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Support & Advocacy Service
for Older People

Responding to the Support & Care Needs of our Older Population

Shaping an Agenda for Future Action

Report of Forum on Long-term Care
for Older People

Dr. Michael Browne

July 2016

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third age
Responding to the Opportunities
and Challenges of Ageing in Ireland



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Support & Advocacy Service
for Older People

Forum on Long-Term Care

CALL FOR SUBMISSIONS

Ireland is ageing and more people are living longer and better lives. A minority of older people – probably one in five – require some form of support. While at any one time less than 5% of older people live in some form of congregated setting, such as a nursing home, one third of women and one quarter of men are likely to spend time in a nursing home before they die.

With appropriate supports many older people can live, and die, in the place of their choice which, for the majority of older people, repeated surveys indicate is their own home. However, lack of resources and supports for people in their homes means that long-term care is now almost synonymous with nursing home care. There is a need for innovation in the development and provision of supports and services for older people and a need for a comprehensive legal framework informed by values such as equity, self-determination and social solidarity.

To address these issues Sage is establishing a Forum on Long-Term Care in partnership with a number of concerned organisations. The Forum will receive and review submissions, meet with and question key informants and prepare a draft report for a public forum prior to submission to the new government by May 2016.

Submissions are now invited from members of the public, voluntary and community organisations, statutory and government bodies, trade unions, employers, cultural and religious organisations.

While all experiences, perspectives and ideas are welcome it would be helpful if the following key areas could be addressed:

- The challenges currently experienced in getting support to live at home or move into support housing or a nursing home.
- What approaches could best provide a continuum of support and care based on choice
- What funding mechanisms should be used to enable such a continuum
- What legislative framework might be required

Further information is available at
www.thirdageireland.ie

Submissions can be emailed to:
forum@sage.thirdageireland.ie
or posted to
Forum on Long-Term Care,
Sage, 24-26 Ormond Quay, Dublin 7.
Closing date Friday 26th February 2016.

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Preface

‘Let this be the last Report’

In January 2016 in the run up to the general election Sage, in partnership with Third Age, Family Carers Ireland and Alone placed notices in the Sunday Independent and The Irish Times inviting submissions from members of the public, voluntary and community organisations, statutory and government bodies, trade unions, employers, cultural and religious organisations on the issue of long-term care for older people. Some 52 submissions were received. In May Sage commissioned a public opinion survey on long-term care for older people and on June 15th the first Forum on Long-Term Care for Older People was held in Dublin. At the Forum, the draft report developed so ably by Dr Michael Browne around the issues raised in submissions to the public consultation, was presented and debated. The results of the public opinion survey by Amárach Research were also presented.

There was remarkable unanimity at this Forum which could be summed up in a question; “Why, despite decades of policy reports and recommendations to government, is there still a systemic bias towards care in congregated settings and no formal legislative basis for support and care in the community?” It is likely that this question is also close to the top of an already crowded Department of Health agenda. Despite consistent criticisms of the lack of a continuum of care there was agreement from the diversity of perspectives provided by campaigners, providers and regulators, that the development of such a continuum was now the key challenge. There was also a consistent message coming through the proceedings, and reflected in many of the submissions, that the issue is as much to do with supports, often minimal but nevertheless necessary, as it is to do with care and the intervention of providers whose focus can often be as much on the priorities of their profession as on the needs, and the capabilities, of the provided for.

In thanking all those who made submissions, attended the Forum or sent good wishes, we want to especially thank those individual members of the public who shared their personal experiences. The insight they provided was invaluable and the frustration of their experiences with ‘the system’ and the lack of serious focus on support and care in the home clearly emerged from their determined handwriting. The gap between the decades of rhetoric supporting home and community and the reality that congregated settings have become synonymous with long-term care, is large. It can however be tackled by effective and determined action. As one Forum participant put it, having heard the presentations and the results of the public opinion survey, “Let this be the last report”

In the face of such an overwhelming consensus of public policy around home and community supports and care, and of a nationwide public opinion survey which reinforced the popularity of such policies, it can be difficult for the public to understand the depth of administrative resistance to change and the lack of political will to challenge this resistance. Public opinion surveys are just that; surveys. The fact that a strong majority favours using the taxation system designed for all to contribute according to their means to fund necessary supports and care for older people – as opposed to certain types of care being charged for while others are not – does not necessarily encourage legislators to act in the public interest. Other voices, in quieter corridors where decisions usually get made, speak of the public interest in terms of ‘affordability’.

What then are the next steps? The experiences of dealing with the state at national level and with services, or the lack of them, at local level suggests the following;

We will not make the changes we seek unless we develop a popular vision of how things could be. Home, hospital, hotel, hospice – all share the same common denominator – hospitality – care for others. We need to develop a vision for long-term support and care which is as compelling as that of the hospice movement at its best.

Commissioning based on outcomes, rather than block grants and outsourcing for particular aspects of care.. The percentage of older people being supported and cared for in the places of their choice according to their will and preference and their changing needs – this has to be seriously considered as one of the objectives of commissioning. Far from the money following the patient the patient currently follows the silo where the money is. Where is the 'Fair Deal' in going where you don't want to go? The Expert Group on Resource Allocation and Financing in the Health Sector stated clearly that "... the key issue is not whether Ireland has a social health insurance model or continues to fund health care out of taxation, but rather how to structure the financing system so that it supports the stated health-care objectives." If there is to be a continuum of support and care then funding for it must reflect that continuum.

Housing and health and social care can no longer remain parallel lines. They must converge. For this to happen we need to focus as much of our energy on local government as on national government; on housing policy as much as health and social care policy. The public sphere must be enriched through innovation and this can best happen at local level. County development plans need to reflect the valuable economic and social roles of older people as well as their healthcare needs.

Resources are limited so we need to make the best use of them. We may also need more resources. This will require challenging the current consensus that taxation and public spending, are of themselves, a bad thing. If we can put a compelling vision before people and show that social innovation can also support economic development then we have at least a fighting chance of being heard.

What gets measured gets focused on. One of the regular indicators of the misery of many older people – 'trolley watch' – is an initiative of a representative organisation for the providers - the Irish Nurses and Midwives Organisation. We need our own measurements and we need to focus relentlessly on them.

We need to aim at the programme for the next government. To do this we need to develop local Forums in key locations where we can engage with local and national public representatives on the issues raised by the Forum on Long-Term Care. We also need to bring this report to Oireachtas committees charged with oversight of issues such as housing, health, economic development, public accounts and public expenditure and reform of public services. In addition to consideration by the Ministers for Health, Older People and Housing we see this report as a useful resource to be considered by the Citizens Assembly chaired by Ms Justice Mary Laffoy of the Supreme Court.

For all of this to happen we need to build a coalition of forces and to have access to legal, financial, research and marketing resources to help us develop compelling messages and arguments so that we can forge a new national consensus.

"An té nach bhfuil láidir ní foláir do bheith glic." We are not strong therefore we must be clever.

Patricia T. Rickard-Clarke. Prof Cillian Twomey.

Joint Chairpersons: Forum on Long-Term Care for Older People.

15th June 2016

There is a broad consensus on the direction that our approach to supporting older people who need care should take. This includes enabling people to stay at home and in their own communities for as long as possible, the need to cater for people at the lowest appropriate level of complexity and the need to provide high quality residential care when and if this is needed.

We know what needs to be done but actually doing it requires new thinking, innovative approaches and the availability of a mix of accommodation choices to enable progression as support and care needs change.

Long-term Support and Care: What the Issues and Concerns Are

General

- There is a major discrepancy in the Irish health care system between the way care for people with acute illnesses and those with a slow debilitating illness (such as dementia) is funded – a core question to be addressed by society is whether or not this is right or equitable;
- Nursing home care is available on a statutory basis but there is no statutory entitlement to home care – the need to address this legislative gap is widely acknowledged and action by Government is required on the matter;
- There is an urgent need to proactively plan for the financing of long-term care of an older population who are living longer and to make decisions about whether this is to be out of general taxation or through the social insurance system;
- We need a single policy framework, societal and political consensus and a properly costed and phased implementation programme;
- While there is broad acknowledgement of the principle of enabling people to exercise their will and preferences in the way care is provided, people regularly end up in nursing homes against their will because of a lack of community-based alternatives;

Quality of Life

- Significant quality of life domains such as social connectedness, companionship and meaningful involvement in the activities of daily living tend not to be factored into care and support needs assessment;
- There is much to be done to ensure that the design and location of care facilities, including, in particular, nursing homes, caters for key quality of life considerations – community access, maximising individual capacity and self-expression and individual preferences;
- People's inability to access the therapies that they require in order to optimise capacity (e.g., occupational therapy, physiotherapy, speech and language therapy) at a level commensurate with need impacts greatly on their quality of life and general well-being;
- A community-based social enterprise model of support and care delivery (a business model that puts people and community before personal gain, while being commercially viable), supported by the State, has significant potential to target interventions at the lowest appropriate level and to optimise quality of life accordingly;

Care in the Community

- The provision of adequate state funding for support and care in the community requires social consensus and related political will and new legislation to achieve equality of access to care in the community and nursing home care;
- Criteria for accessing home care packages and home help need to be transparent and uniform across the country and the system needs to be fully regulated – this is not the case at present;
- People's long-term care and support needs should be assessed in an integrated and holistic manner and provided for and managed accordingly – such practice remains largely underdeveloped despite the emergence of the Single Assessment Tool;
- Multi-purpose community-based units providing a continuum of support and care (day facilities, sheltered accommodation, nursing units) can contribute enormously to enabling people to live independently or semi-independently and should be made an integral part of the community care infrastructure – such models could be developed initially in locations where existing public long-term residential care facilities have been deemed to be no longer fit for purpose;
- The role of family carers needs to be optimised and supported in the way home help and home care packages are delivered – this requires meaningful collaboration between service providers, families and individuals requiring care;
- There is a need to pilot a new national community-led social enterprise model of day resource care which would provide a comprehensive range of services and supports to enable people to continue to live independently in their own homes.

Inter-agency collaboration and inter-disciplinary working

- Providing people with a seamless service often requires much higher levels of co-operation between agencies and between disciplines than is currently the case – a greater integration of resource allocation and policy-making at both national and local levels is required;
- Inter-agency collaboration and interdisciplinary working at local level needs a dynamic impetus and energy on the part of all those charged with delivering supports and services to older persons;
- Inter-disciplinary working needs to be more embedded in the community care delivery system with particular reference to GPs, PHNs, health care assistants, home helps, physiotherapists, occupational therapists, social workers and speech and language therapists;

Maximising the role and contribution of housing

- The potential of appropriately designed housing has not been developed to date in Ireland – there are appropriate models of 'housing with care' that have been developed in other jurisdictions and some in Ireland that can and should be replicated nationwide;
- There is a need for Local Authorities to take on much more responsibility for the provision of sheltered and supported housing;
- Implementing the Building for Sustainable Communities and the future-proofing of housing in respect of adaptations would be beneficial from both a social integration and an economic perspective – these two principles should be embedded in long-term housing policy;

People with complex care and support needs

- More attention is required to ensure that best gerontological practice is always applied in meeting the specific nursing, medical and personal care requirements of people with complex care needs in both residential care settings and in the community;
- There is a dearth of appropriately designed and staffed dementia-specific accommodation, including both assisted living housing and full residential care – this gap in provision needs to be addressed as a matter of some urgency;

The Nursing Home Support Scheme (NHSS)/'Fair Deal'

- While the NHSS is a large area of health expenditure, there is little focus on outcomes, quality of life domains or on the creation of greater choice to reflect the will and preference of people who require nursing home care;
- The current model of fee negotiation between the National Treatment Purchase Fund (NTPF) and nursing homes is unsatisfactory, particularly, because it provides for 'bed and board' only and takes no account of different individual support and care needs;

A preventative approach

- Much more can be done at local community level to prevent or delay the onset of conditions that require more extensive care and support, including, in particular the availability of accessible transport and initiatives to combat social isolation and loneliness;
- Housing policy should include provisions for future proofing in respect of adaptations required to cater for reduced mobility;
- Ageing with confidence programmes have significant potential to equip people with the skills to maintain independence and to anticipate support needs before a crisis arises;
- There needs to be a stronger public discourse about elder abuse and more attention to sharpening public awareness of the matter;

Building on best international practice

- Ireland can learn much from practice in other jurisdictions with particular reference to:
 - Eligibility and access criteria for health, housing and social care support
 - Models of financing
 - The individualised payments approach
 - The optimal balance between funding for community-based care and for residential care
 - The devolved responsibilities of local government (municipalities) in providing long-term care accommodation, support and services
 - Integrating mainstream housing provision and specialised accommodation provision
 - Legal frameworks relating to people's rights in respect of long-term care

Addressing the challenge of long-term care financing

- The matter of funding long-term care needs to be addressed urgently by society generally and by Government with particular reference to:
 - What is the optimal level and type of care and support?
 - How much are we as a society prepared to invest in this area?
 - What are the respective responsibilities of the State and individuals in financing and planning for long-term support and care?
 - How do we get from where we are now to where we want to be?
- There is a need for a national consensus (political and civil society) approach based on the existing broadly agreed parameters of how long-term support and care should be delivered and funded and the development of an agreed action agenda accordingly;
- A comprehensive piece of research funded by Government is required to inform policy thinking and planning in this area which would include an analysis of:
 - The dimensions of support and care
 - The options that are desirable and possible
 - The likely cost of each of these options
 - How these might be funded in the short, medium and long-term
 - An implementation framework and timescale.

What the public said about long-term care and support

The following comments are taken directly from the submissions to the Forum and are indicative of the main points made. Minimal editing has been carried out in order to preserve the voice of the person or organisation who submitted the comment.

The comments have been categorised under a number of headings for ease of reading: cross-cutting matters, community care deficits, family carers, nursing homes, enhancing the role of housing, integrated long-term care and, finally, a need for a national conversation about the need for fundamental change.

Cross-cutting matters

- “Many older people experience a deep fear of institutionalization”;
- “Loneliness and social isolation is a significant and widespread problem”;
- “Care in residential settings should be the ‘option of last resort’ and only put in place when all community-based options have been exhausted – for this to happen, best international practice in integrated housing and care support needs to be implemented”;
- “In some countries, residential care is particularly difficult to access (in terms of financial support, and needs assessment)”;
- “Institutionalising old people, for whatever reason, convenience or whatever, is a tradition only in some countries – in Africa and India, for example, there is no nursing home available to most people and they are looked after by their family”;
- “Poor diet and malnutrition is a problem for many older people who are no longer motivated to or able to cook for themselves”;
- Transport services are often not available to assist people in managing their daily lives”;
- “What is lacking is a coherent plan of action that would provide a full range of measures and supports to allow citizens to continue to contribute to their communities and provide choices as to how and where they will live in advancing years”;
- “Financial considerations frequently determine quality of life in old age – many people simply have insufficient resources”;
- “Policies to create communities in which older people can live autonomous and valued lives and initiatives to implement such policies are urgently required”;
- “There is a lack of financial incentive to remain at home, the only real support being the ‘Fair Deal’”;
- “The ‘money follows the person’ principle needs to be extended to all services – funding needs to be provided on an individualised basis so that responses can be tailored to the current and changing needs of people”;

- “Moving to residential accommodation is a major event for older people and their families and there is a need for support to help deal with the psychological and emotional challenges involved”;
- “There is a need for much more attention to the ‘Think Ahead’ concept and to Advance Care Directives on the part of both society generally, people who are becoming older and service providers and professionals”;
- “There is a need for a significant investment in IT information systems to ensure the safe and efficient management of health records, to eliminate duplication and to ensure continuity of care and support”;
- “Older people need to keep abreast of new technologies – Internet access helps to lessen feelings of isolation and prolong independence”;
- “Service delivery should be informed by the Department of Health Framework for the Management of Chronic Diseases which includes a model of care integrated across organisational boundaries and using a multi-disciplinary team approach”;
- “The needs of older adults with an intellectual disability are complex and are best considered along a spectrum involving social, quality of life, physical and mental health”;
- “The National Dementia Strategy states that ‘people with dementia should be supported to retain skills as much as possible’ – the same is true of other chronic conditions that may cause disabilities which are so severe as to require care”;
- A medical model predominates current provision in residential care services – this needs to be expanded to a more holistic model of care that acknowledges the importance of people’s psycho-social, emotional and spatial well-being”;

Community care deficits

- “Pathways to services are not always clearly defined or understood”;
- “There is a major shortage of occupational therapists in Ireland employed to work with people with neurological conditions”;
- “There are very few community social workers – there is an over reliance on Public Health Nurses (who are already over stretched with a broad remit)”;
- “The greater availability of day centres could mitigate the destructive effects of loneliness and social isolation”;
- “There is huge variance in access to and quality of day care support and lack of transport to same is a significant barrier in some areas”;
- “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”;
- “Many home care packages and home help services do not meet the needs of people who get them”;
- “There is a need to better recognise the value of home help in enriching the lives of older persons and in reducing the risks associated with completing physical tasks”;
- “Access to home help is increasingly scarce with long waiting lists in operation”;

- “A home care package will generally only be approved to provide task focused care (i.e. personal care, meal preparation, medication prompting) – holistic needs are not considered (i.e. social support to address social isolation or complete practical tasks)”;
- “Carer visits of 30 minute duration are common – these visits can be appropriate but also can lead to a rushed, stressful visit which does not engender respect and dignity for the person being cared for”;
- “There is a lack of uniformity in the various HSE areas regarding Home Care Packages – the application process, the hours approved, the tasks covered by the HCP and the amount of funding (hours) available”;
- “Applications for HCPs from acute hospitals particularly for inpatients are prioritised leading to a lack of access to HCPs for those living in the community which can result in inappropriate admission to hospital – a crisis response rather than a preventative approach is in operation”;
- “Better GP services at local level would reduce dependency on hospital services and related hardship in accessing these services”;

Family carers under pressure

- “Carer fatigue is a serious problem with carers becoming over-burdened and unable to continue providing care due to lack of adequate home care packages”;
- “The PHN and community healthcare services are under-resourced and families find it difficult to navigate the system of application for supports and services”;
- “A needs based approach to assessment should include both the needs of the older person and the carer”;

Nursing Homes

- “Home is, of course, best, but a nursing home should be a positive experience for those who require that level of care”;
- “A high percentage of people in nursing homes have multiple chronic conditions, frailty and disability which require gerontological expertise in care, including dementia care and palliative care”;
- “In many cases, increased [nursing home] charges are being passed on to residents, causing worry and hardship”;
- “People on low incomes such as Disability Allowance and basic State Pension can now find themselves with less than the ‘Fair Deal’ stipulated minimum after they have paid the extra charges”;
- “The location of nursing homes should be reconsidered – many are built in isolated areas, cutting residents off from community life”;
- “The practice of building nursing homes on green field sites outside villages and towns should be stopped. It serves no practical purpose and only isolates those residing in them, incapacitating them further”;
- “We need to concentrate on the fact that this [nursing home] is a person’s home – it is not a hospital, it is not a prison, it has medical input but it is not a medical facility”;
- “A big issue for nursing home staff is conflict between risk management and quality of life and a related concern with avoiding litigation”;
- “The ‘Fair Deal’ scheme is not working – it is too legalistic and does not meet the medical and care needs of the person, it does not include pressure relief mattresses or specialised wheelchairs in the cover”;

