

Submission to Sage Forum on Long-Term Care

February 2016

Introduction

The Citizens Information Board (CIB) welcomes the opportunity to make a submission to the Sage Forum on Long-Term Care. The submission draws on feedback from staff working in Citizens Information Services (CISs) and details the challenges faced by older people in getting the supports they need to live at home or to move into supported housing or a nursing home.

The Citizens Information Service¹ dealt with 79,945² health service-related queries in 2015. There were also 50,517 queries categorised generally as 'Older and Retired People', 35,876 relating to 'Carer's' and over 3,880 specifically categorised as 'Health Services for Older People'. Over three quarters of callers to CISs identified their age range, with 13% of these being aged 66 and over.

Some of the queries in these categories refer to the struggles older people encounter when living independently or in residential care. They also highlight the issues older people and their carers face when they are transitioning from hospital into nursing home care or back home again.

The Citizens Information Board also runs the Assist Ireland website and helpline which provides information on assistive technology (aids and appliances) for older people and people with disabilities. In 2015 there were 355,432 unique visitors to the Assist Ireland website and the helpline dealt with over 1,100 queries many of which referred to the difficulty older people had getting the equipment or adaptations they required to live safely and comfortably at home. Some of these queries also referenced the difficulty caused by delays for assessments and adaptations, which often left some waiting in unsuitable accommodation or unable to return home from hospital.

This submission has drawn from the CIS and Assist Ireland data as well as previous Citizens Information Board policy submissions on the area of older people and long-term care.

¹ National network of 42 independent Citizens Information Services supported by the Citizens Information Board.

² Overall services dealt with over 600,000 callers and almost a million queries in 2015.

Current Long-Term Situation and Issues

The current long-term care situation in Ireland is divided into three main solutions, residential care (private, public and voluntary), community care services (such as home help) and home care packages (packages which include a range of community supports tailored to the individual). There are also a number of means-tested housing adaptation grants and schemes that allow a person to adapt their home so it is suitable for their needs as they get older or acquire a disability.

Consistently government health policy has stated the priority to keep people in their homes as long as possible if that is their desire. This marries with findings from most statistics and surveys in this area, which highlight that the majority of older people would prefer to stay at home. These surveys also show that the older person's quality of life is improved at home if they have the appropriate supports in place as they are in a familiar setting and immersed in the community.

But currently there is a disparity between the policy and the reality of what is happening in long-term care due to a legislative imbalance. At the moment there is legislation in place for the Nursing Home Supports Scheme for people accessing residential care but there is no such legislative framework behind home care packages and community supports. This means that community supports are often under-resourced and unreliable which results in an inevitable bias towards residential care.

Due to recent cultural and economic changes in Ireland people who would have historically provided informal care for older people in the community are now no longer available to do so or will be unable to do so into the future. The Central Statistics Office 2012 finds that 114,000 of the 187,000 carers in Ireland are women and half of these are aged under the age of 50. Recent employment equality has seen a growth of women in full-time employment which means that many women will no longer be available to care for older relatives in the home. Recent emigration, migration to Dublin for work and the extension of commuter belts also feed into this reduction of "traditional carers". This population relocation means that many would-be carers no longer live close to their families to provide informal care. These changes all reduce future levels of available carers and increase the responsibility on the State to provide these services into the future.

These cultural and population changes have also resulted in another issue for older people, social isolation. It is important that any new strategy in this area recognises the importance of social interaction for positive mental health and quality of life.

As Ireland's older population increases and with it the demand for long-term care solutions a strategy on how to address the current situation and improve it for future generations needs to be discussed and implemented.

Addressing Forum Questions

Question One: The challenges currently experienced in getting support to live at home or move into support housing or a nursing home?

The challenges currently experienced in getting support to live at home:

Repeatedly research has shown that the majority of older people would prefer to live at home as long as possible. Public health policy also reiterates this goal, though there are currently a number of challenges that older people experience when trying to access supports to live at home some of which are outlined below:

Reduction in community care supports and home care packages

Community care supports such as home help, meals services and public health nurse services can enable many older people to live at home with minimal supports. Though due to cutbacks and restrictions on HSE recruitment many older people are feeling the effect of a reduction, loss or denial of these frontline services which in certain cases mean that the person may no longer be able to remain in their home.

