:

> *Recipients of care*
> This would be people of all ages who receive care at home, which would include those with physical or sensory disabilities, those with intellectual disabilities or mental health issues and people living with dementia
>
> *Family Carers*
> This would include family, neighbours and friends who provide significant levels of care at home.
>
> *Careworkers*
> This would include paid careworkers including those who work in private companies or social enterprises as well as careworkers in public settings. It would also mean including those from migrant communities working as carerworkers.
>
> *Those providing complementary services*
> This would include those who provide the services that can enhance the provision of the scheme and are providing complementary services such as befriending, social activities, meals-on-wheels
>
> *Those providing medical and social services*
> This would be PHNs, social workers, occupational therapists, SLT's, specialist nurses (catheter nurses for example), home phlebotomists, as well as medical gerontologists

In order to achieve such a diverse consultation process, it requires materials and mechanisms that are appropriate to the diverse audiences that need them.

Hard-to-reach audiences

People with disabilities, cognitive impairments, dementia life-limiting illnesses and professional carers, migrant workers and family carers can be hard to reach, but their views and insights, are vital in shaping a robust homecare scheme.

Consultative fora are useful policy processes as they bring people together specifically to discuss a point of policy. In order for this to work for the audiences listed above, however, special provisions may need to be put in place to make sure that they can participate fully. This may inform when and how the process takes place, and may include, the provision of transport, translation services etc.

Other possible approaches may be the commissioning of a parallel research process that will undertake in-depth interviews with a diverse range of people who are in receipt of homecare and with people who provide care.

Providing a context

In consultation processes, it is important to gather the practical experiences of those who are set to benefit from a scheme. It is, however, vital that people understand the context into which they are providing their insight and experiences.

The process should provide material in formats that are suitable for the audiences that will be using them. For example, a Plain English version of the Health Research Board report which will explore different international models of providing homecare should be made available as part of the process. A low-literacy publication explaining the process would also be useful for people with intellectual disabilities or people delivering care who do not have English as their first language.

It should also provide sufficient detail to give people an overview of support needs and costs currently met, unmet and projected, broken down by geographical areas , informed by OECD data and other reputable international providers of research and policy analysis.

Feedback mechanisms

Even with a number of consultation fora, the process will still need to presume that many people receiving care or providing care will not be in a position to attend events to provide feedback. This will require other feedback mechanisms such as a telephone / Skype process and the circulation of a survey on homecare.

Following-up

The process needs to have a dissemination mechanism to follow up with those who provided their insight and experiences to the process. While providing a satisfying affirmation to participants, it is also an ethical approach to participation in a discovery process such as this. It is also a mechanism to prove to people that their participation can have an influence on how policy is shaped.

We also believe that once the consultation has been concluded there is a valuable role that we, as organisations representing homecare clients, Family Carers and careworkers, can play in working with the Department to shape the final design of the proposed homecare scheme and we would like to put on the record our willingness to play our part.

List of NGOs who Contributed to this Paper:

Active Ageing Partnership, Age Action, Age & Opportunity, Alone, Alzheimer Society of Ireland, Care Alliance Ireland, Disability Federation of Ireland, Family Carers Ireland, Irish Association of Social Workers, Irish Hospice Association, Migrant Right Centre of Ireland, MS Ireland, Sage / Third Age