Enhancing the role of housing

- “A range of housing options is a vital component in allowing people to live independently for longer”;
- “The lack of a funding model to support sheltered housing with care services is a significant obstacle to meeting the needs of people who wish to continue to live independently”;
- “Aids to support mobility and adaptation to homes to facilitate independent living are in short supply relative to need”;
- “Sheltered housing in a town or village is a good option for extending independence”;
- “The ideal provision would be a community setting of small houses, not too far from a town or village with a local bus route – the houses should be available to buy and furnish as one would wish or to rent, with an annual fee to be paid towards the upkeep of the facilities, landscaping and garden”;
- “If the needs of a sheltered housing tenant are such that they cannot be met by the sheltered housing they are living in, then the only option for the vast majority is a nursing home, even if they don’t need 24-hour nursing care”;
- “Sheltered housing needs to be properly staffed and supervised and more comprehensive cover and extended medical and care services are required in these situations – at present many such schemes have no staffing from 5.30 p.m. to 9.30 a.m., leaving vulnerable residents without assistance”;
- “There is little point in expecting an older infirm or immobilized person to be able to cope in their own house if their bedroom is upstairs, their kitchen and living room downstairs and their toilet and bathroom a flight of stairs out of reach”;
- “Given their role in maintaining older people in their own homes and communities, housing related support services provided by housing associations need to adequately resourced by Government”;

Integrated Long-term Support and Care: Components Identified

- “Existing community-based services should be integrated under a local formal team structure involving all service delivery stakeholders”;
- “There should be a built-in bias towards community care solutions (while retaining capacity for some funding for residential care facilities)”;
- “The State should take the lead role in pioneering and developing new and innovative models of care and support in the community – collaboration with NGOs has significant potential”;
- “A Case Management approach should be used to assess and determine needs”;
- “All relevant public services should be designed and delivered in an integrated manner around the needs of the care recipient, based on a national standardised needs assessment”;
- “Access to care and support should be on the basis of need and should not be based on ability to pay”;
- “There is a need as a matter of urgency to provide more high-dependency residential care beds, particularly in dedicated units for people with advanced stage dementia”;
- “The funding for long-term care should be comprehensive and commensurate with current and projected need”;

- “A mechanism needs to be put in place to explore in detail the public financing of long-term care – this should build on the previous work carried out by Mercer [a 2002 report commissioned by the Department of Social and Family Affairs] ”;
- “Maximising people’s independence, autonomy and choice is essential to ensure that their constitutional rights and international human rights are protected”;
- “There is a need for a funding model that is financially sustainable over the long-term taking into account demographic, labour market and social changes –there should be appropriate levels of co-payment by care recipients”;

Need for a national conversation about the need for fundamental change

- “There is a need for a national conversation around developing a new approach in Ireland which embraces attitudinal and value changes as well as systemic change;”
- “We need to fundamentally question current practices and create a shift in the way we look at this issue”
- “There is a need for a stronger focus on all older people as unique persons with histories, hopes and aspirations, and preferences as distinct from people who just engage with the health and social care delivery system”;
- “Active community engagement and community connectivity is at the core of citizenship and social solidarity – this requires society to maximise older people’s involvement and independence”;
- “We need to move from the treatment of people with long-term care and support needs as ‘objects’ of health and social care policies towards viewing them as ‘subjects’ with rights who are capable of claiming those rights based on social justice”;

Information and policies that we already have and need to build on

Since the late 1960s, there has been a plethora of policy documents, reviews, strategies and research reports published which refer directly or indirectly to long-term support and care. There is a significant body of research in Ireland relating to long-term support and care mainly carried out by the NCAOP during the 1990s and early 2000s, by the Law Reform Commission, by NESF, NESF, third-level colleges and medical/nursing organisations and by government departments. Since we already have a lot of research evidence and related policy statements and strategies, we do not need to 're-invent the wheel' but rather apply greater urgency to policy implementation (see below for a selected list of documents).

[Age Friendly Strategy \(Various Local Authorities\)](#)

[Healthy Ireland Strategy, A Framework for Improved Health and Wellbeing 2013 – 2025](#)

[National Council on Ageing and Older People \(NCAOP\) \(Various Reports\)](#)

[National Standards for Residential Care Settings for Older People in Ireland \(HIQA 2016\)](#)

[The Irish National Dementia Strategy \(2014\)](#)

[HSE Safeguarding Vulnerable Persons at Risk of Abuse: National Policy and Procedures \(2014\)](#)

[Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy \(2014\)](#)

[Fourth Age Trust \(2014\), Individual Needs – Collective Responses: The Potential of Social Enterprise to Provide Supports and Services for Older People](#)

[National Positive Ageing Strategy \(2013\)](#)

[National Carers Strategy \(2012\)](#)

[NESF \(2012\) Quality and Standards in Human Services in Ireland: Home Care for Older People](#)

[NESF \(2012\) Quality and Standards in Human Services in Ireland: Residential Care for Older People](#)

[Law Reform Commission \(2011\) Legal Aspects of Professional Home Care](#)

[OECD \(2011\) Help wanted? Providing and paying for long-term care](#)

[NESF \(2009\) Implementation of the Home Care Package Scheme](#)

[Report of the Commission of Investigation \(Leas Cross Nursing Home\) \(2006\)](#)

[Law Reform Commission \(2006\) Vulnerable Adults and the Law](#)

[OECD \(2005\), Long term care for Older People](#)

[Mercer \(2002\), Study to Examine the Future Financing of Long-Term Care in Ireland](#)

[NESF \(2005\) Care for Older People](#)

[Quality and Fairness – A Health System for You \(2001\)](#)

[Shaping a Healthier Future \(1994\)](#)

[The Years Ahead \(1988\)](#)

[Care of the Aged Report \(1968\)](#)

Introduction

As is widely acknowledged, Ireland's population is ageing and more people are living longer and better lives. However, a minority of older people (probably one in five) require some form of care and support because of issues arising from conditions such as dementia, Parkinson's, loss of function as a result of stroke or chronic arthritis. While currently, at any one time, less than 5% of older people live in some form of congregated setting, such as a nursing home, one-third of women and a quarter of men are likely to spend time in a nursing home before they die. It is reasonable, based on anecdotal evidence, to form the view that many dependent older people 'put into' long-term nursing home care do not wish it and have not given their full consent. The reality of the nursing home option is that in many instances, it is the only response available currently because of the absence of community and home based care and support commensurate with dealing with chronic age-related disease and disability.

It is also the case that the care and support needs of people who have to go into nursing homes are complex and require a significant planned and integrated response if their needs are to be met in a manner that respects their dignity, will and preferences and ensures that best practice is applied in the medical, nursing and social care provided.

Sage¹ - Support and Advocacy Service for Older People, takes the view that, with appropriate supports, the majority of older people can live, and die, in the place of their choice which, for the majority of older people, as research repeatedly shows, is their own home. However, lack of resources and supports for people in their homes means that long-term care has become largely synonymous with nursing home care.

Guided by rights-based principles, components of quality service delivery and informed by research into the factors that enhance the wellbeing of older people, Sage is committed to identifying and addressing both individual and systemic issues that impact on older people's ability to access services commensurate with rights and needs.

The Forum Process

In the foregoing context, Sage initiated the Forum on Long-term Care in partnership with Third Age, ALONE and Family Carers Ireland. This was deemed necessary because of the perceived urgent need to identify clearly what needs to be done to achieve a model of support that is more in keeping with the core values of choice, dignity, equality, self-determination, social solidarity and, indeed, social justice.

The Forum was envisaged at the outset as a three-stage process:

- (i) A public consultation on the matter
- (ii) A forum event involving key stakeholders to consider a draft report based on the public consultation
- (iii) The establishment of structures and mechanisms to implement an action agenda arising from Stage 1 and Stage 2.

¹ Sage is an organisation operating under the governance of Third Age Ireland, with HSE and Atlantic Philanthropies funding.

This report presents the outcomes of the public consultation process and the related Forum event.² It integrates these with relevant research findings and locates these outcomes within the broader policy and legal context.

Public Consultation

The public consultation was carried out during the month of February 2016. The consultation was based around four main themes:

- 1) The challenges currently experienced in getting support to live at home or move into support housing or a nursing home
- 2) What approaches could best provide a continuum of support and care based on choice
- 3) What funding mechanisms should be used to enable such a continuum
- 4) What legislative framework might be required

A total of 54 responses were received.

Category of respondent	Number
Individual citizens	17
Professionals	12
NGOs	10
Community groups	7
Family carers	5
Others	3
Total	54

As perhaps might have been expected, the responses were very wide-ranging and included:

- General perceptions of what long-term care should involve
- Deficits in community care provision
- Issues around the operation of the NHSS
- Personal experiences of difficulties getting services
- Central but underdeveloped role of housing
- Priorities listed in various policy and strategy documents
- Suggestions for a new approach to eldercare and an urgent need for a national conversation on the matter

The Submissions highlighted:

- The need for a continuum of provision
- The need for preventative measures including combating loneliness and social isolation and enhancing social connectedness

² This Forum event was held in Dublin on 15th June 2016 and had over 200 participants from around the country.

- The need to focus on quality of life (both in the community and in nursing homes) as well as on quality standards

Different groups and professionals understandably highlighted their own role – as it operates currently and how it could be enhanced. A number of the submissions included lists of relevant and useful references and some referred to what they considered to be good models of long-term care and support.

A synthesis of indicative comments to reflect the content of the submissions has been included at the beginning of the report.

Defining Long-term Support and Care

Long-term support and care is understood here as the processes that society puts in place to enhance the quality of life and well-being of people who, because of failing health or reduced physical or cognitive functioning require help from others. These processes include (but are not limited to) medical and social services designed to support the needs of people living with chronic health problems that affect their ability to perform everyday activities.³

While there are people with disabilities in receipt of long-term care, either in the community or in residential care settings, this document is primarily concerned with the needs of older people who require support and care as a result of a disability or impairment. It is noted, however, that there are some younger adults with disabilities in Ireland currently inappropriately placed in nursing homes, including those with an acquired brain injury and those with a long-term intellectual disability. This practice is contrary to both stated government policy as set out in the National Disability Strategy and to the UN Convention on the Rights of Persons with Disabilities.

It must be noted at the outset that the term 'older people', as commonly used, includes a wide diversity of people within that population, ranging from those actively engaged in society (paid work, volunteering, ongoing education, child-minding) to people with impaired physical health or impaired cognitive functioning (or both) and who, because of such impairment, require support to a greater or lesser extent.

The ageing of the population means that the demand for long-term care is growing and social and technological change will no doubt impact on future needs and preferences in relation to long-term care in ways that are difficult to predict. According to Census 2011, there were 535,000 people aged over 65 in the country as a whole (11.7% of the total population). According to current population projections, by 2041 there will be an estimated 1.3 million to 1.4 million people aged over 65 years, representing 20-25% of the population. The greatest increases are expected in the over-80 year's age group, where numbers are expected to more than treble from 128,529 in 2011 to about 440,000 in 2041.

³ See Mc Call, N., Long Term Care: Definition, Demand, Cost, and Financing <http://www.ache.org/pubs/1mccall.pdf>

Outline of Forum Report

The Report contains five main sections.

Section One describes the background and current policy context relating to long-term care.

Section Two sets out six relevant considerations – respecting the rights of older persons; quality of life; choice and preferences; integrated medical, nursing and social care provision; meeting the specific needs of people with dementia; and equality of access between community and residential care.

Section Three identifies the components of a framework for long-term care – integrated needs assessment; a continuum of provision; inter-agency collaboration; supports for family carers; maximising the role of assisted living/sheltered housing; case management and inter-disciplinary working; and independent support and advocacy.

Section Four discusses the question of financing long-term care and summarises the relevant factors.

Section Five includes a synthesis of the main issues and an outlines and Agenda for Action.

Section One

Long-term Care: Background and Current Practice

Focus on Community Care

During the 1990s there was a convergence of policy in respect of older persons in many Western countries and a consensus emerged on the key elements of care policy for older persons:

- (i) Care should be provided in the community for as long as possible, minimising the number of people in residential care services;
- (ii) Active ageing should be promoted;
- (iii) Family carers should receive back-up from the State.

Research and policy documents in Ireland have continually stated the primacy of community or home-based care over residential care. The emphasis in all policy documents since the late 1960s has been on enabling older persons to live in their homes for as long as possible. This principle was strongly stated in *The Years Ahead* (1988)⁴, in successive reports by the National Council on Ageing and Older People (NCAOP)⁵, in various Health strategy documents, in particular, the *Shaping a Healthier Future, A Strategy for Effective Health Care in the 1990s*⁶ and in all government programmes and health and care strategies since.

It has been strongly argued over the years, particularly by the NCAOP, and also by the Equality Authority, that community care should be underpinned by clear legislative entitlement and dedicated funding provided to ensure that this legislative entitlement is delivered. Legal entitlement to community care services would require the State to provide the services to all those who need them on the grounds of dependency or social circumstances. It is also generally recognised that a clear legal entitlement to services would mean that resources would have to be allocated. In addition, the establishment of a right to services inevitably results in greater demands for improved services.

While the 2011 Programme for Government committed to supporting older people to continue to live in their own homes and communities for as long as they wished and promised to facilitate this by ensuring that the eligibility criteria for the home help and the Home Care Package Scheme would be applied consistently, the matter of legal entitlement was not addressed. The current Programme for Government (2016) merely commits to increasing funding for homecare packages and home help year on year.

4 Department of Health (1988), *The Years Ahead: A Policy for the Elderly*. Report of the Working Party on Services for the Elderly. Dublin: Stationery Office.

5 The NCAOP was previously known as the National Council for the Elderly and prior to that, The National Council for the Aged.

6 <http://lenus.ie/hse/bitstream/10147/46579/1/1688.pdf>

Home Care Packages

Home Care Packages (HCPs), first introduced in 2006, are the main current community care policy fulcrum. These are packages of care tailored to the needs of individuals whose needs cannot be met by mainstream Primary, Community and Continuing Care (PCCC) services. The overall objective of HCPs is to maintain older people at home and in their communities, particularly those at risk of inappropriate admission to long-term care or acute hospitals. HCPs provide a broader range of supports than home helps and can include some therapy and nursing support for a few weeks after a hospital stay to ongoing, daily visits from a home care assistant to help a person get out of bed, washed and dressed. They can include a range of services, such as public health nursing, day care, occupational therapy, physiotherapy, home help, home care and respite care, that are shaped around each person's individual needs. HCPs can either be provided through a cash grant, which the recipient can use to purchase the care and support they need or through the organisation of care services by the HSE.

The positive aspects of HCPs have been noted⁷ :

- Enabling older people who are at risk of having to go to a nursing home to remain living at home, where that is their preferred option
- Enabling families to continue caring for their older relatives
- Giving older people and their families a greater say regarding the source and types of care services used
- Providing a more cost effective response relative to the cost of nursing home or extended hospital care (except in the case of those with the highest levels of dependency requiring extensive nursing or medical care)
- Reducing the number of delayed hospital discharges
- Reducing pressure on existing, often over-stretched, HSE services, such as public health nursing and home help services
- Flexibility in the way services are provided
- Stimulating employment creation in the area of care services

In looking at the role of HCPs, it should be noted that in many instance the alternatives would be either increased pressure on carers and/or the person with care needs having to move into a long-term care residential setting which would often be much more expensive. Those who succeed in getting a HCP are usually satisfied, even where the grant falls short of what they feel they actually need.⁸

Notwithstanding the many positive aspects of HCPs that have been noted, some shortcomings have been identified relating to their implementation⁹, including:

7 Department of Health and Children Home Care Packages Evaluation Report (2009) <http://www.lenus.ie/hse/bitstream/10147/87555/1/hcp.pdf>

8 See, for example, Timonen, V. (2004), Evaluation of Homecare Grant Schemes in the NAHB and ECAHB, SPARC, Trinity College; Timonen, V., Doyle, M. and Prendregast, D. (2006), No Place Like Home: Domiciliary Care Services for Older People in Ireland, Liffey Press and Department of Health and Children (2009), Evaluation of Home Care Packages

9 National Economic and Social Forum (NESF) (2009) Report on the Implementation of the Home Care Package Scheme

- Double or even triple assessments of the care needs of an older person, e.g., by medical staff in hospital, by the HSE community staff co-ordinating HCPs, and by the organisation appointed to provide the care
- Double or triple means-testing , e.g., for home help services, for HCPs, and for a Medical Card
- Little data collection or analysis on the outcomes of HCPs at either national or local levels

The Department of Health and Children 2009 Home Care Packages Evaluation Report¹⁰ set out a number of recommendations aimed at improving the HCP service. These referred in the main to the need for more standardisation relating to planning, delivery, management and financial information systems. Producing national standardised guidelines for the operation of the Home Care Package Scheme was seen as a priority and National Guidelines and Procedures for Standardised Implementation of the Home Care Packages Scheme¹¹ were published in 2010.

These guidelines and procedures noted that the extent of the support available through the Home Care Package Scheme is subject to the limit of the resources allocated each year to the HSE for the running of the scheme. The limited resources available may be one of the reasons for the TILDA (2011)¹² finding that only 1% of the older population in Ireland had the help of a state-provided personal care attendant.

It is noted that the HSE is to carry out a pilot project over the next two years in one of its Community Healthcare Organisations to test the concept of Consumer-Directed Home Care (CDHC). A 2015 Evaluation Report of Home Care Packages by the DHSS in Australia focused largely on the transition to Consumer Directed Care (CDC). This model adopts an approach to the planning and management of care which provides consumers and their carers with power to influence the design and delivery of the services they receive, including what services are delivered, and where and when they are delivered.

Need for clarity about the purpose of the Home Care Package Scheme

A key question relating to Home Care packages that needs to be addressed is whether the primary focus of the scheme is to give people a realistic option of remaining in their own homes or to expedite hospital discharge – the latter is likely to result in a continuing piecemeal and ad hoc approach. If the primary aim of the Scheme is to ‘divert’ people with high levels of dependency away from nursing homes and towards home-care, it is essential that the level of the Home Care Package available is equivalent to, or even higher, than the level of funding available under the NHSS.

It is also essential that the Home Care Package should be additional to basic community care services such as home help and should be clearly targeted at those on the margins, i.e., those with multiple care needs who would otherwise have to go into a residential care setting. People should have a realistic choice between a Home Care Package and the Nursing Home Support Scheme.

10 Department of Health and Children (2009), Home Care Packages Evaluation Report, <http://www.lenus.ie/hse/bitstream/10147/87555/1/hcp.pdf>

11 <http://lenus.ie/hse/bitstream/10147/120850/1/hcpsguidelines.pdf>

12 Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA), http://tilda.tcd.ie/assets/pdf/glossy/Tilda_Master_First_Findings_Report.pdf

Shortfalls in community care services

While the main policy thrust has been towards the development of community support services, provision has remained unsatisfactory for several reasons:

1. The State has a statutory obligation to provide support to people in nursing homes; but is under no legal obligation to provide community-based services – it is almost certain that the inadequacy of support services for care in the home continues to be a key factor in determining the need for residential care;
2. There is a limited range of accommodation between people's own home and residential care, consisting mainly of the relatively marginal sheltered housing sector – there is an obvious need for more intermediary levels of home-type/assisted living/sheltered accommodation with a range of support services;
3. Mechanisms and facilities for meeting more complex care needs in the community remain underdeveloped – people are either being looked after at home by families (sometimes with relatively little State support), or they move to a nursing home;
4. Support services for people being cared for by family carers are in short supply relative to demand, e.g., home help, respite care places, day care, occupational therapy and physiotherapy;
5. Collaborations between statutory and voluntary services on the one hand, and between health and housing services on the other hand, are underdeveloped;
6. The system of support and service provision is very fragmented and characterised by the presence of myriad agencies, associations, support groups and structures that sometimes duplicate the provision of services;
7. An obvious downside of a flexible approach to home care packages is a difficulty in delivering a standardised service in each part of the country in accordance with identified need;
8. Ireland's relatively poorly funded systems maximise organisational diversity and are subject to constant tinkering at the edge and, therefore, result in a model of service provision that is complicated, and variable;
9. Increased reliance on the private sector for the provision of care (nursing home and home care) is problematic for two reasons:
 - (a) It reduces the core responsibility of the State to develop innovative responses to changing long-term care needs;
 - (b) The focus on regulation and inspection, while clearly necessary, may result in a lessening of focus on needs assessment and individually tailored community-based responses;

Long-term Residential Care

Residential care in Ireland is provided through a mix of public, voluntary and private provision.¹³ It is worth highlighting that the net budget for long-term residential care in 2016 is €940m and the Nursing Home Support Scheme (NHSS) will support 23,450 people (on average per week) - an increase of 649 clients per week on 2015 numbers. With regard to private facilities, it was announced in Budget 2016 that nursing home expansion works would henceforth be included in the Employment and Investment Incentive Scheme.