“No HSE home help hours provided on weekend evenings even though the person has full care needs at all rising/bedtimes. Her husband who is her full-time carer has a heart condition and is the only other person in the house. The prospect of long-term care looms large and would not yet be necessary with the proper support”

The Home Care Package scheme, which provides a tailored range of home supports to the older person, is not established in law which means the individual has no automatic right to avail of services under the scheme. Each HSE Area has responsibility for the operation of the scheme within the resources allocated for it in that area. This means that the level of service or support a person receives may vary considerably in different parts of the country.

Transitioning from hospital to home care with community supports

There is a lack of linkages between hospitals and community health services, which results in people being discharged from hospital without adequate supports in place for them in the community, which in turn can lead to readmission.

“Elderly patient, suffered a stroke two weeks ago, is to be discharged from hospital and sent home without any provision for follow up care.”

Delays in getting adaptations and specialised equipment for people moving out of hospital mean that they may have to stay in hospital longer or move to a nursing home until their home has been adapted to suit their requirements.

Waiting times and funding for Adaptation Grants and Aid and Appliances

The Housing Adaptation Grant for People with a Disability and the Mobility Aids Grant Scheme provide funding through the local authority's for adaptations to the person's home so it is accessible and safe for them. The grants are means-tested and funded from each local authority budget which means that funding can run out so a person may have to wait until the local authority's budget is allocated for the next year to access the grant. This also means that coverage differs from area to area, with some areas running out of funding earlier than others.

No work can begin on adapting the house until the application has been completed and approved as grants are not be paid retrospectively. An Occupational Therapist's assessment is required to complete the application process. There are currently long waiting lists for occupational therapy services in Ireland which can lead to long delays in applications and getting the work done.

“Elderly lady looking for housing adaptation grant, Occupational therapist report required, HSE waiting list for OT assessment long, delaying application, impact on patient dignity re. toileting”

The Housing Adaptation Grant in its current incarnation is only really useful if the person has a slow onset of a difficulty and can wait for the funding for these grants to come through. Due to the slow administration of the grant and limited funding it is not really suitable when there is a sudden change in a person's mobility or ability that requires immediate changes to their home.

There is a lack of information about adaptation schemes and the provision of aids and appliances to medical card holders. Clients are unclear of their entitlements and where to access them. Often people and their families are in a stressful situation when trying to find out information about care options and equipment, therefore the information should be more readily available and the process should be more transparent and reactive.

If you do not have a medical card you may end up having to buy the equipment you require to live at home. As this equipment is often quite specialised it can be very costly, for example a curved stairlift has to be made to measure to fit the stairs and costs approximately €7,000, which is a large expense for most people. To avoid this issue into the future, universal design should be promoted to ensure that all everyday items are designed to be accessible to everyone. Also houses should be future-proofed to ensure that they can be easily and inexpensively adapted as the person requires when they are older.

Accessible Transport

In order for an older person to live comfortably at home they need to have access to accessible public transport to attend hospital appointments, maintain social relationships and for general leisure needs. The CIB 'Getting There Report – Transport and Access to Social Services', 2009, highlights the fact that many people encounter difficulties in accessing social and health services because of the poor availability of public transport and the continuing inaccessibility of such transport. It

also links these issues to their effects on social isolation of older people in rural areas. Currently many older people, especially those living in rural areas hold a free travel pass but do not have access to any suitable public transport in their area. Often the only alternative is a taxi service which can be expensive for someone living on the State pension. This lack of accessible and affordable transportation may lead to further social isolation, worsening health conditions if they cannot get to hospital appointments and in some cases result in people having to move into nursing home care.

“This client is living in a rural area. Since the rural transport scheme was cancelled she is finding it difficult to cover transport costs for her husband to his various appointments & to the Alzheimer Day Care centre. Client rang HSE & told funding for transport is only for those who are in wheelchairs. Client feels there is very little support & that she may have no alternative but to place her husband in a home.”

As the hospital system moves to ‘centres of excellence’, outpatients may need to travel substantial distances from their home for appointments and there may not be public transport links to and from their home to the hospital.

The closing of the Mobility Allowance scheme and the Motorised Transport Grant in February 2013 has compounded transport issues for people with disabilities and older people. The Motorised Transport Grant provided funding to buy a car in order to retain employment and the Mobility Allowance provided financing for the occasional taxi journey for people unable to use public transport. These schemes did provide some older people and families with access to alternative transport options but since February 2013 they have been closed to new applicants and new schemes to replace them have not yet been devised. When being reviewed the upper age limit of 66 for the Mobility Allowance should be removed so that older people can access funding for these taxi journeys so that they can continue to live at home independently while still accessing their appointments and interacting with the local community.