A marked shift has occurred in recent years towards the private sector, and to a much lesser extent the voluntary sector, in the provision of nursing home care, with a correspondingly smaller proportion in public (state provided) nursing homes. For example, in 2008, public provision accounted for 29% of long-stay beds while in 2013, 66.8% of all beds were provided by the private sector, 10% by the voluntary sector, and only 23.1% by the public sector. Most places are majority-funded by the state, regardless of the sector.

Current regulations for constructing nursing homes do not specifically incorporate modern concepts in nursing home care, such as the Green House or Eden Alternative (see Appendix One). Neither is it clear to what extent enforcement is carried out of design elements such as those contained in Section 25 of the HIQA regulations (i.e., regularly spaced seating areas, areas of interest and diversion). For example, HIQA's 2014 Overview Report on Regulation of Designated Centres for Older People¹⁴ found that only 29% of inspections showed compliance with Outcome 12 'Safe and Suitable Premises'. It is also the case that much of the recent growth in the private nursing home sector has been in the form of relatively large units at the periphery of urban areas, distant from the localities where the residents formerly lived.

Nursing Home Support Scheme: Main Provisions

The Nursing Home Support Scheme (NHSS) (also known as the 'Fair Deal' scheme) provides financial support towards the cost of the standard components of nursing home care:

- Nursing and personal care appropriate to the level of care needs of the person
- Bed and board
- Basic aids and appliances necessary to assist the person with the activities of daily living, and
- Laundry service

The statutory basis for the NHSS is the Nursing Homes Support Scheme Act 2009, which was signed into law on 1st July 2009. A person's eligibility for other schemes such as a Medical Card, GP Visit Card or the Drugs Repayment Scheme is unaffected by participation in the NHSS or by residence in a nursing home.

13 There is an estimated 29,600 residential care beds operational in Ireland at present. The breakdown is private (76%) and public (24%). These beds are a mix of long stay and short stay beds. Some 1,866 out of 7,180 public beds (26%) are short-stay, while the number of short stay beds in the private sector is approximately 1,800.

14 <https://www.hiqa.ie/publications/annual-overview-report-regulation-designated-centres-older-people-%E2%80%93-2014>

Nor is existing eligibility for therapies and supports affected including occupational therapy, physiotherapy, speech and language therapy, chiropody and social work supports.

Under the NHSS, the person makes a contribution towards the cost of his/her care in the nursing home (the level of which is determined in accordance with the criteria laid down in the Act of 2009) and the State pays the balance of the cost of the applicant's care.¹⁵

Nursing Home Charges

Under the NHSS, prices charged by Private Nursing Homes are agreed between the Private Nursing Home and the National Treatment Purchase Fund (NTPF). A weekly price for the cost of care in Public Homes is also provided. These agreed prices are the basis for the financial support payable by the HSE under the Scheme.

NHSS Provisions

Under the NHSS, all entrants into long term residential care, both public and private/voluntary, are dealt with in a similar fashion in respect of their care needs and means assessment. The scheme makes available two types of financial support:

- State Support
- Ancillary State Support (Nursing Home Loan)

People are assessed financially on the basis of both income and assets.¹⁶ Individuals can contribute up to 80% of their assessable income and 7.5% of the value of their assets per annum. The principal residence is only considered as part of their assets for the first 3 years. Where an individual's assets include land and property in the State, the contribution based on these assets may be deferred and collected from their estate after their death. This is the optional nursing home loan element of the scheme, legally referred to as Ancillary State support. This creates a financial charge to be collected from the estate of the person.

There are a number of safeguards built into the NHSS to protect both the person entering a nursing home and his/her spouse/partner. These include:

- Nobody paying more than the actual cost of care
- The first €36,000 for a person's assets (€72,000 for a couple) not taken into account during the financial assessment
- The principal residence (and farms/businesses in certain circumstances) only included in the financial assessment for the first three years of a person's time in care
- Individuals retaining a personal allowance of 20% of their income, or 20% of the maximum rate of the State Pension (Non-Contributory), whichever is the greater
- A spouse/partner remaining at home retaining 50% of the couple's income, or the maximum rate of the State Pension (Non-Contributory), whichever is the greater
- Certain items of expenditure, 'allowable deductions', taken into account during the financial assessment – health expenses, levies required by law (e.g., Local Property Tax), rent payments and borrowings in respect of a person's principal residence.

¹⁵ See http://www.citizensinformation.ie/en/health/health_services_for_older_people/nursing_homes_support_scheme_1.html

¹⁶ Where a person is deemed to lack decision-making capacity, s/he is appointed a Care Representative by the Circuit Court.

Care Needs Assessment

The care needs of applicants for the NHSS are assessed by HSE staff in order to establish their need for support under the NHSS. The assessment relates to abilities to carry out activities of daily living, including-

- Cognitive ability
- Extent of orientation
- Degree of mobility
- Ability to dress unaided
- Ability to feed unaided
- Ability to communicate
- Ability to bathe unaided
- Degree of continence

Issues relating to the NHSS

While it is generally acknowledged that the NHSS has been successful in providing access to nursing homes for older people of all financial means, a number of important issues relating to the operation of the scheme have emerged, some of which are documented in the Review of the Nursing Homes Support Scheme published in 2015.^{17 18}

Issues identified relating to the NHSS are outlined here under four main categories:

- Access to therapies
- Additional charges in Nursing Homes
- Availability of suitable chairs, aids and appliances
- NHSS application process

Access to Therapies

The 2015 Review of the NHSS referred to concerns that were raised about the lack of uniformity for nursing home residents when accessing certain services, and in particular therapies, e.g., physiotherapy that they need and may be eligible for. It was noted that therapy services are not funded under the NHSS, but are funded by the HSE Community Health Organisations (CHO). In some areas where demand exceeds what can be provided, there appears to be a de-prioritisation of nursing home residents and in these circumstances the only option remaining is to pay for such therapies privately.

17 <http://health.gov.ie/wp-content/uploads/2015/07/Review-of-Nursing-Homes-Support-Scheme.pdf>

18 An Interdepartmental /Agency Working Group has been set up to progress the recommendations contained in the Review. This Group is chaired by the Department of Health and includes representatives from the Department of the Taoiseach, the Department of Public Expenditure and Reform, the HSE, Revenue and, when required, the National Treatment Purchase Fund.

Once a person is in private nursing home care, in practice, there is little or no access to primary care professionals, including physiotherapy, occupational therapy and social work. This is contrary to national policy which promotes equal access to primary care services regardless of place of residence.

Additional Charges in Nursing Homes

Nursing homes typically ask people to pay additional charges for services not covered under the NTPF contract. As the NTPF contract provides for just bed and board in nursing homes, there are extra mandatory charges in most private nursing homes for activities and other items ranging from €100 monthly to €100 a week. This results in people not being able to spend their money as they wish and in some cases paying for activities in which they do not wish to participate or are unable to participate.

The additional charges are also an added burden on the families of older people on low incomes. Those who are reliant on the State Pension as their only source of income have only a small amount of discretionary income left over after paying their contribution towards Nursing Home Support Scheme. This issue is particularly pertinent in the case of spouses in some instances. Where a person's spouse is in a nursing home s/he is effectively very much worse off because of having many of the same costs, (e.g., house insurance, health insurance, water charges) as well as the additional nursing home charges on a significantly reduced household income.

A particular issue arises where the spouse of an NHSS recipient is a Qualified Adult in social welfare terms¹⁹. This spouse still living at home may end up with reduced income but having increased costs in relation to, for example, visiting their spouse in the nursing home, paying the additional nursing home charges and buying aids and appliances.

Availability of suitable seating and other aids/appliances in nursing homes

A number of instances have been reported where nursing home residents do not have access to appropriate seating to meet their needs, e.g., wheelchairs. One case reported referred to a woman who needs a larger wheelchair due to her size/weight. She is currently on a HSE waiting list and informal feedback from the HSE is that only a limited budget is available for such purposes and that this tends run out relatively early in the year.

In theory, nursing home residents should have the same entitlement to assessment for and provision of equipment as people living at home, i.e., entitlements under the Medical Card scheme. In practice, there is a wide variation in access to that entitlement from area to area. Anecdotal evidence suggests that priority in allocating scarce resources is given to people living in the community who are deemed to be more at risk than those in nursing homes, as the perception is that those living in residential care are safer.

The Sage experience suggests very different practices in different HSE catchment areas. In some areas, equipment needed and recommended by OTs is extremely limited while in other areas Primary Care teams are reported providing a comprehensive service to nursing homes and, indeed, providing access to their seating clinic for specialised equipment.

A factor which impacts directly on equipment provision is a lack of agreement nationally as to where responsibility lies for the funding of equipment for nursing home residents. Nursing Homes Ireland argue

¹⁹ Some people may no longer be able to get the Household Benefits package because they happen to be Qualified Adults on their spouse's social welfare pension.

that the NHSS funding package does not provide for the provision of anything other than basic equipment and that, therefore, nursing homes have no obligation to provide specialized equipment and that residents should access such equipment via HSE Primary Care Services. This debate is ongoing and unresolved, and in the meantime the arbitrary provision as outlined above is what is in place and vulnerable nursing home residents may have to rely on their own resources or on the goodwill of relatives, friends or charitable bodies.

Although the HIQA regulations state that residents should be referred to care services, they do not specify how these should be provided. The Irish National Audit of Stroke Care²⁰ has indicated a low level of provision of such services to residents with stroke.

NHSS Application Process

The NHSS application process presents its own difficulties in some instances. The Regulations stipulate that where a person has reduced ability to make decisions, the application for State Support on their behalf can be made by a specified person²¹. However, a specified person can only apply for State support and not for the nursing home loan element of the scheme, which can only be done by a Court appointed Care Representative.

The National Treatment Purchase Fund (NTPF)

The NTPF has been designated by the Minister for Health pursuant to Section 40 of the Nursing Homes Support Scheme Act 2009 as a body authorised to negotiate with proprietors of registered nursing homes to reach agreement in relation to the maximum price(s) that will be charged for the provision of long-term residential care services to Nursing Homes Support Scheme residents. The NTPF has statutory independence in the performance of its function.

The NTPF role within the NHSS is to negotiate and agree prices with private and voluntary nursing home owners on behalf of the State. There is also provision for examination of records and accounts of participating nursing homes. The Guidelines for Negotiating Prices include the following:

- Costs reasonably and prudently incurred by the nursing home and evidence of value for money
- Price(s) previously charged
- Local market price
- Budgetary constraints and the obligation of the State to use available resources in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public;
- The existence of a specialist unit may be included as part of the discussions at the time of the price negotiations.

20 http://www.stroke.ie/media/pub/strokereports/ihf_hse_national_stroke_audit_2015__web_version.pdf

21 A specified person is defined as a) the Committee of a Ward of Court, b) a person appointed under a valid, registered enduring power of attorney who is not restricted from applying for the scheme, c) a care representative appointed under the Nursing Homes Support Scheme Act, d) the applicant's spouse or partner, e) a relative of the applicant who is 18 years of age or over, f) a next friend appointed by a court, g) the applicant's legal representative, or h) a registered medical practitioner, nurse or social worker.

It is noted that Nursing Homes Ireland, the representative body for private nursing homes, take the view that the current NTPF funding model fails to recognise the reality of the costs incurred to provide nursing home care.

The negotiations by the NTPF are with each nursing home (as opposed to collective negotiations with a representative body). This typically involves a series of contacts and face-to-face meetings with each proprietor. As part of this function, the NTPF²² enters into “Approved Nursing Home Agreements” with registered private and voluntary nursing homes to record the maximum price(s) that have been negotiated. The NTPF provides the HSE with the details of all Approved Nursing Home Agreements. The function of the NTPF in respect of the NHSS is solely to negotiate prices with private and voluntary nursing homes. Neither the Department of Health nor the HSE has any role in such individual negotiations.

The role of the HSE includes liaising with NHSS applicants, assessing their eligibility for the scheme and determining financial co-payment arrangements between nursing homes and individual residents, and disbursing State payments to private and voluntary nursing homes.

The NTPF’s role does not include setting standards for Private Residential Facilities or the assessment of individuals for the purposes of determining their eligibility under the NHSS. HIQA sets nursing home standards and inspects facilities to ensure that these standards are being met.

Deed of Agreement

The Deed of Agreement is the contract between the nursing home and NTPF specifying the maximum price that the nursing home can charge NHSS residents for long-term residential care as defined in the deed. These prices are fixed for the term of the deed. The Deed of Agreement specifies the commencement date and the expiry date of each deed. Prices agreed are fixed for the term of the Deed of Agreement. At the end of the agreement term a new process of negotiation on pricing will be entered into with the nursing home and all issues, including price, will be open for discussion and agreement.

The NTPF price agreement covers the provision of Long-term Residential Care Services as defined in the deed. Changes in operating conditions as a result of new regulations or standards will form part of the discussions at the time of the price negotiations. However, once agreed prices will be fixed for the term of the agreement. The existence of a specialist unit (e.g., Dementia Unit) may be included as part of the discussions at the time of the price negotiations. The NTPF only deals with nursing home owners and managers for the purpose of agreeing a maximum NHSS price and does not deal directly with residents or families whose link with the NHSS is through the HSE.

The NTPF Funding Model: Issues Identified

A number of criticisms have been made of the NTPF role in the NHSS. The main one refers to the fact that the NTPF is an agency of State under the HSE which ‘negotiates’ prices with the non-statutory sector based on an approach which does not really take account of the complexity and challenging nature of the care required by people with complex care and support needs, particularly people with dementia. This is the case despite the fact that a large majority of residents in nursing suffer from cognitive decline and dementia. Another issue identified is that the HSE’s own providers do not seem to be subject to ‘negotiation’ and are only prohibited from charging more than the actual cost of the care.

The NTPF model runs contrary to the ‘money follows the person’ principle articulated by the HSE as well as

22 <http://www.ntpf.ie/home/nhss.htm>

to the emphasis on moving all people with disabilities out of congregated settings proposed in the Time to Move On Report.²³

The 2015 NHSS Review recommended that the National Treatment Purchase Fund (NTPF) review the present pricing arrangements with a view to:

- Ensuring value for money and economy, with the lowest possible administrative cost for clients and the State and administrative burden for providers
- Increasing the transparency of the pricing mechanism so that existing and potential investors can make as informed decisions as possible; and
- Ensuring that there is adequate residential capacity for those residents with more complex needs.

Nursing Homes: Issues Identified in HIQA Inspection Reports

A HIQA Overview Report for 2014²⁴ referred to its regulation of public and private nursing homes for 2014. The analysis of compliance with regulations and standards indicated that, while nursing homes had become safer for residents, many centres needed to improve care quality and the quality of life for residents. While most centres had an acceptable level of overall compliance with the regulations and the National Standards for Residential Care Settings for Older People in Ireland, many were identified as needing to improve their individualised person-centred care planning and how that care is delivered. A need for improvements in their approach to risk assessment and risk management was also identified.

The inspections clearly found examples of good care and good procedures. Good practice in end-of-life care and food and nutrition was found in most centres inspected, and at least 84% of centres were found to be fully or substantially compliant during the inspections. However, a need for improvements in end-of-life care and food and nutrition was noted.

There was also a call for more investment by nursing home providers in staff recruitment and training, and in ensuring that enough staff with the relevant skill mix are available to support residents “Nursing homes must continue to ensure that the basics of safe care are in place, while prioritising and developing a culture of quality improvement and person-centred care” (HIQA Director of Regulation).²⁵

Aspects of nursing home care requiring improvement identified in the 2014 inspections were:

- A need within the sector to better understand how to safeguard dependent older persons in their care
- A need to further develop expertise in risk management

23 http://www.fedvol.ie/_fileupload/Next%20Steps/Time%20To%20Move%20On%20From%20Congregated%20Settings.pdf

24 <https://www.hiqa.ie/publications/annual-overview-report-regulation-designated-centres-older-people-%E2%80%93-2014>

25 <https://www.hiqa.ie/publications/annual-overview-report-regulation-designated-centres-older-people-2015>

- Making the transition from complying with regulations and standards to providing a truly individualised service for each individual resident
- Better physical design to ensure privacy and dignity (some residents still live in large and outdated open-plan wards)

The HIQA Overview Report for 2015²⁶ again reported good levels of compliance with regulations relating to provision of appropriate healthcare, food and nutrition and end-of-life care. The three most common areas of non-compliance included issues related to premises, health and safety and risk management, and fire safety. The report noted that “many residents continue to be accommodated in large and outdated open-plan Nightingale-style wards, which give residents little privacy and dignity” (p.9).

Individual nursing home reports published more recently²⁷ highlighted a number of less than satisfactory aspects of provision:

- Inadequate access to showers and toilets
- A failure to notify HIQA about money going missing
- Questions about the use of chemical restraints and one instance of a person being prescribed psychotropic medication as a result of ‘behaviour that challenged’
- Allegations, which could be construed as allegations of abuse, having been investigated as complaints

Issues around the care of people with dementia were reported in 2016 HIQA Inspection Reports, including, in particular:

- The lack of a specific dementia unit in a nursing home which had a high proportion of people with dementia
- Staff not having access to appropriate training in dementia, moving and handling and fire safety
- Inadequate staff engagement with residents who had dementia, especially those with sensory deficits
- The layout of the centre not meeting the needs of people with dementia

Other issues identified in reports of inspections carried out during 2016 were:

- Out-of-date policies to deal with prevention, detection and response to abuse and an absence of relevant mandatory training
- Care plans not sufficiently comprehensive to address residents’ social, emotional and psychological needs
- No annual review of the quality and safety of care delivered to residents
- Non-compliance with complaints procedures
- Insufficient provision for residents’ privacy and dignity

²⁶ <https://www.hiqa.ie/publications/annual-overview-report-regulation-designated-centres-older-people-2015>

²⁷ <https://www.hiqa.ie/social-care/find-a-centre/inspection-reports>

A DKM report for the Department of Health published in 2015²⁸ found that the lack of reference to efficient cost levels and return on efficient capital in the Fair Deal negotiations represents a disconnect from the reality that the State expects the private sector to potentially provide 80% of nursing home capacity going forward. The report concluded that this was unsustainable in terms both of rational market operation and enabling new investment in areas of the country where payment rates are lower. The report also noted that the current pricing model has been developed in an ad hoc way and acts as a barrier to investment and stated that the lack of reference to the level of dependency of residents discourages the development of more specialised facilities (for dementia, etc.) where more expensive care is required, and creates an incentive to actively discourage acceptance of high-dependency residents by nursing homes.

Issues identified in the Leas Cross Review Report ²⁹

The 2006 Leas Cross review which was carried out by Professor Des O'Neill, following a number of system failures identified, made a number of recommendations to address the issues identified. While some of the 2006 Leas Cross Report recommendations have been implemented or partly implemented – for example, the development of care standards and inspections for nursing homes by HIQA, significant aspects remain unfulfilled, including the requirement for gerontological training, provision of multi-disciplinary team and geriatrician/old-age psychiatrist support, and the public health overview of residential care through universal application of the Single Assessment Tool.