“A couple who are pensioners are seeking support to purchase a car as their car broke down and is beyond repair. The husband suffered a heart attack and is in very poor health. His wife, who is his carer drives but he is unable to drive due to illness. They are seeking support to help the husband (who has mobility difficulties) to socialise and get out of the house. The mobility allowance closed to new applicants in 2013. It was stated that there would be a new scheme provided but to date this has not happened. There are people who hold free travel passes but there is no suitable transport in their areas to allow them to use the free travel pass. They cannot afford taxis as they are expensive unless for absolutely necessary journeys. A car is therefore essential. This couple do not have means to buy a car on a limited income. If they had the means to buy a car the husband would have to hold a primary medical certificate to avail of tax reliefs for disabled drivers and buy a specially adapted car. Again this is not an option for this couple.”

Quality of life and social isolation

An important finding of TILDA (The Irish Longitudinal Study on Ageing), highlighted

by McKeown *et al.* (2014)³, is the significance of social connectedness as a key to well-being for older people. “Social connections, in the broadest sense, have a particularly large influence on personal well-being among older people” (McKeown *et al.*:17). Such connections typically involve the quality of relationships with partners, children, relatives and friends. Enhancing these relationships and therefore well-being can be particularly challenging in the case of older people who may be socially isolated and outside of networks of social engagement, information and supports.

Home care supports and packages should recognise the importance of social interactions on well-being and should prioritise social supports and befriending services in tandem with medical supports to ensure that the older person has a daily or weekly social interaction.

The recent erosion of certain social and community supports that helped people feel secure and provided social interaction has led to the further isolation of older people. For example, the removal of Garda stations in rural areas and the reduction in Garda numbers has left older people feeling vulnerable in their homes. These cutbacks have also removed a source of social interaction as there is less time for community policing.

The current policy of digitalisation of public services can also be difficult for older people who may not be computer literate and also means that another route of social interaction is no longer available to them. For example the closure of post offices, the move to online applications for public services and the payment of benefits directly to bank accounts mean that many older people have lost many of the ongoing face-to-face interactions with public services in the community.

Recognition and increased supports for family carers

A range of formal and informal care is provided by family carer’s enabling many older people to live in their own homes or with their families for longer. Reductions in additional home care supports (home helps etc) and respite places mean that family carer’s are providing even more care hours, which can lead to difficulty coping and burn out. This type of family care needs to be valued and recognised by the State by enhancing supports to carers. For example by increasing home care supports hours and respite care places and amending eligibility for Carers Allowance to ensure that this type of caring is financially valued.

“Availability of respite care in local community hospital very limited - v often depending on a death. The carer’s spouse is 80 years old, finds it increasingly

³ McKeown K., Pratschke, J. and Haase, T. (2014), Individual Needs – Collective Responses: The Potential of Social Enterprise to Provide Supports & Services for Older People: Assessment of National Business Case, Dublin: Fourth Age Trust.

difficult to cope and often has to pay for local help out of his old age pension. Home help is only 45mins each of 7 mornings and 30mins each night from Mon to Fri (not Sat or Sun)”

“A client is a family carer for her brother. She is not eligible for Carer’s Allowance due to means. She provides unpaid informal help in the region of 40–45 hours per week yet it would appear there is no value on the work undertaken by her and the savings to the state by her fulfilling this care role. Assuming she did not provide this care, her brother would not be able to live independently in the community and would either be placed in a residential care facility or need home care services funded by the State.”

“Client is a Carer and is caring for one hour per day this means that she must sign off Jobseekers Allowance and cannot survive on the money which she makes for her caring job. This is a query which we have had a lot recent times as the HSE have cut the hours. It means that clients are refusing to do caring as they cannot sign off JA due to the income levels.”

“Client was in receipt of Carer’s Allowance for a number of years but her father’s health deteriorated and he got a nursing home place in May six months after applying to the Fair Deal Scheme. Her Carer’s Allowance payment ceased and also her Respite Care Grant. Client has advised she is now emotionally exhausted and was quite upset discussing this matter. Service explained to client the criteria re: Respite Care Grant - the Carer must be caring for the person for at least six months and this period must include the first Thursday in June. Client was less than 1 week out from this date when her father got his place.”

The challenges currently experienced when moving into support housing or a nursing home:

In some cases people’s needs mean that they can no longer live safely in their own home and require more supported care, either through supported housing or nursing home care. Currently less than 5% of older people live in some form of congregated setting but as our population ages demand for these places will continue to grow, with Nursing Homes Ireland predicting in a 2012 report that a further 13,324 residential care places will be required by 2021. Below find some of the challenges faced by people moving into supported housing or a nursing home:

Lack of information about supported housing schemes

There is a general lack of information and awareness about supported housing schemes amongst the public and healthcare professionals. Many people know little about supported housing and are unclear how to access it. Supported housing doesn’t really feature as a recommended or referral option in the recognised continuum of care offered by the health service and GP’s; this may be due to the low number of supported housing places.

Person-centred decisions about nursing home care and location

Residential care should always be the last resort and the person requiring care

should always be consulted about their wishes. Currently due to lack of community supports people who would prefer to live at home are ending up in nursing homes.

Also due to a lack of nursing home spaces people often don't get a place in their preferred home, which means they may not be near their family or based in the community where they lived, which means they don't benefit from the opportunity to have regular social interactions. The person's wishes should be respected and the importance of place should be recognised in these situations so the most appropriate care plan can be created to ensure the persons total well-being.

Nursing Home Support Scheme issues

The Nursing Homes Support Scheme (NHSS), also known as the "Fair Deal Scheme", provides financial support to people who need long-term nursing home care. Under the scheme, you make a contribution towards the cost of your care and the State pays the balance. The Department of Health completed a 'Review of the Nursing Homes Support Scheme, A Fair Deal' in 2015 and a number of issues were identified, though issues are still occurring some of which are outlined below:

- There is a set level of spending under the NHSS so there can be a waiting list for funding, which means people can be left waiting in unsuitable care situations for a place to become available
- Delays in processing applications mean that people get into financial difficulty trying to pay for interim care privately
- The Scheme does not backdate payments to the application date so people are not reimbursed for any care they have provided privately
- The application form for the scheme is too complicated and can cause added stress for families already in a stressful situation

"Fair deal scheme still taking too long in Tipperary, the wait is 10 weeks minimum. The Scheme should be backdated to date of application. Families selling cars and obtaining expensive personal loans to pay for nursing home care."

"Client was in receipt of Carer's Allowance for a number of years as she cared for her father who has Dementia. This care progressed in recent years due to the nature of her father's illness and the family made the decision to apply under the Fair Deal Scheme. The Fair Deal Application was submitted in November 2014. On 27th May 2015 the client's father was admitted to a Nursing Home - this was the first available date and the whole Fair Deal process had taken this long to complete."

"Caller aged 80. Her husband is residing in a nursing home under the Nursing Home Support Scheme. As a result of the contribution to care she is struggling financially to pay house insurance, health insurance and extras for nursing home. She is considering taking up a cleaning job to help make ends meet. This additional income will not impact on her state pension contributory but because she is jointly assessed with her husband for the NHSS she will lose almost half this income to nursing home costs."

Community supports for families of older people in nursing homes

The NHSS and nursing home care does not cover certain community supports and grants for people in nursing home care. Nor are these community supports made available to families of older people in residential care so they can adapt and get the equipment required to have their family member out for a day or overnight from the nursing home. This means that the older person is often isolated from the community in the nursing home and cannot visit family as they cannot finance the equipment required to have them at home for visits.

“Client’s mother is in a private nursing home availing of the Nursing Home Support Scheme for her care. HSE have done assessment and advised that she will benefit from a particular chair which costs €5,000. Nursing home will not fund cost. Client feels if her mother was in HSE nursing home that the chair would be provided. She believes the levels of care are different in relation to equipment needs.”

Reduced finances for spouse of person in nursing home care

When one spouse goes into nursing home care, the other spouse still living at home may end up with reduced income and benefits due to the way their initial Social Welfare claim was set up. This can lead to financial hardship as the spouse living at home has reduced income and supplementary benefits but may have increased costs in relation to visiting their spouse in the nursing home. Some examples of this are outlined in the cases below:

“Woman left with very little money to live on as her husband is in a nursing home. This lady had earned her own occupational pension and finds herself with only the contributory pension now.”