Standards and Regulation in Long-term Care

The regulation of long-term care and the implementation of standards is an important area and one that has received some attention in Ireland in recent years. The National Economic and Social Council (NESC) has published two reports which discuss standards in both home care and residential care for older people.^{30,31} Some of the key points noted in the NESC reports are:

- Care of older people in residential centres is regulated by mandatory regulations and standards through the Health Act 2007 and through HIQA;

28 Potential Measures to Encourage Provision of Nursing Home & Community Nursing Unit Facilities, <http://health.gov.ie/blog/publications/potential-measures-to-encourage-provision-of-nursing-home-community-nursing-unit-facilities/>

29 https://www.hse.ie/eng/services/publications/olderpeople/Leas_Cross_Report_.pdf

30 Quality and Standards in Human Services in Ireland: Home Care for Older People http://files.nesc.ie/nesc_reports/en/NESC_130_Home_Care_Main_Report.pdf

Quality and Standards in Human Services in Ireland: Residential Care for Older People http://files.nesc.ie/nesc_reports/en/NESC_128_main_report.pdf

31 NESC also produced a report on Standards on End of Life Care (2012) which built on the Hospice-friendly Hospitals Programme and its Quality Standards on End-of-Life care in Hospitals

- The new regulatory regime (refers to the 2009 regulations under the Health Act) has been beneficial in restoring public confidence after scandals;
- HIQA independence was seen as positive as was the inclusion of HSE centres under the regulations;
- Care at home is unregulated (whether public, private sector or NGO)³²;
- Areas for improvement/change identified by NESC included:
 - Sharing of learning based on best practice
 - Supporting culture change to promote person centred care
 - Collecting standardised data to assess quality and costs of different services
 - Coordinating decisions of providers, the Department of Health and HIQA to ensure that services for older people are provided at an optimum level.

There continues to be an absence of a regulatory structure for the delivery of professional care in the home – this issue was addressed in a 2011 Law Reform Commission report³³. The Commission noted that debate in this area has, in general, focused on whether the State is in a position from a financial perspective to extend the statutory regulatory role of HIQA under the 2007 Act and the extent to which the detailed standards and requirements of such a statutory regime could be met by all home care providers. An NESF 2009 report (already referenced) called for clarification on:

- HCP outcomes
- Planning, targeting and needs assessment (the latter individually and by local area)
- Regular monitoring and periodic evaluation
- Strong accountability – who is responsible for what, measurement of whether or not this is achieved, and a form of incentive/sanction to help ensure goals are achieved
- Detailed delivery plans – covering matters such as leadership, budget, implementation milestones, reviews, co-ordination mechanisms, communications with all stakeholders, methods of delivery, monitoring of delivery, links with clients etc.
- Standards for allocation and delivery of HCPs agreed and passed

The NESF report emphasised the need to align all aspects of HCP policy design, decision-making and working practices, so that sustainable implementation can occur. The report also called for a greater focus and direction from the Centre, at both political and Departmental levels and suggested the establishment of a high-level committee chaired by the Minister of State with Responsibility for Older People, with representation from the main stakeholders to drive the implementation agenda forward.

The LRC 2011 report called for action on a number of fronts to ensure that home care packages were delivered in a transparent manner and to the highest quality standards and set out a number of important recommendations in this regard.³⁴

32 A variety of draft standards for home care exist and are being implemented on a voluntary basis (See also Law Reform Commission 2011 report)

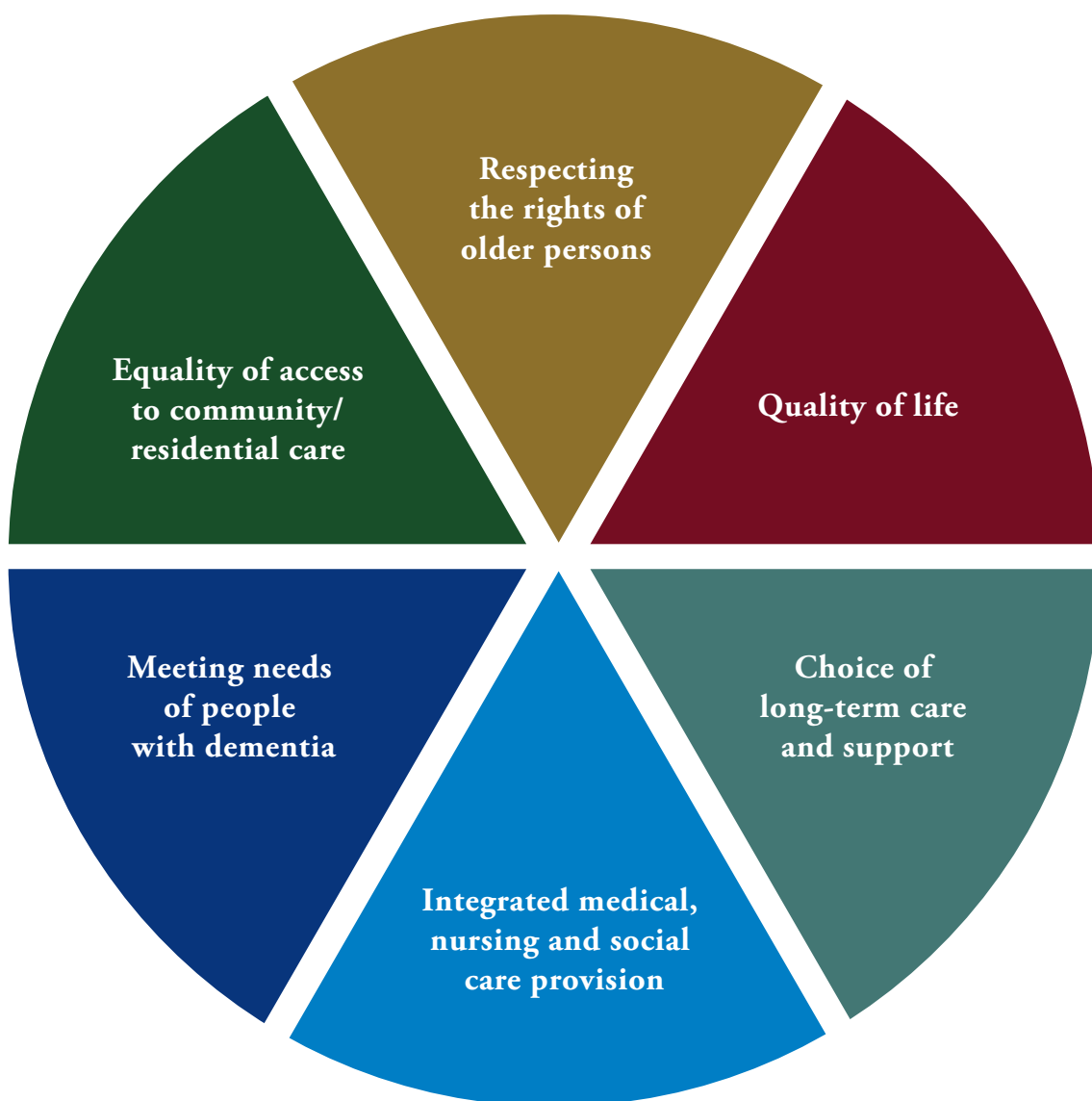
33 Law Reform Commission (2011), http://www.lawreform.ie/_fileupload/Reports/r105.htm

34 Ibid.

Section Two

Long-term care: six core considerations

The analysis of the Long-term Care Forum consultation responses and existing research and policy documents suggests that long-term care should be underpinned by six core considerations:



Respecting the rights of older persons

The provision of long-term care must have at its core the safeguarding of the rights of individuals and groups. Protecting the rights of older people is part of various action plans and conventions from the United Nations and the Council of Europe.³⁵

The European Social Charter, adopted in 1961 and revised in 1996, was the first human rights treaty to specifically protect the general rights of older people. Article 23 concerns the right of older people to social protection and seeks to ensure that older people remain full members of society for as long as possible by means of adequate resources to help them play an active part in public, social and cultural life. It also seeks to ensure that older people can choose their life-style freely and lead independent lives in an environment with which they are familiar for as long as they wish and are able to do so.

In 1991, the United Nations Principles for Older Persons saw the principles of independence, participation, care, self-fulfilment and dignity as core to older people. Principle 14 states that:

Older persons should be able to enjoy human rights and fundamental freedoms when residing in a shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.

These UN Principles were followed up in 2002 by the Madrid Plan of Action on Ageing. It called for changes in attitudes, policies and practices so that the enormous potential of ageing in the 21st century may be fulfilled. This was necessary in order to ensure that people can age with dignity and security while continuing to participate in their community.

Because neither the principles nor the action plan are legally binding, States are under a moral as opposed to a legal obligation to follow their recommendations regarding the treatment of older people.

Council of Europe Statement on the Rights of Older Persons

The Council of Europe Statement on the Rights of Older Persons³⁶ includes a requirement on States to provide medical, health and care supports in accordance with need. The following are some of the relevant provisions in the Council of Europe Statement:

- Older persons in principle should only be placed in residential, institutional or psychiatric care with their free and informed consent. Any exception to this principle must fulfil the requirements of the European Convention on Human Rights, in particular the right to liberty and security (Article 5).
- Older persons should be able to fully and effectively participate and be included in society.
- All older persons should be able to live their lives in dignity and security, free from discrimination, isolation, violence, neglect and abuse, and as autonomously as possible.
- The full and equal enjoyment of all human rights and fundamental freedoms by all older persons should be guaranteed and respect for their inherent dignity promoted.
- Older persons shall enjoy their rights and freedoms without discrimination on any grounds, including age.
- Older persons are entitled to lead their lives independently, in a self-determined and autonomous manner.
- Older persons have the right to receive appropriate support in taking their decisions and exercising their legal capacity.

³⁵ The general principles of the European Convention on Human Rights are also relevant to the rights of care recipients

³⁶ Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons. (Adopted by the Committee of Ministers on 19 February 2014 at the 1192nd meeting of the Ministers' Deputies).

- Member States should provide adequate measures of support to enable older persons to have housing adapted to their current and future needs.
- Member States should take appropriate measures, including preventive measures, to promote, maintain and improve the health and well-being of older persons. They should also ensure that appropriate health care and long-term quality care is available and accessible.
- Services should be available within the community to enable older persons to stay as long as possible in their own homes.
- Older persons should receive medical care only upon their free and informed consent, and may freely withdraw consent at any time.
- In case an older person is unable, in the particular circumstances to give consent, the wishes expressed by that person relating to a medical intervention, including life-prolonging measures, should, in accordance with national law, be taken into account.
- When an older person does not have, according to law, the capacity to consent to an intervention, in particular because of a mental disability or a disease, the intervention may only be carried out with the authorisation of his or her representative, an authority or a person or body provided for by law.
- Member States should provide for sufficient and adequate residential services for those older persons who are no longer able or do not wish to reside in their own homes.
- Older persons who are placed in institutional care have the right to freedom of movement. Any restrictions must be lawful, necessary and proportionate and in accordance with international law.
- Member States should offer palliative care to older persons who suffer from a life-threatening illness or an illness limiting their life expectancy, to ensure their well-being and allow them to live and die with dignity.

Assisted Decision-Making (Capacity) Act 2015

The Assisted Decision-Making (Capacity) Act 2015 is based on a rights-based approach. Supported decision-making is a central component of the Act³⁷ which reflects the recommendations of various Law Reform Commission reports.³⁸

The Act sets out guiding principles that are intended to safeguard the autonomy and dignity of the person with impaired capacity, as follows:

- There is a presumption of decision-making capacity unless the contrary is shown;
- No intervention will take place unless it is necessary;
- Any act done or decision made under the Act must be done or made in a way which is least restrictive of a person's rights and freedoms;
- Any act done or decision made under the Act in support or on behalf of a person with impaired capacity must give effect to the person's will and preferences.

37 The Act was passed by the Oireachtas in December 2015 but its implementation will require the establishment of the Decision Support Service) within the Mental Health Commission.

38 See, in particular, Law Reform Commission (2006), Vulnerable Adults and the Law, http://www.lawreform.ie/_fileupload/consultation%20papers/cpCapacity.pdf.

Capacity Assessment

The Act changes previous provisions based on an all or nothing status approach to decision-making capacity to a flexible functional definition, whereby capacity is assessed only in relation to the matter in question and only at the time in question. The Act recognises that capacity can fluctuate in certain cases.³⁹

Decision-Making Support Options

The legislation recognises different levels of decision-making capability and, therefore, provides for three different categories of interveners to assist a person in maximising his/her capacity.

- 1) Assisted decision-making: a person may appoint a decision-making assistant – typically a family member or carer – through a formal decision-making assistance agreement to support him/her to access information or to understand, make and express decisions;
- 2) Co-decision-making: a person can appoint a trusted family member or friend as a co-decision-maker to make decisions jointly with him or her under a co-decision-making agreement;
- 3) Decision-making representative: for the small minority of people who are not able to make decisions even with help, the Act provides for the Circuit Court to appoint a Decision-making Representative.⁴⁰

Enduring Powers of Attorney

The Act requires attorneys to be subject to supervision by the Director of the Decision Support Service which will also have the role of registering enduring powers of attorney.

Advance Healthcare Directives

The Act provides a statutory framework for Advance Healthcare Directives. The purpose of an Advance Healthcare Directive 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. A person may, in an advance healthcare directive, appoint a designated Healthcare Representative to take healthcare decisions on his/her behalf when s/he no longer has the capacity to make those decisions. Designated healthcare representatives will be supervised by the Director of the Decision Support Service.

Decision Support Service

The Act provides for the Decision Support Service to be set up within the Mental Health Commission to support decision-making by and for adults with capacity difficulties. The Director of the Decision Support Service will supervise and handle complaints against decision-making assistants, co-decision makers, decision-making representatives, attorneys of enduring powers and designated healthcare representatives. The Director will also prepare codes of practice for specific groups and will promote awareness of the legislation among the general public.

³⁹ The Act provides for a review of capacity of wards of court who are adults.

⁴⁰ A decision-making representative will make decisions on behalf of the person but must abide by the guiding principles and must reflect the person's will and preferences where possible. The functions of decision-making representatives will be as limited in scope and duration as is reasonably practicable.

Quality of life considerations

In looking at long-term support and care in the broadest sense, quality of life considerations are paramount. The World Health Organisation defines quality of life as the individual's own perception of their position in life, having regard to their value systems, goals, expectations, standards and concerns. Furthermore, the World Health Organisation recognises that quality of life is affected by a person's physical health, psychological state, level of independence and salient features of their environment.⁴¹

Quality of life is broadly-based and includes a range of domains including physical health, psychological and emotional well-being, degree of independence, social relationships and relationship to the environment in which people live. For example, quality of life domains for people with dementia have been identified as including:⁴²

- The opportunity to perform activities of daily living (ADL)
- The opportunity to engage in meaningful use of time
- Social interactions
- Achieving a favourable balance between positive emotion and the absence of negative emotion
- Expression of the religious /spiritual dimension of life

Older people requiring additional support face the same daily stresses that affect people of any age. They may also have the added concerns of age, illness, retirement, and other lifestyle changes, all of which may lead to difficulties with intimacy and sexuality.⁴³ Many people in later life must reconcile a sense of closeness with the experience of being alone.⁴⁴ In some long-term care settings, resident's attempts at sexual expression may be viewed as 'problem' behaviour. However, there is an increasing recognition that interest in, and the right to, sexual expression and intimacy exists throughout the life span and that healthy sexuality among older adults should be supported.⁴⁵

Quality of life and the physical and sensory environment

The relationship between the physical and sensory environment, healthcare outcomes and quality of life has been recognised for some time. Internationally, there is a growing body of evidence reflecting a move toward smaller or domestic style environments that encompass homeliness and more nurturing environments that encourage greater involvement with children, plants and animals.⁴⁶ The role of the visual arts, music and entertainment in enhancing hospital environments is increasingly appreciated. The importance of having specified standards of accommodation in residential care facilities, e.g., own room with an en-suite bathroom and a physical and social environment to fulfil recreation, social interaction and stimulation needs has been noted.⁴⁷

41 <http://apps.who.int/iris/bitstream/10665/206411/1/B4966.pdf>

42 Cahill, S. and Diaz, A. (2010), Living in a Nursing Home, Quality of Life: The Priorities of Older People with a Cognitive Impairment, in association with Dementia Services Information and Development Centre, http://www.nhi.ie/zuploads/page_docs/living%20in%20a%20nursing%20home%20quality%20of%20life%20dr%20suzanne%20cahill.pdf

43 <http://retirement.berkeley.edu/pdf/Sexuality%20and%20Intimacy.pdf>

44 www.nia.nih.gov/health/publication/sexuality-later-life

45 [http://www.gnjournal.com/article/S0197-4572\(08\)00266-8/pdf](http://www.gnjournal.com/article/S0197-4572(08)00266-8/pdf)

46 Brownie, S. & Nancarrow, S. (2013), "Effects of person-centered care on residents and staff in aged-care facilities: a systematic review", *Clinical Interventions in Aging* 8, 1-10, <http://dx.doi.org/10.2147/CIA.S38589> Kane, R.A, Lum T.Y., Cutler, L.J., Degenholtz, H.B. and Tzy-Chyi Yu. (2007), "Resident Outcomes in Small-House Nursing Homes: A Longitudinal Evaluation of the Initial Green House Program", *Journal of the American Geriatrics Society* 55, 832-839. <http://www.beingblocked.com/wp/wp-content/uploads/2014/02/Resident-outcomes-in-small-house-nursing-homes-A-longitudinal-evaluation-of-the-initial-Green-House-program.pdf>

47 O'Neill D, Gibbon J, Mulpeter K. Responding to care needs in long-term care. A position paper by the Irish Society of Physicians in Geriatric Medicine. *Ir Med J.* 2001 Mar;94(3):72. <http://archive.imj.ie/ViewArticleDetails.aspx?ContentID=1601>

The HIQA National Standards for Residential Care Settings for Older People in Ireland⁴⁸ contain a number of references to the design and physical environment aspects of the buildings. There is reference to each resident having a choice of a separate bedroom (1.2.1) and the importance of the sensory environment is also referenced and access to outdoor spaces (2.6.7). Another important quality of life consideration is the role of pets and the related sense of loss and bereavement people experience when, for example, they have to live in residential care facilities where there is no provision for keeping pets.

Mobility as a key determinant of quality of life

Mobility is another important consideration in determining quality of life in that it is an important component of independence. The ageing process and related disease can impact on a person's ability to maintain his/her independence. The UN Convention on the Rights of Persons with Disabilities refers to the importance of personal mobility in ensuring that people have the greatest possible independence (Article 20). Meeting the personal mobility needs of people should thus be a central factor in long-term health and social care provision. The provision of mobility aids to those who need them, in particular, appropriately designed wheelchairs,⁴⁹ is at the core of quality long-term care. Related easy access to occupational therapy, physiotherapy and speech and language therapy is also of paramount importance.

Links between social connectedness and well-being in old age

The significance of social connectedness as a key to well-being for older people has been identified as an important finding of TILDA (The Irish Longitudinal Study on Ageing)⁵⁰. "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. While living alone is not the same as loneliness, living alone was identified by McKeown et al. as a risk factor which directly reduces personal well-being.

McKeown et al. conclude that, since the *raison d'être* of services for older people is to improve their well being, there is a related need to identify clearly the determinants of personal well-being. They state, however, that existing provision seems to be heavily influenced by an 'illness and disability' model of ageing, whereas the TILDA analysis suggests that a well-being model may be more appropriate and more inclusive of the relevant influences on older people's well-being.

The analysis carried out in the McKeown et al. report suggests that a focus on developing and maintaining well-being, as opposed to focusing on illness and disability, must be central to any long-term care strategy. Enhancing well-being can, of course, be particularly challenging in the case of people who are socially isolated and outside of networks of social engagement, information and supports. This is a key consideration and one which should be to the forefront of policy deliberations relating to long-term care and support. The links between socio-economic status and health and well-being also need to be taken into account in understanding the well-being of older people.⁵¹

Quality of life in nursing homes is thus also a key element in long-term care policy. A 2001 National Council on Ageing and Older People Report, A Framework for Quality in Long-Term Residential Care for Older

48 <http://hiqa.ie/publications/draft-national-standards-residential-care-settings-older-people-ireland-2014>

49 O'Gorman, E. and Gowran, R.J., (2014), "Invisible Policies: A Scoping Literature Review of Wheelchair and Seating Provision for Older People in Irish Nursing Home Settings" Poster, Irish Gerontological Society, 62nd Annual and Scientific Meeting, Iway 9th-11th October 2014.