“Client is a qualified adult on her husband’s contributory pension. Her husband is now in long term care and she therefore is no longer entitled to the Household Benefits package at their home address. She continues to have the same costs in the running of their home which they own. At 64 she is not entitled to a pension in her own right but having spent her life as a carer and homemaker she states she is not a jobseeker. The client feels completely abandoned by the system. We have advised that she may seek an exceptional needs payment for support with travel costs to the nursing home as there is no transport in her rural area. We have also advised on the rural transport scheme which provided a limited service in her area.”

Question Two: What approaches could best provide a continuum of support and care based on choice?

The healthcare system should be a fluid system that allows the individual to move seamlessly between different types of care without experiencing bottle-necks, delays or restrictions in their choices. This care should not be a rigid one-directional system but should provide individualised packages that meet the needs of each person and allow for step-down as well as step-up supported care. There are a number of measures which could encourage this approach, which are outlined below:

- There should be better linkages between hospitals and community care. When leaving hospital the person should be signed over to community care with an agreed set of community supports in place when they are ready to move home. A contact person in the hospital should be listed for each person moving from hospital to community care in case there are any follow-up questions or treatment required.
- There should be better linkages between healthcare and housing solutions. New homes should be future-proofed to ensure they are suitable and adaptable for their owners when they are older. Existing houses should be adapted and relevant aids and appliances sourced prior to moving home from hospital to ensure a person with a deteriorating condition can stay at home. There should also be more supported housing solutions so the person has more alternatives to residential care.
- There should be more care solutions on the healthcare spectrum in Ireland, these are currently limited to home care, residential care and limited supported housing care. Other options which could suit people in the long and short-term should be considered. For example extension of the existing boarding out scheme or newer ideas such as care hotels, house sharing, home-stay options, high-level supported housing with nursing aids and low-level supported housing with monitored alarms etc.
- The older person, their family, carer and advocate if relevant should be included in the decision about where the person will live and what is required and suitable.
- The importance of where an older person lives on their quality of life should be recognised and should inform these decisions.
- People should be encouraged to plan for their future so their wishes will be known and followed in the future especially if they are unable to communicate their preferred choices when they are older. Healthcare providers should have access to these documents and should be bound to respect them. The *Think Ahead* initiative developed by the Forum on End of Life in Ireland (an Irish Hospice Foundation (IHF) project) encourages people to plan ahead by recording their wishes in the event of an emergency, serious illness or death. *Think Ahead* urges people to record and review their personal preferences for future medical, financial and personal care. This initiative should be promoted more widely to ensure that people's wishes are followed in their later life.
- Nursing homes should be integrated into the community more fully so residents remain active members of the local community and feel less isolated. For example befriending and homework programmes with local schools and colleges may help make the nursing home more visible to local people and integrated in the community. Community healthcare services and other community initiatives should also have access to the nursing home.

- A pre-emptive health approach should also be encouraged so future generations have a better chance of avoiding nursing homes due to ill health. Enhanced health promotion agendas should focus on healthy ageing by encouraging good nutrition, ongoing health monitoring and addressing the importance of social connectedness.

Question Three: What funding mechanisms should be used to enable such a continuum?

If State funding is unavailable to provide an individualised continuum of care for older people with a range of options that meets their needs and wishes, there are a number of possible ways to fund all or part of this care.

For example if legislation is provided for home care packages a means test could be put in place where the person (if able) would pay for a percentage of their care as per the Nursing Homes Support Scheme.

Alternatively, a State insurance scheme for future care as per the PRSI model could be drawn up. People would pay into the scheme during their working life to finance Long-Term Care if required later in life.

Question Four: What legislative framework might be required?

Currently Home care Packages are not established in law so there is no automatic right to them. This means that even though current health policy reiterates that home care takes precedent where possible often nursing home care is the offered solution as the Nursing Home Support Scheme is legislated for. Therefore legislation is required to put home care packages on an equal footing with residential care legislation.

The Assisted Decision-making (Capacity) Act 2015 should be implemented without delay. This legislation requires that people (irrespective of cognitive ability) have the support they need to make decisions and to assert their will and preferences in all matters affecting them, including health care and place of residence. The Act also makes provision for advance healthcare directives, the purpose of which is to enable a person to be treated according to their will and preferences and to provide healthcare professionals with important information about the person in relation to their treatment choices.

The National Carer's Strategy, Housing Strategy for People with Disabilities and Positive Ageing Strategy should all be implemented in full and there should be a holistic and interconnected approach when implementing these policies.

Given the predicted explosion in the population of older people in Ireland in the future a national strategy planning for this is required so ensure a consistent holistic approach is taken for long-term care.