50 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.

51 Layte, R. and Fahey, .T (2001), "Living Standards and Health of Older people" in Towards a Society for All Ages: Conference Proceedings, National Council on Ageing and Older People;

People in Ireland (2001), noted that quality standards for long-term residential care need to be addressed in the context of, inter alia, quality of life, having regard to the dignity, independence and autonomy of the older people resident in long-term care settings.

Balancing the requirements of care and people's needs to avoid over-care and learned helplessness is an important quality of life consideration. The distinction between decisional autonomy and the autonomy of execution is an important one in empowering people living in residential care facilities. The Assisted Decision-making (Capacity) Act 2015 provides a solid basis for promoting both decisional and positive autonomy.

Choice and preferences regarding long-term care and support

In keeping with the provisions of the Council of Europe Statement on the Rights of Older Persons, the UN Convention on the Rights of Persons with Disabilities and the Assisted Decision-making (Capacity) Act 2015, it is of crucial importance that the will and preferences of older people (individually and collectively) in relation to how they receive long-term care and support are fully acknowledged and taken into account. It is generally accepted that people have a preference for home care.⁵²

A recent public opinion survey⁵³ confirmed that being cared for at home is the most preferred option for people should they ever require long-term care. Overall, there is greater preference for the HSE to be responsible for providing long-term care to older people who require it. Family and relatives were ranked as most important in enabling people with a long-term illness to remain in the community.

Indeed, much of the policy to date relating to the provision of home support packages focuses on complementing, rather than substituting for, care by family members and others. The role of health and social services is seen as one of supporting individuals and families to this end by the provision of support services such as home help, community nursing and respite care. As already stated, it is reasonable, based on anecdotal evidence, to form the view that many dependent older people 'put into' long-term nursing home care do not wish it and have not given their full consent. The reality of the nursing home option is that, in many instances, it is the only response available currently in the absence of community and home based care.

Home Care Services: What older people want

Research evidence also tells us what older people need and want from their home care service. For example, a 2014 qualitative research study⁵⁴ with service users in the UK identified the following as important to older persons.

- Home care is not seen simply as fulfilling practical needs – older people want their home care to meet their social and emotional needs too. No matter how frail or physically disabled they are, they want to go outside, continue friendships and take part in community life.

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

53 Amárach Research (2015), Presentation to Forum on Long-term Care (See Appendix 2).

54 <http://www.scie.org.uk/publications/guides/guide54/files/guide54.pdf>

- Older people want to develop good relationships with their carers. However, many users feel that their paid carers are constrained by time during their visits – they can either talk or do, but not both.
- Continuity of care is seen as vital by users, who want a few regular carers who they can get to know well. A high turnover/variety of staff has an emotional impact on service users, who get embarrassed when strangers carry out intimate personal tasks for them, or find it exhausting having to constantly repeat personal information to new people.
- People want a personalised and flexible approach to their care, which respects them as individuals. They want support from one person who can help them prioritise the competing demands of their multiple conditions. They want a care plan that is explained to them clearly and is easy to understand. They want information about all the different services that are available to them in their local area.
- People value professionals who provide care services that meet their own understanding of their needs and help to give them a feeling of being in control and of wellbeing.

Integrated medical, nursing and social care provision

Long-term care encompasses medical, nursing, social and personal care dimensions, all of which need to be provided for irrespective of whether the care is provided in people's own homes, in community-based settings or in residential care facilities. The care and support provided should clearly be the best possible and should be based on the most up to date clinical, nursing and social care practice using a multi-disciplinary approach.

Need for a gerontologically attuned approach to care

The need for a gerontologically-attuned approach to nursing home care has been articulated⁵⁵ on the basis that a high percentage of people in nursing homes have multiple chronic conditions, frailty and disability which require gerontological expertise in care, including dementia care and palliative care. Indeed, this approach can be regarded as equally applicable in the context of providing care in their own homes to people with high dependency.

Elements of a standard for medical care for physicians working in nursing homes have been identified by the European Union Geriatric Medicine Society (EUGMS) in 2015⁵⁶, including, inter alia:

55 O'Neill D, Gibbon J, Mulpeter K. Responding to care needs in long-term care. A position paper by the Irish Society of Physicians in Geriatric Medicine. *Ir Med J.* 2001 Mar;94(3):72. <http://archive.imj.ie/ViewArticleDetails.aspx?ContentID=1601>

56 Cited in the Submission to the Forum on Long-term Care from the Policy Group on Ageing of the Royal College of Physicians of Ireland (RCPI), <https://www.rcpi.ie/wp-content/uploads/2016/05/Sage-Long-Term-Care-final-Format.pdf>

- 1) All patients under consideration for admission to nursing home care should have an assessment by a specialist in geriatric medicine or old age psychiatry or both, prior to admission;
- 2) Physicians providing medical care to people in nursing homes should have a formal competence in geriatric medicine and old age psychiatry;
- 3) Nursing staff should have gerontological training, including training in dementia and palliative care and care attendants who have due training in the care of older people;
- 4) Associated disciplines – physiotherapy, occupational therapy, speech and language therapy, clinical nutrition and pharmacy and access to dentistry, social work and psychology – as required;
- 5) The medical care needs should be supported by specialist gerontology services, including geriatricians, old age psychiatry, gerontology and clinical nurse specialists as required.

It has been argued⁵⁷ that gerontological nursing needs greater recognition as a speciality in its own right in undergraduate curricula and throughout the system. It is further pointed out that a current position paper from the Irish Nursing and Midwifery Board on nursing older people makes no mention of gerontological nursing or specialist nursing of older people - this is seen as in stark contrast to the near contemporaneous position paper from the UK Nursing and Midwifery Council.⁵⁸

The important role of GPs who provide care in nursing homes has been highlighted⁵⁹, in particular, the importance of effective liaison between GP and the family (especially where there is a degree of cognitive impairment.⁶⁰ The need for people to be educated and aware of the crucial distinction between chemical restraint (regarded as inhuman and degrading treatment under the European Convention on Human Rights and not allowed) and the administration of medication for therapeutic reasons was noted.

The essential role of ancillary support services and therapies

There is a clear need to incorporate into long-term care the pivotal role played by social workers, occupational therapists, physiotherapists, speech therapists as well as care attendants, nurses and physicians, in order to determine the limits of independent functioning for an individual and to enable him/her to learn adaptive procedures and to use adaptive devices that may be necessary where there are motor, sensory, or cognitive limitations.

A critical factor in enabling older people with impaired mobility to continue living at home is having the right enabling aids and adaptations and housing design. The provision of appropriately adapted housing and mobility equipment is likely to be very cost effective in that it enhances quality of life, promotes independence and lessens the need for more costly interventions. For example, occupational therapists can potentially play an important role in facilitating early mobilization, restoring function, preventing further decline, and coordinating care, including transition and discharge planning.

57 Ibid

58 Ibid

59 Meade B. GPs and nursing homes, referenced in Submission to Forum on Long-term Care by the RCPI Policy Committee, <https://www.rcpi.ie/wp-content/uploads/2016/05/Sage-Long-Term-Care-final-Format.pdf>

60 This includes knowing that GP is not available 24/7 except for emergencies, speaking to one nominated family member only, and the family knowing when the GP visits the centre.

The difficulties nursing home residents have in accessing therapies and related aids have been noted above. There is a reported lack of hospital based occupational therapists in acute hospitals to complete home assessments to determine whether or not a person is likely to be able to be discharged home with/without support services. Also, it is reported that the Primary Community Continuing Care (PCCC) Occupational Therapy Services (also known as Community Occupational Therapy Services) focus is on equipment provision rather than carrying out a wider remit due to insufficient resources.⁶¹ Pressure to 'close' cases despite people living with conditions that require on-going care (in particular for progressive and palliative conditions) is also reported

Meeting the specific needs of people with dementia

As a society, we are now supporting a growing older population with cognitive impairment, including Alzheimer's disease and other dementias. The number of people with these conditions is expected to double by 2031 to over 90,000.⁶² These are progressive conditions that not only have a huge impact on the physical, psychological and emotional state of the person with dementia but also on their families and carers.

It has been suggested⁶³ that, while not all dementia can be prevented, there are a number of factors that could contribute to delaying its onset:

- Being physically active appears to reduce some of the risk of developing dementia;
- There may be a relationship between smoking and dementia in later life;
- Heavy alcohol consumption has been associated with dementia risk and cognitive decline;
- Staying mentally active and socially engaged may reduce some of the risk of developing dementia;
- There is consistent evidence of an association between cardiovascular risk factors and dementia risk in later life;
- Addressing psychological distress, depression and sleep disturbance throughout the life course may confer significant benefit in later life.

A Research Review, *Creating Excellence in Dementia Care: A Research Review for Ireland's National Strategy*⁶⁴, (completed in 2012) provided the following guidelines as to the future direction of public policy for dementia in Ireland:

61 One reported example was of a LHO area where there is a monthly budget of €25,000 for all occupational therapy equipment for all clients from birth to death – the 2011 census for this area indicates a population of 130,563 people (this area has one of the highest percentages of older people in the country). This budget has to cover the purchase of such equipment as powered wheelchairs/specialised seating systems; which can cost up to €10,000 for one client alone, and also cover small appliances such as a raised toilet seat or a bath board.

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

63 Cleary, O., & McAvoy, H. (2015). *Brain Health and Dementia Prevention in Ireland - A discussion paper*. Institute of Public Health in Ireland and the Alzheimer Society of Ireland, <http://www.publichealth.ie/document/iph-report/brain-health-and-dementia-prevention-ireland-discussion>

64 Cahill, S., O'Shea, E. and Pierce, M. (2012), *Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy*, http://www.atlanticphilanthropies.org/app/uploads/2015/09/Creating_Excellence_in_Dementia_Care_2012.pdf

- Greater emphasis on prevention
- Increased public awareness about dementia
- Increase in early diagnosis
- Development of a case management model of integrated care
- Expansion of dedicated community-based services, e.g., day care
- Development of new and expanded psychosocial approaches
- Development of small-scale, appropriately designed, residential care units
- Development of appropriate services for people with early-onset dementia

This blueprint is mirrored in the National Dementia Strategy 2014⁶⁵ which emphasises the integration of services, supports and care for people with dementia and their carers by increasing awareness, ensuring early diagnosis and intervention, enhancing community based services to improve quality of life and quality of care for those with dementia. This was seen as requiring the HSE to:

- Critically review health and personal social services for people with dementia to identify gaps in existing provision and prioritise areas for action;
- Consider how best to configure resources currently invested in home care packages and respite care;
- Evaluate the potential of assistive technology to provide flexible support both to carers and to people with dementia;
- Ensure that information on how to access advocacy services and other support services is routinely given to people with dementia and their families/carers.

While the balance of care between the community and residential is very sensitive to marginal changes in any of these factors, the availability of family care is critical for people with dementia living at home. Such care imposes significant financial and emotional costs on carers.

Community support services for people with dementia and their carers continue to be under-developed and fragmented. For example, generally, people with dementia do not come into contact with the health and social services until a crisis occurs, involving the person with dementia, their carer, or both parties. Late intervention is, in turn, more likely to lead to long-term residential care, as a carer may no longer feel that s/he is able to cope. The result is a system geared to providing substitute in-patient care for people with dementia rather than providing anticipatory and on-going community care in partnership with individuals and their family carers.

In 2016, a number of research projects⁶⁶ were launched to support the implementation of the National Dementia Strategy.

- 1) Look at the best ways to provide care for people living with dementia based on choice rather than just relying on the traditional residential care model, and
- 2) Examine personalised, non-pharmacological approaches to care such as physical exercise and the beneficial effects of non-pharmacological interventions.

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

66 http://www.hrb.ie/about/in-the-news/?no_cache=1&tx_ttnews%5Btt_news%5D=690&tx_ttnews%5BbackPid%5D=19&cHash=d279876542edf6894a039f6f86bce042

Integrating people with dementia into residential care settings

The majority of people with dementia currently reside in generic residential care facilities. While some nursing home units are dementia specific, many residents with mild or no cognitive impairment find themselves living in an environment surrounded by others with a more severe cognitive impairment and associated challenging behaviours. This can result in a situation where there are competing human rights, for example, the right of one resident to walk about freely in the nursing home vs. the right of another resident to be undisturbed in their room etc.

There appears to be little done to equip residents with the skills and knowledge that they need to navigate the environment they find themselves in. While nursing home staff are offered appropriate training to enable them to communicate with people who have a cognitive impairment, nursing home residents are usually not offered any training, information or induction. This problem can also be exacerbated by the fact that, while the people are adapting to the challenges of living in a communal setting, they are also coping with the numerous losses associated with the move into long stay care itself (e.g. loss of health, home, status, control, relationships etc.).

Guidelines from Professional Bodies

An ICGP Quality in Practice Committee 2014 Report⁶⁷ set out guidelines and clinical evidence in the management of dementia in general practice. The report includes a section on advanced dementia in nursing homes and suggests a number of strategies to improve care in nursing homes, as follows:

- Senior staff member with lead for quality improvement in care of persons with dementia
- Local strategy for care and management of persons with dementia
- Only appropriate use of anti-psychotic drugs
- Specialist in-reach services from older peoples community health teams
- Specification and commissions of other in-reach services (e.g., primary care, dentistry)
- Design features underpinning best practice in dementia care

Genio Dementia Projects

The Genio Dementia Programme, which was established in 2011 in four regional programme areas⁶⁸, focuses on six main areas of activity:

- Developing the provision and integration of person-centred, community-based supports to people with dementia and their families/carers that enable them to live longer within their local community – thus diverting them from institutional care;

67 Dementia, Diagnosis and Management in General Practice Cited in Submission to Forum on Long-term Care by the RCPI Policy Committee, <https://www.rcpi.ie/wp-content/uploads/2016/05/Sage-Long-Term-Care-final-Format.pdf>

68 These are Kinsale, South Tipperary, South Dublin, and Mayo. A fifth Cognitive Health Project is aimed at developing and sharing online films which will promote positive cognitive health behaviours.

- Supporting services and their personnel in the four programme areas to work with a person-centred focus and in a more collaborative and integrated way with enhanced awareness and skills; identifying barriers and solutions around integrative working;
- Using a community development approach to identify and harness existing community resources (including all resources, not just those with a focus on older people), to develop community-based responses which use local strengths and resources to meet local and individual need and building a range of community supports across each area;
- Applying and testing principles and best practice models from other sectors including disability, mental health and children's services; for example, person-focus, early intervention, prevention, community integration, consultation and participation.

It is reasonable to suggest that, despite the NCAOP Action Plan for Dementia Care in Ireland and the more recent 2014 National Dementia Strategy, there has been a lack of urgency in dealing with the problems of people with dementia and their carers. Responding to the needs of people with dementia, whether living in the community or in residential settings, is a particular challenge which requires innovative thinking to ensure that the very best practice in care delivery and support is implemented in all instances.

Equality of access between community and residential care

While virtually all health policy documents assert the desirability of promoting community care over residential care, in practice, this has not happened. Access to community care services (see Glossary) has been limited by a number of factors, including, in particular, the fact that the HSE is empowered but not obliged to provide such services. In contrast to clear legislative entitlement to general practitioner, hospital services and support for nursing home care, there is no such legislative entitlement to the services necessary for living in the community. This has resulted in a situation where access to such services has been both limited and variable across the country. There are gaps, mostly due to budget constraints and staff shortages, in the availability of many services, including public health nursing, occupational therapy, physiotherapy and chiropody, day care and specialist services (e.g., dementia services and night sitting services). The TILDA 2011 study concluded that 12% of older people who suffer from impairments in the activities of daily living, some of whom are severely impaired, do not receive any formal or informal help.⁶⁹

The National Economic and Social Forum (NESF) (2005) noted as a matter of serious concern the fact that no details have been published of how people qualify for services such as home helps. "This means that it is not possible to know whether or not an individual was treated correctly and, among other things, reduces the possibility of seeking a remedy" (p. 60). The 2005 NESF Report recommended increased spending on care services for older people to attain, at least, the OECD average of 1% of GDP. However, the onset of a recession in the latter half of 2008, together with the lack of national standards for home care packages made the provision of services for older people more susceptible to a lack of resources and served to perpetuate existing inequities in the delivery of services.

69 Fifty Plus in Ireland 2011: First Results from the Irish Longitudinal Study on Ageing (TILDA)

The Expert Group on Resource Allocation and Financing in the Health Sector, in its 2010 Report⁷⁰, described the poorly developed system of community health services as the greatest deficiency in the current provision of public health services in Ireland. The Group noted that the community health sector in Ireland remains small and weak when compared to provisions in other European countries. The fact that, as already stated, many community care services are provided on a discretionary rather than a statutory basis creates problems for providers as well as service users. Difficulties in relation to community care services identified by Convery (2001)⁷¹ remain to a greater or lesser extent:

- Lack of service planning and development because of the low level of funding
- Inconsistencies in allocation of services to people with the same level need because of lack or absence of standardised application processes
- Lack of sensitivity to certain areas of need (e.g., social circumstances)
- Inconsistencies in treatment because of weaknesses in assessment procedures
- Stigmatisation of services (e.g., home help) because of lack of universal entitlement to service.

The provision of a legislative framework for core community services remains an essential requirement and it is unlikely that adequate funding will be provided for services unless there is a clear legislative entitlement to services.

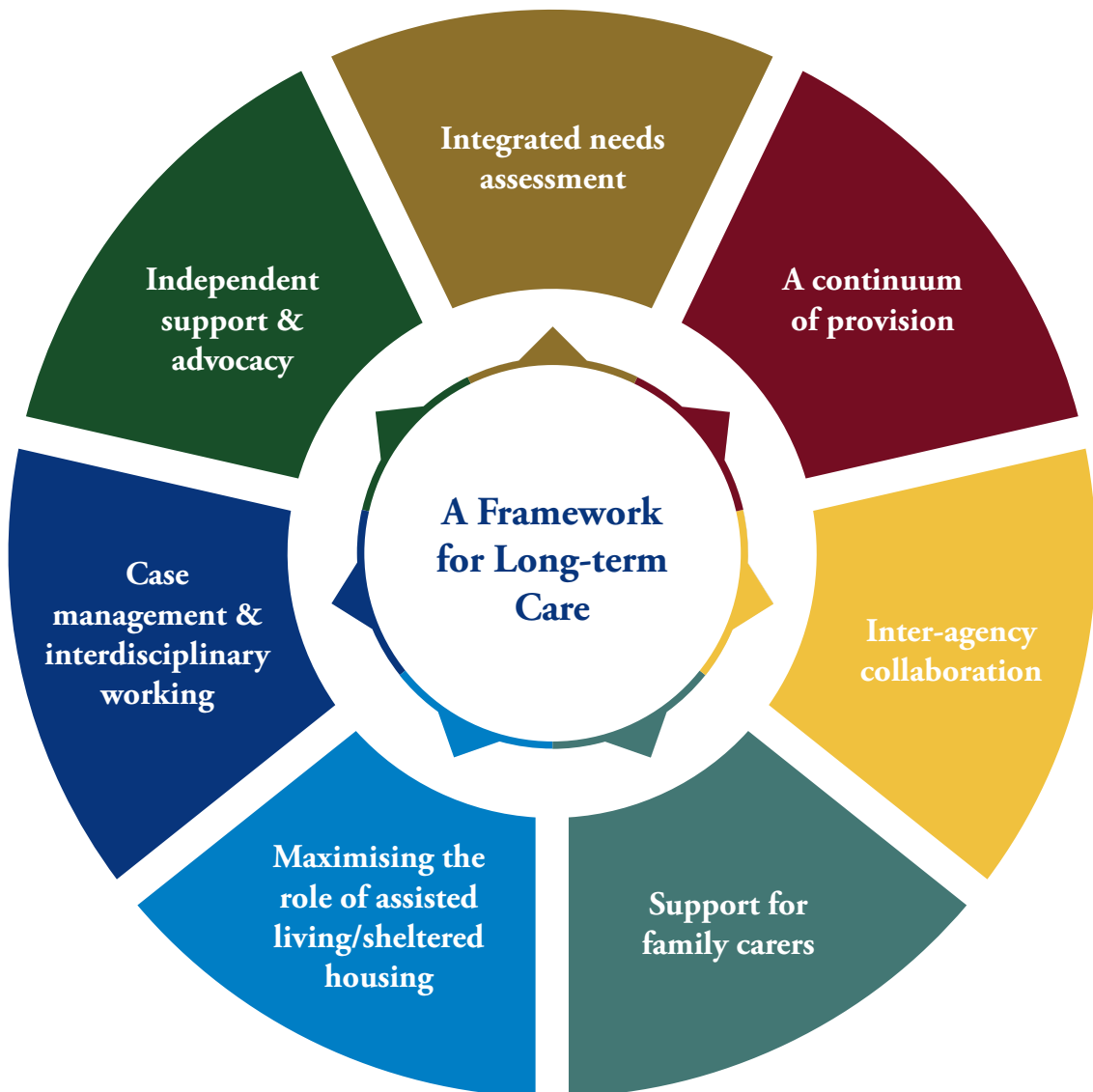
70 Report of the Expert Group on Resource Allocation and Financing in the Health Sector (Department of Health and Children 2010)

71 Convery, J. (2001), "Social Inclusion of Older People in Health and Social Services in Ireland" in Towards a Society of All Ages: Conference Proceedings, National Council on Ageing and Older People.

Section Three

A Framework for Long-term Care: Seven Inter-related Components

Seven inter-related and overlapping components of a framework for long-term care can be identified, as illustrated diagrammatically below.



Integrated needs assessment

An objective, independent, comprehensive, consistent, integrated and nationally standardised needs assessment process is required to determine the nature and scale of long-term care required.⁷² The purpose of needs assessment should be to help determine an individual's eligibility for or entitlement to benefits or services on the basis of agreed and transparent criteria. Such criteria should include the following essential components:

- The level of dependency and/or needs of individuals in respect of health, housing, social care and transport needs
- Establishing the will and preferences of individuals as to how the care and support they require should be provided
- Using a multi-disciplinary approach to assess needs and design appropriate responses
- Identification of the role of different State agencies in meeting identified needs relating to accommodation, home care supports and nursing requirements
- Establishing in a realistic and transparent manner the respective potential contribution of family members, community/neighbourhood networks and voluntary/community organisations
- Providing for choice of provider where the services required have to be purchased from private providers to enable people to choose those that best suit their preferences

A positive development in more recent years is the implementation of a Single Assessment Tool (SAT) to uniformly assess dependency levels, allow resources to be targeted towards those with the greatest needs and enabling supports and services to be designed in the most appropriate way possible.⁷³ The mainstreaming of the SAT approach would provide a standardised assessment tool to be applied in ascertaining the care needs of individuals requiring health and social care services which would address at least some of the deficiencies and duplications of effort identified in various reports. For example, a 2009 Evaluation of Home Care Packages noted that the absence of a standard needs assessment for home care packages has led to inconsistency and duplication. However, the reference to the SAT in the in the HSE's National Service Plan 2016⁷⁴ is not wholly encouraging from a community care perspective. The Plan refers to phased implementation being planned with an initial focus on access to long-term care, resulting in a minimum of 50% of NHSS applications assessed using SAT by the end of 2016 with implementation for applications to home care services following resulting in a minimum of 25% of Home Care Packages applications assessed using SAT by the end of 2016.

The National Quality Standards for Residential Care Settings for Older People in Ireland require that each resident must have their needs assessed before they move into residential care. Each potential resident's health, personal and social care needs must be assessed, the resident must participate in the assessment and information from a range of sources must be included in order to demonstrate clearly why long-term residential care is, or is not, required.

72 http://www.ncaop.ie/publications/research/reports/72_Assessment%20of%20Older%20Peoples%20Health%20and%20Social%20Care%20Needs%20and%20Preferences.pdf

73 <https://www.iasw.ie/attachments/1d2210cd-89c2-4b62-b95d-1ac3392234e8.PDF>

74 HSE National Service Plan 2016 www.hse.ie

The Law Reform Commission (LRC) (2011)⁷⁵ stated that “the personal contribution of the proposed care recipient during the assessment of needs is essential to ensure that all aspects of a person’s care needs are assessed and not simply those needs which a professional person may consider ought to be assessed. This will ensure that there is a holistic approach to the assessment of needs. This is necessary in order to ensure that the needs of older people are met in the most appropriate setting, to provide care that is properly co-ordinated to enable older people to remain living at home independently for as long as possible. Assessments should thus give due weight to the will and preferences of people both in respect of the care and support to be provided and the outcomes desired (2.16).

The LRC recommended that care needs should be assessed under the following range of headings in respect of the care recipient:

- Companionship needs⁷⁶
- Care needs⁷⁷ and
- Advanced home care needs (see Glossary)

The Commission also recommended that the level of care should be appropriately attuned to the actual needs of the person, thereby promoting the autonomy and independence of the care recipient to the fullest degree (2.19). The Commission concluded that examining a person’s needs under companionship needs, home care needs and advanced home care needs would ensure that their needs are adequately assessed and the appropriate level of care provided.

“It is important that the level of care should be appropriately attuned to the actual needs of the person and that special care is taken to ensure that the level of care provided is not too high because to do so may negatively impact on a person’s independence ...” (2.17).

A continuum of provision

Meeting the health and quality of life needs of older people requires the provision of a range of interventions in the home, in the community, in acute hospitals and in residential care centres for older people. There is thus a need to have strong linkages in the continuum of support and care – between housing, community support, acute hospital care and long stay residential care. The quality of life of people in long-term residential care is also a key part of the continuum. The need for an integrated care pathway across all services for people with dementia has been identified as has the need to take account of the potential of new residential models, including housing with care (National Dementia Strategy 2014). The role of income maintenance, transport, infrastructural policies and opportunities for social engagement and education in determining the quality of life of older people is also an important consideration.

75 Law Reform Commission (2011), http://www.lawreform.ie/_fileupload/Reports/r105.htm

76 Companionship needs may include preparing snacks, monitoring diet and eating, arranging appointments, reminders for medication, overseeing home deliveries and organising visits to neighbours and friends.

77 Home care may include meal preparation, light housekeeping, providing transport, assisting with walking and exercise, assisting with personal hygiene and dressing.

A key issue is how the concept of 'home care package' is understood and defined and where it fits in the overall continuum of support. As it currently operates, it is primarily a HSE-funded package which is not integrated with other aspects of community support, for example, house adaptations, income support, transport and heating, mobility aids and supports for carers. This is crucially important in that the ability of a person to remain at home can frequently be determined by one or more of the above factors in addition to the availability of the Home Care Package. Difficulties relating to any of these can impact on people's ability to remain living in the community.

There are currently no national policies to provide a mix of long-term care accommodation to include, for example, duplex units for sharing with spouse/partner or assisted living accommodation where people who are socially isolated but who do not have care needs can be accommodated. Also, there is limited availability in nursing homes for couples/spouses/siblings/friends to share appropriately configured rooms.

Greater use of supported living accommodation

There is universal acknowledgement that supporting older people to age at home makes sense socially. Delivering on this requires all sectors to work together to deliver integrated support packages to people either in their own homes or in purpose-built housing. These would include:

- Specific provisions for people with cognitive impairment and for people with physical disabilities
- Coordination of medical, social, family, technological and community supports
- Individual care and support plans capable of adaptation to changing and evolving needs
- Services to cater for low, medium and high support needs
- On-site social facilities with 24-hour support
- Links with the community to enable social connectedness

The Report on the Review of the NHSS recommended that the Departments of Health and Environment, Community and Local Government (DECLG) and the HSE, explore the potential for developing sheltered or supported living arrangements. The existing network of supported housing schemes provided by housing associations⁷⁸ has the potential to be a useful starting point for this potential.

Stronger cross departmental links between the housing and health sectors at national and local levels are necessary to implement Government policy as outlined in the Positive Ageing Strategy. Most local authorities have established a Housing and Disability Steering Group and Homeless Fora. However, there is no local authority mechanism to enable the development of housing-related support services to support independent living by older people. The Social Housing Strategy also does not refer to housing or supports for older persons.

Housing and related supports for older persons need to be addressed at Local Authority level through a multi-agency approach. An example of this is through the Age Friendly Alliances and the newly established Dublin City Council Working Group exploring Housing with Care options.

⁷⁸ These include Alone, Clúid and Respond.

Inter-agency collaboration

Inter-agency collaboration and cooperation has been part of the policy discourse for a considerable duration and is widely acknowledged as providing the cornerstone for success in the area of provision of accommodation and related supports for people with a disability and older persons requiring care and support. Good practice in long-term care requires strong inter-agency collaboration. However, the bringing together of government departments, other statutory agencies, and NGOs has tended to present considerable challenges.⁷⁹

Older persons in need of care and support who have different needs clearly require a range of accommodation, care, nursing and medical responses and a continuum of delivery and intensity. Disjointed delivery of services can result in confusion and missed opportunities.

While it is not clear to what extent deficiencies in inter-agency collaboration regularly highlighted in research findings are a result of organisational deficiencies or a simple lack of funding, it should be noted that difficulties arising from organisational diversity are likely to be exacerbated by inadequate funding. Systems that are well-funded (by whatever method) and are operated by a specially-designed and relatively uniform structure are more likely to provide a high-quality standardised service.

Within the statutory sector nationally, the broader community and voluntary sector and within the local development sector, there has been a strong emphasis in recent years on issues relating to partnership, coordinated services, networking, inter-agency co-operation and service integration. Himmelman's⁸⁰ continuum of inter-agency working involves five stages – networking, co-ordination, co-operation, collaboration and integration (see Figure 1). Clearly, there is a substantial difference between organisations coming together to exchange information and to network on an informal basis and organisations that are involved in joint planning and in the provision of integrated, co-ordinated services.

While the environment for collaborative initiatives has been enabled to some extent by statutory funding streams which favour joint projects, the work required to develop and implement a truly inter-agency approach with shared goals and funding commensurate with those goals continues to present significant challenges. Questions arise, for example, as to the implications of the compartmentalisation of service planning under categories of 'health' and 'housing' for developing a holistic response to people's needs.⁸¹

Inter-agency Collaboration: Blockages

The following general blockages to inter-agency collaboration in relation to meeting the health and social care needs of older persons can be identified:

- Overall budgetary constraints
- Separate prioritisation of needs by different agencies in accordance with their functional responsibilities,

79 Rourke, S. Collaboration and Inter-Organisation Work within the Disability Sector: Opportunities and Challenges, Disability Federation of Ireland Conference, 2007; Taft, Nuala Crowe "Our Stories" Current Examples And Case Studies Of Inter-Organisation Work Within The Disability Sector Disability Federation of Ireland Conference, 2007.

80 Himmelman, A.T., (2002), Collaboration for Change: Definitions, Decision-making models, Roles, and Collaboration Process Guide, https://depts.washington.edu/ccph/pdf_files/4achange.pdf

81 See, for example, Cotter, N., Silke, D. and Browne, M. (2010), Review of Good Practice Models in the Provision of Housing and Related Supports for People with a Disability, Centre for Housing Research, Dublin.

- Difficulty in agreeing common goals, e.g., health and housing
- Agency defensiveness and professional protectionism
- Providers determining the content and nature of services rather than the recipients
- Competing interests at both national and local levels
- Inadequate provision for joint financing
- Entitlement to community care services arbitrary on the part of the provider
- Inter-agency working not prioritised within the planning system or in the allocation of resources.

Figure 1: Himmelman’s Continuum of Inter-agency Working

Networking	Entails meeting to exchange information for mutual benefit and can be a key building block for good co-operation. By networking, agencies can widen their knowledge base, identify shared values and goals and develop agreed ways to achieve these common goals.
Coordination	Similarly involves identifying shared values and goals and exchanging information, but also altering activities for mutual benefit and to achieve a common purpose. Coordination requires more organizational involvement than networking. Co-ordination of services can be a pathway to developing shared strategies to meet common goals. In order for the organizations involved to benefit, it is necessary for them to define ways in which they can each alter their activities so that they can co-ordinate their efforts more effectively and achieve common goals.
Cooperation	Can be defined as exchanging information, modifying activities and sharing resources for mutual benefit to achieve a common goal. This type of collaboration can be short term or long term, but in all cases it requires a level of risk and trust for the organizations involved. Cooperative working generally requires that each of the organizations involved share resources, and engage in a level of risk and mutual trust.
Collaboration	Involves exchanging information for mutual benefit, altering activities, sharing resources and enhancing the capacity of other organisations to achieve a common purpose. Organisations work together by engaging in activities where the parties are willing to invest in and share trust, resources and risks, to create a common entity, separate from their own organisations. For successful collaboration, organisations have to be willing to enhance the capacity of each organisation involved. Inter-organisation competition has no place when the engagement is at this level.
Integration	A further stage requiring a greater commitment than coordination, cooperation and collaboration. It requires a commitment to joint planning and delivery of services and joint evaluation of impact and effectiveness. Integration can also involve pooled budgets, common management, outcomes and structures. Integration often entails co-location of services, sharing of staff and sharing of information about clients and service users. Full integration can sometimes result in amalgamations and mergers between individual organisations.

Developing an Integrated Response at Local Level

A strong underlying feature of Irish local government, acknowledged in a 2008 Green Paper⁸², is that it has a much narrower range of functions than local government in most other European states, which often plays a role in the provision of policing, health and education.

In practice, in Ireland, there is a very wide range of organisations – statutory, NGO and private – involved in delivering services at a regional and local level. Indeed, it is the case that services have become increasingly fragmented as voluntary/community organisations and private providers have become more involved in frontline service delivery.

Role of Central Government

Despite the existence of an extensive local administrative infrastructure, the majority of public expenditure decisions continue to be made at national level⁸³. The emphasis at the general policy level⁸⁴ on the need to co-ordinate and integrate services at the point of delivery is frequently not translated into actual practice on the ground. Indeed, it has been noted that the approach taken at central level has in practice not supported local integration and does not encourage decentralisation of power and, as a result, has arguably served to keep the local government much weaker than it should be.⁸⁵ In addition, demand for services may outstrip supply, impacting on the ability of providers at local level to deliver in the integrated manner which they themselves would value.

A related and equally important consideration is the fact that there is no overall national strategic framework for meeting a range of different needs, e.g., the higher costs associated with high support sheltered housing, because of separate functional responsibilities and budgetary processes on the part of the HSE, the Department of the Environment and local authorities.

The OECD⁸⁶ has noted that responding to more complex, cross-cutting issues will require an integrated Public Service that acts increasingly through networks rather than top-down structures. The Council of Europe (2013) has stated⁸⁷ that Ireland does not have enough constitutional protection for local government and called on the Irish Government to implement legislation to address this deficit. The report noted that local governments “only manage a modest amount of public affairs” and that the administrative supervision of their activities by the central level remains high. While the Council of Europe Congress rapporteurs⁸⁸, citing the Putting People First Action Plan, welcomed the fact that Ireland has made “substantial changes” in the past decade and, also, the commitment of the Irish authorities to move from an almost fully centralised system to a certain level of decentralisation, the Report recommended to the Irish authorities that they revise their legislation in order to ensure that the subsidiarity principle is better enshrined and protected in the law.

Adapting services to meet local and individual needs may mean giving local administrators more autonomy in developing and implementing policies within a local partnership framework involving end users, frontline staff, managers and relevant representative organisations. It would mean greater transparency in the way decisions are made and in relation to the underpinning eligibility criteria for different services and, most importantly, a greater devolution of decision-making responsibilities and related budgets to local level.

82 Stronger Local Democracy – Options for Change, Department of the Environment, Heritage and Local Government, April 2008.

83 See O Broin, D. and Waters E. (2007), *Governing Below the Centre: Local Governance in Ireland*, TASC, Dublin.

84 See Putting People First, Action Programme for Effective Local Government, http://www.environment.ie/sites/default/files/publications/files/putting_people_first.pdf

85 Stronger Local Democracy – Options for Change, Department of the Environment, Heritage and Local Government, April 2008.

86 OECD Review of Public Services (2008) http://www.oecd-ilibrary.org/governance/oecd-public-management-reviews-ireland-2008/executive-summary_9789264043268-2-en

87 <https://wcd.coe.int/ViewDoc.jsp?p=&id=2113703&direct=true>

88 Andris Jaunsleinis (Latvia) and Merita Jegeni Yildiz (Turkey)

Supports for family carers

The role of the family in providing long-term care is critical in Ireland as is the case in many other countries. Census 2011 shows that 187,112 people were providing unpaid care in the home at that time. The majority (61%) of carers were women and women provided almost two-thirds (66%) of all care hours. There is a particular caring demand on women in their fifties. Substantial amounts of care were also provided by older people (aged 70+) who were providing almost 800,000 hours of unpaid care per week in April 2011.⁸⁹

A 2014 study of family carers of older people⁹⁰ found that, in general, carers reported caregiving to be a positive experience. However, the study also found that:

- Almost half of carers (48%) provided care for more than 80 hours a week;
- More than 2 in every five carers (44%) were at risk of developing clinical depression;
- Approximately a third of carers reported that they experienced moderate to severe or severe burden;
- More than half of carers (56%) experienced some form of mistreatment by the care recipient in the previous three months;
- More than half of carers (56%) reported that they experienced some form of psychological mistreatment and 1 in 7 carers (13%) reported being physically mistreated by the care recipient in the previous three months;
- Over a third of carers reported engaging in 'potentially harmful behaviours' (PHB) in the previous three months;
- Overall, a third of carers (37%) reported engaging in PHBs in the previous three months, with 17% reporting that they did so at least sometimes.

Ireland's first National Carers' Strategy, published in 2012, focused on:

- Progressing the development of supports and services
- Recognising and respecting carers as key partners and supporting them to maintain their own health and wellbeing
- Enabling carers to care with confidence and to participate as fully as possible in economic and social life

The majority of people with dementia live in their own communities which puts a huge demands on family caregivers and can adversely affect carers' health, psychological well-being, finances, social life and the carer/care-recipient relationship. Apart from being very stressful for the primary caregiver, caring can seriously affect other family members, including children, grandchildren and siblings. Furthermore, given the degenerative nature of dementia, care is characterised by continuous adjustment and adaptation. Unlike many other forms of informal care, caring for a relative with dementia can extend around the clock.

Services such as day care, home help and particularly home care packages can clearly assist family carers

89 <http://www.cso.ie/en/census/census2011reports/census2011profile8ourbillofhealth-healthdisabilityandcarersinireland/>
 90 National Centre for the Protection of Older People (NCPOP), Family Carers of Older People, http://www.ncpop.ie/userfiles/file/ncpop%20reports/Carers%202014/NCPOP_Family%20Carers%20of%20Older%20People%2092pg%20A4%20FINAL%20PREVIEW_4th%20June%202014.pdf

to continue providing care, but their availability is uneven. Given the intensive nature of caring for someone with dementia, particularly during its later stages, respite services which are responsive and tailored to the needs of the person with dementia as well as the carer can make a vital contribution to achieving the best possible outcomes for all.

The potential pool of available carers may be narrowing significantly because of demographic factors relating to both an ageing population and labour force participation by women. In addition, the intensification of work means that people are struggling to find a work/life balance, particularly where they have children to care for. Therefore, the State is called on to provide more of the supports in the community for older people that may have been provided free of charge by daughters, wives and sisters in the past.

Research repeatedly shows that older people express a clear preference for care in their own homes provided by family members.⁹¹ Policy continues to be based on the premise that the family has a responsibility to provide for the care needs of their older relatives. However, the ability of families to provide the levels of care required is undermined by the fact that services for people being cared for in the community (older people and people with disabilities) – continue to be characterised by:

- Fragmentation
- Low levels of provision
- Inadequate needs assessment
- Entitlement which is frequently arbitrary
- Geographical inconsistencies
- Poor availability of good-quality community respite care services
- Prioritisation of funding for nursing home care under the NHSS

There is a scarcity of imaginative, diversified, dependency-graded respite care (residential and day care). Clearly some family carers of older persons have needs over and above the normal needs of carers which need to be identified specifically and addressed.

- Carers who are older themselves
- Carers living in more isolated rural areas
- Carers of people with dementia
- People who find themselves in the caring role 'overnight' as a result of stroke or the sudden onset of illness

It is very likely that lack of support for carers is going to cost the State more in the long run in that if carers are unable to provide the level of service required, more people will almost certainly end up in nursing homes – against their own wishes and, indeed, in many instances against the wishes of their relatives.

Increased provision for family carers who are able and willing to provide care, both in terms of income and other supports, would thus be likely to make financial sense as well as being crucial in respect of supporting people's will and preferences.

91 See, for example, Amárach Research (2016), Presentation to Forum on Long-term Care (see Appendix 2)

The NCPOP 2014 study⁹² concluded that:

- Routine screening of both the carer and care recipient is necessary in order to identify carers at risk of engaging in abusive behaviours;
- Family carers should be supported in having their own physical and mental health assessed, so that they are best able to cope with the challenges of caregiving;
- Efforts need to be directed at promoting a healthy relationship between the family carer and the older care recipient;
- Preventive intervention efforts need to focus on alleviating the pressures experienced by many carers as a result of the difficult and demanding work of caregiving.

In this context, there are three key questions relating to family carers that require further consideration:

- 1) How are family responsibilities to be negotiated with statutory health and social care providers and agreed in a clear and equitable manner?
- 2) Is the role of families in caring for older people changing and, if so, what are the implications?
- 3) What is the optimum balance of responsibility between the State and the family and is this being achieved?

Maximising the role of housing in long-term care

Appropriate well-designed housing and related preventative services are centrally important in promoting the health and well-being of older people. This will become an even more important consideration as demographic pressures intensify.

It is, therefore, of critical importance that the need for housing and housing related services are included in the assessment of needs both within local authority functional areas and in relation to individuals. This is necessary in order to ensure that measures that can potentially combat deteriorating health and wellbeing sometimes associated with inappropriate housing are put in place. This will, of course, require better partnership between housing, social and health care providers and strong and visible planning leadership across the sectors.

Local authorities have a critical role to play and are well placed to engage with, understand and plan for the local housing needs of the older population and to liaise with different people and organisations in the development of housing to ensure that the needs of older people locally are met.

92 http://www.ncpop.ie/userfiles/file/ncpop%20reports/Carers%202014/NCPOP_Family%20Carers%20of%20Older%20People%2092pg%20A4%20FINAL%20PREVIEW_4th%20June%202014.pdf

Enabling people to stay in their homes

Enabling older people to stay in their homes as their needs change requires intervention at three levels:

- 1) People's current houses may need adaptations if they are to continue to be a safe and secure environment – these include relatively inexpensive adaptations such as:
 - Bathroom aids, e.g. walk-in shower, grab rails
 - Assistive technologies such as monitored alarms, and other monitors and aids
 - Front door spyhole and keychain
 - Intercom
 - Non-slip floor surfaces
 - Outside lights
- 2) People may have support and care needs which require the provision of a range of services.⁹³
- 3) There is evidence of significant fuel poverty among older person households which requires to be addressed both through energy efficiency measures and through the social welfare system.

Assisted living housing

Not everyone can continue to live indefinitely in mainstream housing. Because of a range of reasons, some of which have been outlined above, it may not be possible to meet people's housing and support needs in their current dwelling. Sheltered/assisted living housing has long been promoted as having the potential to bridge the gap between living independently at home and residential care.

The Years Ahead (1988) envisaged that sheltered housing would form a central part of the continuum of care for older people and recommended that where it is not feasible to maintain a person in his/her own house or in ordinary local authority housing, sheltered housing should be considered as a first choice. To date voluntary housing organisations have been the largest provider of sheltered housing. However, there is a relatively limited supply of fully developed sheltered housing as defined by the Irish Council for Social Housing (ICSH).⁹⁴ In view of the increasing numbers of people with additional care and support needs and their expressed wish to remain living in their own communities, there is a clear need for the development of more supported or sheltered housing. Of crucial importance here is the availability of communal facilities and services, homecare packages and, crucially, easy access to medical and nursing care as required.

This is an area that requires further development in Ireland. Housing with care clearly offers a dignified response to many people who can no longer live in their own homes but who do not require nursing home

93 Clúid Housing and ALONE are currently operating a pilot support co-ordination service which is being independently evaluated. OPRAH – Older People Remaining at Home, which is part of Ireland's Age Friendly Cities & Counties Programme, runs on similar lines.

94 The ICSH define sheltered housing as schemes with on-site communal facilities for assisted independent living. Sheltered housing schemes usually have an on-site warden, may include care supports such as the provision of meals and assistance with personal hygiene, and on site facilities can include recreation areas, alarm systems, and a laundry. <http://www.icsih.ie/sites/default/files/attach/publication/358/reportonshelteredandgrouphousing.pdf>

care. A UK Department of Health funded evaluation of “extra care” housing schemes found “similar or lower costs” than residential care but better outcomes. Clúid has recommended flexible schemes with varied house types, and the careful design of homes which would allow for multiple uses as the person’s needs change over time. The Centre for Excellence in Universal Design has similarly outlined key principles for the design of housing for dementia that may facilitate ageing in place.⁹⁵

There is scope for much more development of assisted living facilities. A public initiative to increase this type of provision is required, having regard to the need to find an intermediate form of care – between home care and full residential care. Such development would require, inter alia,

- Legislation requiring all developments above a prescribed size to include a specified proportion of assisted-living accommodation
- A system of tax incentives to developers and builders who meet specified criteria in relation to assisted-living accommodation
- The Departments of Health and Social Protection financing or directly providing the required health care and social services needed to enable the assisted-living programme to operate.

The NGO sector, supported through the Capital Assistance Scheme, already plays an important role in the provision of sheltered housing and has the potential to do more in the future. However, it is essential to ensure that the ongoing care element of such provision is addressed at the same time as the construction element. This will require a structured and inter-agency approach to deciding on and providing ongoing support for care services in sheltered housing settings.

Linking housing needs to care provision

It is important that supported accommodation facilities can cope with increased dependency, including, in particular, that associated with the onset of dementia and, in this regard, the continuum from home to nursing home needs to be more closely examined and planned for. The National Dementia Strategy 2014 includes a number of relevant actions and objectives in this regard.

- The need for an integrated care pathway across all services for people with dementia
- Exploring the potential of new residential models, including housing with care, for people with dementia.

Integrated Housing Provision

In the longer-term, the concept of ‘Sustainable Communities’ outlined in Delivering Homes, Sustaining Communities⁹⁶ should be developed and promoted as an underlying approach to meeting the diverse needs of current and future citizens. Sustainable communities are seen as communities that are well planned, built and run, offer equality of opportunity and good services for all across the life-cycle.

In order to develop the concept of sustainable communities fully inclusive of older people requiring care and support, the following macro-level questions will have to be addressed across Departments:

⁹⁵ Clúid (2015), A Home for Life
⁹⁶ [http://www.environ.ie/sites/default/files/migrated-files/en/Publications/DevelopmentandHousing/Housing FileDownLoad,2091.en.pdf](http://www.environ.ie/sites/default/files/migrated-files/en/Publications/DevelopmentandHousing/Housing%20FileDownload,2091.en.pdf)

- 1) What is required to increase provision for people with long-term care requirements in 'regular' Local Authority housing?
- 2) How can more lifetime adaptable and accessible housing be provided in the private sector?
- 3) How can the separate components of sheltered/supported housing be better conceptualised as an integrated package and funding stream?
- 4) What needs to be done to develop new forms of assisted living housing
 - (a) Through better supports for the NGO sector already involved in social housing and
 - (b) Exploring the potential of the social enterprise model in this area

The following measures set out in Delivering Homes, Sustaining Communities need to be progressed:

- Develop new inter-agency responses on a more holistic basis to coordinate housing support interventions with other supports through joint agency/individual commitment according to individual need
- In particular, establish inter-agency protocols to improve services in areas where there is an accommodation and care perspective.

Case management and inter-disciplinary working

It would seem logical that an integrated response to needs assessment and inter-disciplinary working can only be fully effective where there is a designated case manager with responsibility for overseeing and co-ordinating the process. Case management is the process of service co-ordination and planning at management level to deliver individually tailored care plans through a multi-disciplinary approach. The advantage of a case manager is that they can co-ordinate the assessment of need from a range of perspectives and the delivery of services from more than one source.

A 2001 NCAOP study⁹⁷ identified the following barriers to a case management approach:

- Staffing and recruitment problems throughout all sections of health and social care
- Poorly organized referral pathways
- A reluctance to identify older people, especially those with dementia, as a priority target group
- Communications and inter professional difficulties
- High demands placed on informal carers

The NCAOP study reported that older people expressed the view that the implementation of care and case management as a model of service delivery would ensure that their preference for remaining in their own homes would become a reality. A case management approach should thus be a fundamental part of the Home Care Package scheme.

Case management can be said to be effective to the extent that the following components are present:

- A clear care and support plan based on integrated needs assessment
- Early diagnosis and intervention
- Dedicated and flexible community based services
- Housing availability to meet a range of needs
- Psychosocial approaches to complement existing medical and neurological models of service delivery
- Dementia-specific services, including dedicated residential care units
- Easy access to acute hospital care when required
- End-of- life care services in the community, in hospitals and in nursing homes

The central role of an inter-disciplinary approach to meeting the long-term care needs has been well articulated in Ireland over many years⁹⁸. The medical, nursing and social care needs of people are strongly inter-related and gaps or deficiencies in any one area will almost certainly have knock-on effects in other areas. Despite approaches and policies that strongly endorse a multi-disciplinary approach, current delivery systems and protocols are inadequate to deal with the complexity of people's long-term care needs.

An inter-disciplinary team based model of primary care has been developed in the form of Primary Care Units (PCU) including GPs, nurses/midwives, health care assistants, home helps, physiotherapists, occupational therapists, social workers and administrative personnel. A wider primary care network of other care professionals such as speech and language therapists, community pharmacists, dieticians, chiropodists, psychologists, community welfare officers, dentists has also been mooted as providing services for the enrolled population of each PCU. However, it is not clear to what extent these models have been implemented across the country or how effectively they are operating.

Independent support and advocacy

There is general acknowledgement that some older persons need support in asserting their rights, in having their voice heard and in articulating their will and preferences in relation to long-term support and care. It is also widely accepted that support and advocacy plays an important role in enabling individuals and groups who require additional support to get it. There are a number of references in HIQA Standards to the role of advocacy and the need to make provision for people to have access to independent advocates.

⁹⁸ See, for example, Browne, M. (1992), *Swimming against the Tide*, National Council for the Elderly.

The Ombudsman has noted that advocates can perform a very valuable function in hospitals by solving small problems before they become large ones and by helping people feel that they are being treated fairly and with respect by the hospital. The Ombudsman concludes that independent advocacy services should be sufficiently supported and signposted within each hospital so patients and their families know where to get support if they want to raise a concern or issue. The HIQA Report of the investigation into the safety, quality and standards of services provided by the HSE to patients in the Midland Regional Hospital, Portlaoise makes reference to the role of a patient advocate.

The underlying principle of all independent support and advocacy is to facilitate people in speaking for themselves and in articulating their own needs. This includes supports at various points along a continuum which includes the provision of information, assistance with negotiating health and social care pathways and engaging in representative advocacy with or on behalf of people. While many service professionals and service delivery personnel have an advocacy role,⁹⁹ it is necessary to recognise that service providers may sometimes experience a conflict between advocacy and their role in the organisation and, for this reason, an independent advocacy service offers a different type of intervention and is usually seen as 'the better option' (Reed 2004:62)¹⁰⁰.

Advocacy has of course an important role in helping to address larger systemic issues. For example, the Ombudsman's 2014 Report, *A Good Death*,¹⁰¹ refers to complaints about end-of-life care in Irish hospitals and sets out some pointers as to how shortfalls in such care might be addressed. It is also the case that the experiences of individuals and groups engaging with the health and social care delivery system as mediated through advocates can provide a rich data source for feedback to Government and related policy development.

The availability of independent advocacy is a central component of long-term care, particularly in relation to safeguarding the rights of people with dementia or other cognitive impairment. It is crucially important that independent advocacy services are available to all people requiring long-term support and care irrespective of the care setting and that these operate to the highest quality standards. The Quality Standards for Support and Advocacy Work with Older People¹⁰² developed by Sage are particularly pertinent in this regard.

99 O'Mahony-Browne Researchers (2005), *Feasibility Study on the Use of Volunteers in an Advocacy Role for People Dying in Hospitals and Their families*, Study for the Irish Hospice Foundation, Dublin: Irish Hospice Foundation.

100 Reed, J. (2004). "Involvement, Empowerment and Advocacy", in Nies, H., and Berman, P., (Eds.), *Integrating Services for Older People: A Resource Book for Managers*, Dublin: European Health Management Association, p http://catalogue.iugm.qc.ca/GEIDEFile/19367.PDF?Archive=196566891474&File=19367_PDF

101 <https://www.ombudsman.gov.ie/en/Publications/Investigation-Reports/Health-Service-Executive/A-Good-Death/A-Good-Death-Report.pdf>

102 http://www.thirdageireland.ie/assets/site/files/pr/Quality_Standards_for_Support_and_Advocacy_Work_with_Older_People_FINAL_061015.pdf

Section Four

Financing Long-term Care

Currently, long-term care in Ireland is financed principally from general taxation and personal contributions. The public health system provides both residential and community services, but current funding arrangements clearly favour residential care. The cost of care, particularly community care, increases with the level of dependency. It is important to note that home-based care should not be seen as the cheap option, despite the fact that in some cases it can yield substantial cost savings to the State. Clearly, realistic levels of funding are required to ensure that those with higher levels of need can access additional supports and services over and above the services that are routinely available.

The challenge is to find a financing system for long-term care which achieves similar levels of service supply in both the community and in residential care facilities. Another core issue to be addressed is the distinction between the funding of acute medical services and the funding of long-term care and personal social services. This distinction results in the division of organisational responsibilities and fragmented long-term care provision for older people.

A recent Amárach public opinion survey¹⁰³ found that the greatest overall preference for funding long-term care is through general taxation. Clearly, there are no simple or immediate solutions. However, the integration of health care, long-term care and social services should be a policy priority in order to ensure that the latter are not treated as less important than the former.

In looking at the financing of long-term care, the following questions are relevant:

- 1) What are the current and projected long-term care needs of the older population?
- 2) What are the lengths that we, as a society, are prepared to go to meet the long-term care needs of our older population?
- 3) How are we planning for the provision of long-term care which is part of the normal risk of growing old?
- 4) How do we find a way of spreading the costs of long-term care that is efficient, equitable and socially and politically acceptable?

There is a need to broaden the debate from a focus on the health care needs of older people to one which includes social, psychological, quality of life and well-being dimensions. There is a related need to look at integrating spending on health care, social care, housing and social welfare pensions.

103 Amárach Research (2016), Presentation to Forum on Long-term Care (see Appendix 2)

Factors relevant to financing long-term care

The following are some of the factors that are relevant to the financing of long-term care:

- Most countries have an ageing population – this has moved the issue of long-term care into the front line of policy debate;
- In most countries, the majority of long-term care is provided ‘informally’ by families and local community networks – in Ireland, as in other countries, there are concerns that this informal provision will reduce significantly;
- The shift to a home-based care support system presents major challenges because of both programme fragmentation and budgetary structures;
- Countries seeking to enhance home-based care have generally adopted two approaches:
 - Provision of services that support carers, such as day care, respite care and home help
 - Provision of cash benefits to enable people to purchase the supports they require;
- There are two broad perspectives on how long-term care should be financed:
 - The State should provide comprehensive long-term care for all people – similar to acute hospital services
 - The primary responsibility should fall on individuals and their families, with additional support from the State and the private insurance market;

It has to be noted at the outset that there is no blueprint solution to financing long-term care. However, it can be reasonably suggested that private financing arrangements, as they currently exist, fail to satisfy the conditions necessary for an equitable, efficient and affordable system of long-term care. Problems exist both on the demand and supply side of the private insurance market. On the supply side, insurance companies may fear being left with a high risk, high cost group. On the demand side, factors such as affordability, restrictions to coverage and intrusive screening are likely to be inhibiting factors. The public financing of long-term care, therefore, seems the only viable option.

There is a strong case to be made for the State taking a lead role in the matter and developing sustainable structures to address the question of the equitable distribution of the cost of long-term care. In looking at the question of state financing of long-term care in Ireland, there are a number of important inter-related factors that need to be taken into account:

- 1) Systems which are well-funded (by whatever method) and are operated by a specially-designed and relatively uniform structure are more likely to provide a high-quality standardised service;
- 2) A significant shift in financing towards home care services is needed, in line with both people’s preference and Government policy;
- 3) The provision of care by family members can no longer be presumed upon – for this care to continue to be the bedrock of home care provision, more extensive support for family carers will be needed;

- 4) Ireland's current health care financing system, combining a "national health service" with voluntary private insurance covering some 50% of the population, means that there is no long-term care financing solution that is an obvious "fit" with the system of financing health care generally;
- 5) It would seem necessary from a resource perspective and reasonable to require people to make some provision for themselves in respect of long-term care requirements;
- 6) Statutory entitlement to home care must be introduced if the policy of maintaining people in the community, insofar as possible, is to be achieved;
- 7) There is scope for demand and consequently costs to escalate if universal entitlement to long-term care supports is provided – this highlights the vital importance of an objective and explicit needs assessment process;
- 8) The current NHSS model (co-funding by the State and the individual) may not offer the best model for financing all long-term care (community-based and residential) in the future;

It is beyond the scope of this document to explore and assess the various potential long-term care financing options. A Mercer 2002 Report¹⁰⁴, commissioned by the Department of Social and Family Affairs, reviewed options for long-term care financing in Ireland.¹⁰⁵

The Mercer Report considered possible financing options, including:

- 1) Private sector or combined public/private sector approaches
- 2) Use of the PRSI system to finance/fund long-term care
- 3) Whether the current system of long-term care financing (through taxation) should remain the status quo

While noting that long-term care may include both personal care and medical care, the primary focus of the Mercer Report was on financing personal care, whether on a residential basis or in the community.

Private financing options – savings, and private insurance as well as equity release schemes – were regarded by Mercer as at best having only a marginal role in the area of financing long-term care. The public financing of long-term care from either general taxation or compulsory social insurance programmes was identified in the Mercer Report as having advantages and disadvantages. One of the main advantages is that it spreads the financial risk and is more equitable. There is no welfare stigma (arising from means-testing) associated with consumption because contributions or citizenship confers entitlement on users. The same quality of care is available to all on the basis of need rather than on an ability to pay.

The major problem with public financing is the cost of implementation. Setting up a public financing system would almost certainly involve a big financial outlay and what would be perceived as additional taxation would be likely to be strongly resisted.

104 <http://www.welfare.ie/en/downloads/stetffolcii.pdf>

105 A 2011 Law Reform Commission Report (http://www.lawreform.ie/_fileupload/Reports/r105.htm) also considered the financing of long-term care in Ireland and drew significantly on the Mercer 2002 Report

Public financing option 1: General taxation

Two questions were raised by Mercer in relation to the funding of long-term care and support through general taxation:

- 1) Whether access to supports and services should be means-tested or universally available and
- 2) Whether or not people have an entitlement to (as distinct from eligibility for) or services

The report noted that means-tested public provision has the advantage of targeting public resources to those with the greatest need (both those on low incomes and those on higher incomes whose care needs are so extensive that their own resources become insufficient to meet the continuing costs of care).

A crucially important distinction between entitlement and eligibility was highlighted by Mercer. If an individual has a statutory entitlement to a benefit based on specified criteria, then that benefit must be provided, notwithstanding any budgetary constraints to which the public body charged with providing the benefit may be subject. If, however, an individual is eligible for a service or benefit, then it is possible that that service or benefit may only be provided if resources permit. Mercer concluded that there are arguments in favour of providing long-term care benefits on a universal basis without means-testing.

Public financing option 2: Social insurance

The following advantages of a social insurance public financing model were identified by Mercer:

- 1) Social insurance would eliminate means-testing for those whose contributions qualify them for benefits;
- 2) The public may be more willing to pay additional social insurance contributions than higher taxes to fund long-term care;
- 3) Social insurance financing for long-term care would provide a reasonable “fit” in the Irish context;
- 4) The strong entitlement to benefit that social insurance financing would confer, along with earmarking of the contributions made to pay for the benefit, would be likely to engender good public support;

Section Five

Synthesis of Issues and an Agenda for Action

Overview

The policy scenario and related context outlined points to a complex and challenging long-term support and care environment. Key questions to be addressed relate to resource implications but, also, and, perhaps, more fundamentally, to the need for creative thinking and capacity-building within relevant statutory agencies and NGOs and throughout society generally. This applies in particular to the way we conceptualise and deliver supports and services and whether or not as a society we choose to provide the required resources – financial, infrastructural and personnel in key disciplines – to respond creatively and imaginatively to the challenge. Another key question is how we fill the ever-widening gap between supports provided by families and informal networks and those currently provided by the State.

There is a broad consensus on the direction that our approach to long-term support and care should take, including the importance of allowing more older people to stay at home and in their own communities for as long as possible, the need to cater for people at the lowest appropriate level of complexity and the need to provide high quality residential care when and if this is needed. The Programme for Government commits to increasing funding for Home Care Packages and Home Help year on year, additional funding for the NHSS and seeking ways to incentivise private nursing home investment and new supported living/assisted living arrangements. However, much more is required in order to embed community care legally and financially and to put it on a par with nursing home care.

While there have been significant developments in relation to community care over the past three decades, for the most part, these have been piecemeal and subject to ad hoc budgetary cuts. Despite the many policy recommendations over the years supporting community care, this is still not prioritised in any significant way. It is also the case that Ireland is one of the few countries which gives priority to nursing home care even when it is not appropriate or suitable.

There is clearly an unmet need for services and supports, as shown in various research reports. However, the discussion needs to be broadened to embrace human rights principles, including, in particular, enabling people to exercise their will and preferences. We also need to take seriously quality of life as a key factor and what this means for people with significant care and support needs. This requires a different balancing of priorities and resourcing within the health sector and by Government.

The demographic trends are clear – Ireland along with many European countries, is witnessing a steady ageing of our population. This presents both opportunities and challenges. We know what people individually want and we know where the policy gaps are.

In order to avoid the 'dismal scenario' of a proportion of our older population not receiving the type and quality of care that they deserve and in the way they want it, we need to urgently re-configure the narrative

relating to long-term support and care. This needs to involve a cross-fertilisation between best international practice and related research, the experience of professionals and NGOs in Ireland working in the field and the stated will and preferences of people. This requires a significant shift and related buy-in by society generally as well as by Government.

Enhancing the Social Support Infrastructure

While hospital and residential services to meet the needs of older people are important, they may have assumed disproportionate importance relative to the social support infrastructure which sustains the well-being of older people in their home environment. There is a wide range of well-established interventions at community level that can play a significant role in supporting older people.

At the most basic level, these include combating loneliness and assisting with transport, housing maintenance and supporting people to use technology optimally. A second tier of potentially effective interventions are home adaptation schemes, greater use of supported living accommodation and greater supply of therapies to enhance mobility and functioning. A community-based social enterprise model of support and care delivery supported by the State has significant potential to target interventions at the lowest appropriate level. However, this requires a shift from a charitable to a social enterprise approach. Social investment, based on quality of experience and achievement of outcomes, could replace block grants and traditional 'outsourcing'. It is noted that the Public Service Reform Plan (2014-16)¹⁰⁶ commits to a move away from a system of historical disbursements to a more strategic approach focused on the outcomes of service users being met in return for monies spent.

Building on best international practice

Ireland can learn much from practice in other jurisdictions with particular reference to:

- Models of financing
- Eligibility and access (universal, co-payment, means-testing, healthcare needs)
- The implementation of the concept of Individualised Payments
- The balance between funding for community-based care and for residential care
- The devolved responsibilities of local government (municipalities) in providing long-term care accommodation, support and services
- Links between mainstream housing provision and specialised provision
- Legal frameworks relating to people's rights in respect of long-term care

The Voice of Older Persons

The views and perspectives of older persons themselves are crucial in determining appropriate response to needs as is the social and community infrastructure in which they live and within which services are delivered. Older people cannot, any more than any other group in society, be passive recipients of long-term care. Their needs are multi-faceted as are their abilities to cope with these needs. Therefore, user participation is essential in the provision of appropriate and timely supports

Action required at different levels

In order to progress the long-term support and care agenda, actions are required at a number of different levels – societal, government, inter-departmental, HSE, local government/administration, community and inter-disciplinary working.



At societal level

- Developing a strong social awareness about the impact of the ageing process
- Making the choice to provide the required resources – financial, infrastructural and personnel in key disciplines – to respond creatively and imaginatively to the long-term care and support needs of citizens
- Identifying ways of filling the ever-widening gap between supports provided by families and informal networks and those currently provided by the State

At Government level

- Examine how the financing of long-term can be incorporated into the social insurance system
- Fully implement the Local Government Reform Programme with devolved functional responsibilities
- Provide a legislative framework for community care services
- Promote an open and honest discussion about the respective responsibilities of the State, families and local communities in providing long-term care for those who require it
- Fundamentally reviewing the NHSS model and the role of the NTPF therein

At Inter-departmental Level

- The Departments of Health, Environment and Social Protection working collaboratively to develop and implement integrated housing and support models and to provide joint funding streams accordingly
- Exploring ways of delegating functional responsibility and related funding for integrated housing and care supports to local government and local administrative structures

At HSE Level

- Developing realistic alternatives for the provision of support and care to people who do not wish to spend the last years or months of life in a nursing home
- Working collaboratively with assisted living initiatives in the provision of long-term support and care
- Developing a fully transparent national set of eligibility criteria for Home Care Packages
- Formalising and developing a regulatory framework for home care

At Local Government/Administrative Level

- Implementing and enhancing the Age-friendly Strategies
- The HSE and Local Authorities working collaboratively to deliver integrated assisted living housing
- Using local development structures to pioneer and develop innovative housing with care initiatives by:
 - (a) Building on the strong track record of NGOS in this area
 - (b) Developing innovative social enterprise initiatives

At Local Community Level

- Responding at the most basic level to people's care and support needs in the community
 - Combatting loneliness
 - Assistance with transport
 - Assistance with housing maintenance and repair
 - Enabling people to maximise the use of technology
- Statutory agencies and community groups working together to enhance the social support infrastructure to promote social connectedness for people whether living in the community or in nursing homes

At Case Management and Inter-disciplinary Level

- Adopting a case management approach to long-term care needs assessment and to delivering packages of support services
- Fully implementing the inter-disciplinary team based model of PCU as it applies to older persons
- Including a gerontological perspective in all needs assessment relating to long-term care and support

Implementing the long-term support and care action agenda

The Forum deliberations point to a need for a series of short-term, medium-term and longer-term targets and related implementation processes to progress the long-term support and care agenda.

Short-term

- Engage stakeholders at local and national levels in a focused conversation on the matter – people from the relevant statutory agencies, politicians NGOs, the private nursing home sector and other private providers and, of course, older persons;
- Work towards achieving a national social and political consensus about the optimal nature and level of long-term care and identify an action agenda accordingly;

Medium-term

- Carry out a comprehensive piece of research funded by Government to inform policy thinking and planning to include:
 - The dimensions of support and care
 - The options that are desirable and possible
 - The likely cost of each of these options
 - How these might be funded in the short, medium and long-term
 - An implementation framework and timescale.
- Identify appropriate development templates for Ireland based on relevant international best practice;
- Identify a sustainable model for financing long-term care;
- Review the NHSS and Home Care Packages with particular reference to quality of long-term care provision and related outcomes;
- Identify how the legislative changes required can best be implemented

Longer-term

- Support and care available according to the highest international standards and human rights provisions
- Equality of access and legal entitlement to community-based care and nursing home care
- A sustainable long-term care financing mechanism in place
- People's long-term support and care needs delivered to nationally agreed optimal levels in accordance with both their will and preferences and their legal and human rights

A Transformative Approach

We now need a transformative approach which challenges and changes current thinking and discourse and which:

- 1) Focuses on the rights of all citizens to receive support and care with dignity and in accordance with their will and preferences in the context of citizenship and inter-generational solidarity
- 2) Shifts the balance from long-term care in nursing homes to long-term care in a range of community-based settings (including people's own homes)
- 3) Ensures that medical, nursing and social/personal care are of the highest possible quality (taking full cognisance of current medical knowledge and expertise)
- 4) Moves beyond the simplistic public vs private sector debate to a focus on innovative quality services
- 5) Includes a strong public interest representation in decision-making – in this case the 'voice' of older persons requiring care

Glossary

This Glossary provides a brief description of the meaning of some of the key terms as used in this document.

Abuse

The physical, psychological, emotional, financial or sexual maltreatment, or neglect of a vulnerable adult by another person. The abuse may be a single act or repeated over a period of time. It may take one form or multiple forms, including inappropriate restraint or use of medication. Abuse can occur both in a relationship where there is an expectation of trust and outside such a relationship.

Acute Hospital

This refers to regular hospitals which provide active short-term treatment and care for an acute illness, injury or medical condition.

Advance Care Planning

Advance Care Planning refers to a process which enables people to have their preferences for their care documented in the event of them losing the ability to express their own wishes in the future. Advanced care planning usually takes place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others. Such planning can be facilitated by use of the Think Ahead Framework Document (see Think Ahead).

Advance Healthcare Directive

An Advance Healthcare Directive means an advance written expression of will and preferences made by a person with capacity concerning treatment decisions that may arise in the event that the person subsequently loses capacity. Provision for such directives is made in the Assisted Decision-making (Capacity) Act 2015.

Advanced Home Care

Advanced home care involves the highest level of care and may include nursing, personal care, respite care, dementia care, assistance with continence and toileting and palliative care.

Advocacy

A process of empowerment of individuals or groups which includes taking action to help people say what they want, secure their rights, represent their interests or obtain the services they need. Advocacy can be undertaken by individuals themselves, by their friends and relations, by peers and those who have had similar experiences, and/or by trained volunteers and professionals (see Independent Advocacy).

A Rights-based Approach

A rights-based approach focuses on the right of each individual in society to be equally included in all aspects of society, to have access on an equal basis with others to services and supports and to self-determine. The rights of people with disabilities are stated in the UN Convention on the Rights of Persons with Disabilities and the rights of older persons are stated in the Council of Europe Statement on the Rights of Older People (see also Human Rights and Rights Safeguarding).

Assessment of Need

The systematic identification of the needs of an individual or population to determine the appropriate level of care or services required. It is a process by which people's health and social care support needs are identified so that they can be addressed through appropriate services and interventions. Engaging the individual in identifying his/her needs and in determining appropriate responses is an important feature of needs assessment.

Assisted Living Housing

A facility which provides accommodation and care for people who cannot live independently but do not need nursing care. Residents are typically provided with various supports, including meals, personal care and laundry. This type of accommodation is sometimes referred to as housing with care (see also Sheltered/Supported Housing).

Assisted Decision-Making (Capacity) Act, 2015

The Assisted Decision-making (Capacity) Act 2015 sets out guiding principles that are intended to safeguard the autonomy and dignity of people with impaired capacity. The Act stipulates that there is a presumption of decision-making capacity unless the contrary is shown, that no intervention will take place unless it is necessary, that any act done or decision made [under the Act] must be done or made in a way which is least restrictive of a person's rights and freedoms and must give effect to the person's will and preferences (see also Advanced Healthcare Directive).

Autonomy

The perceived ability to control, cope with and make personal decisions about how one lives on a day-to-day basis, according to one's own preferences. Some people making autonomous decisions may need support in executing these decisions.

Capacity (Decision-making)

The ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is being made. Each individual should be presumed to have capacity to give or withhold consent unless the contrary is established. A person lacks the capacity to make a decision if s/he is unable to understand the information relevant to the decision, unable to retain that information, unable to use or weigh that information as part of the process of making the decision or is unable to communicate the decision by any means even with the assistance of a third party (see also Consent and Legal Capacity).

Care and Support Plan

A care and support plan is a formally agreed statement which is based on information gathered with and from an individual and those responsible for his/her care. It identifies a person's individual care and support needs and states how these needs will be met. An individual care and support plan should cover all aspects of health and personal care, and show how needs identified are to be met.

Case Management

A continuous process of planning, arranging and coordinating multiple social and health care

services across time, place and discipline for persons with high-risk conditions or complex needs in order to ensure appropriate and optimum quality care and support.

Circle of Support

The concept Circle of Support broadly refers to a group of people who work together on a regular basis to help a person accomplish his/her personal goals in life. The Circle acts as a community around an individual (the 'focus person') who, for one reason or another, is unable to achieve what s/he wants in life on his/her own.

Community Care

Personal and social care services delivered in the community. Community care services include home helps, home care packages, respite care, day care and supports for independent living (see also Primary Care and Community Care Services).

Community-based Services/Programmes

The blend of health and social services provided to an individual or family in his/her place of residence for the purpose of promoting, maintaining or restoring health or minimizing the effects of illness and disability. These services are usually designed to help older people remain independent and in their own homes. They can include day centres, transport, delivered meals and home helps.

Community Care Services

The term community care services is used typically to refer to domiciliary nursing, home help, day care services, meals services, occupational therapy, physiotherapy, chiropody, speech therapy and social work services.

Companionship

Typically includes helping people with preparing snacks, monitoring diet and eating, arranging appointments, reminders for medication, overseeing home deliveries and organising visits to neighbours and friends.

Consent

Consent is agreement by a person who has capacity, voluntarily given, without any element of duress and based on the person having the requisite information, in a form and language that

s/he understands (see Informed Consent). Consent would also include directions given in an Enduring Power of Attorney or an Advance Healthcare Directive that has come into effect.

Continuum of Support and Care

This refers to the entire spectrum of supported housing, health, hospital, rehabilitative and residential services available to people who are frail, have a significant disability or are chronically ill. It includes assistance with personal daily living activities as well as interventions that are essentially medical or nursing in nature.

Core Services

These are support services which are essential for people to maintain a quality of life and a level of functional autonomy which enables them to live independently in the community and, consequently, to avoid unnecessary hospitalisation or admission to nursing homes. A distinction is usually made between these core services and other important community support services provided by voluntary/community organisations or self-help groups, e.g., social clubs, active retirement associations.

Data Protection

Data Protection legislation requires that any information recorded and held about people must be kept secure and available only to those who have a right to access such information, for example, those with a duty of care to an individual or those who have a safeguarding role in relation to alleged abuse or, the Gardaí, where criminality is alleged or suspected.

Day Care Centre

A facility providing activities for older people, usually during the day for a determined period, and intended to promote independence and enhance living skills. Personal care, social activities and meals are frequently provided.

Dementia

Dementia describes a set of symptoms that include loss of memory, mood changes, and problems with communication and reasoning. Dementia is the loss (usually gradual) of mental abilities such as thinking, remembering, and reasoning. It is not a disease, but a group of symptoms that

may accompany some diseases or conditions affecting the brain. The fact that a person has been diagnosed with dementia does not mean that that person lacks decision-making capacity.

Disability

Disability, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment (Disability Act 2005).

Empowerment

Empowerment is the process, based on a trusting relationship, of providing information and support to enable people to assert their rights, make choices and decisions and contribute to wider policy making in the areas that affect their lives. Provision of basic information on an individual's rights and entitlements can in itself be hugely empowering.

End-of-Life Care

This refers to the care that a person with a terminal illness gets at the final stage of life, i.e., during the period when death is imminent, and life expectancy is limited. The term has been used to describe the last 12 months of life. Quality Standards for End-of-Life Care in Hospitals can be accessed at www.hospicefoundation.ie

Enduring Power of Attorney (EPA)

An Enduring Power of Attorney is a legal device that enables a person to choose a person (called an "attorney") to manage his/her property and affairs in the event of him/her lacking capacity to do so. The Assisted Decision-Making (Capacity) Act 2015 extends the authority of an EPA to include healthcare decisions. A person may choose one attorney or more than one. An Enduring Power only comes into effect when the person lacks decision-making capacity and the EPA is registered in the High Court.

Equality

Equality is the prevention, elimination or regulation of discrimination between people on the grounds of, for example, gender, marital status, race, disability, age, sexual orientation, language, social

origin or other personal attributes, including, but not limited to, religious beliefs or political opinions.

Ethics

The basic evaluative principles which (should) guide “good” care. These typically refer to respect for the dignity and personhood of each human being. Basic dimensions are “autonomy” (respect for self-determination), “well-being” (respect for happiness, health and mental integrity) and “social justice” (justifiable distribution of scarce goods and services). More specifically, ethics of care refer to ethical standards developed for the care professions which are designed to implement ethical principles in the provision of health and social care.

Family Carers

The term refers to people who look after a relative who requires full-time support and care to live at home. Carers may be paid a means-tested Carer’s Allowance on a long-term basis or Carers Benefit on a short-term basis, the latter if they have the required number of PRSI contributions.

Gerontologically-attuned Care

This is an approach to support and care based on a multidimensional assessment of a person with increasing dependency, including medical, physical, cognitive, social and spiritual components. It is an integrated and interdisciplinary response to an individual’s assessed needs – medical, nursing and psychosocial.

Healthy Ageing

An approach which recognizes that growing older is a part of living and emphasises the interdependence of generations. It fosters a positive attitude throughout life to growing older and eliminates age as a reason to exclude any person from participating fully in community life. Activities which enhance well-being and health, choice and independence, and quality of life for all ages are promoted. Communities are encouraged to value and listen to older people and to cater for the diverse preferences, motivations, characteristics and circumstances of older persons in a variety of ways.

Health Information and Quality Authority (HIQA)

An independent Authority established in May 2007 to drive continuous improvement in Ireland’s health and social care services. HIQA is the regulatory, standard-setting and inspection body for residential care settings and hospitals.

Home Care Packages (HCPs)

These are packages of care tailored to the needs of individuals whose needs cannot be met by mainstream provisions. The overall objective of HCPs is to maintain older people at home and in their communities, particularly those at risk of inappropriate admission to long-term care or acute hospitals. HCPs provide a broader range of supports than home helps and can include public health nursing, day care, occupational therapy, physiotherapy, home care and respite care, which are shaped around each person’s individual needs.

Home Help

A person or a service providing practical help in the home, such as household chores, to support an older person with impaired functioning to remain living in his/her own home.

Human Rights

Human rights are rights held by individuals because they are part of the human race. They are rights shared equally by everyone regardless of gender or nationality. They are universal in content (see also A Rights-based Approach and Rights Safeguarding).

Independent Advocacy

Advocacy provided by an organisation that is structurally, financially and psychologically separate from providers of services.

Independent Living

Living at home without the need for continuous help and with a degree of self- determination and control over one’s activities and over any assistance required.

Informed Consent

Voluntary authorisation by a person who has full comprehension of the risks and benefits involved in any of the following: the application of any medical treatment or intervention; the provision of personal

care and supports; participation in research projects; provision of personal information to a third party. Informed consent is required for the making of an Enduring Power of Attorney and an Advance Healthcare Directive.

Integrated Support and Care

The methods and strategies for linking and coordinating the various aspects of care delivered by different care systems, such as the work of general practitioners, primary and specialty care, preventive and curative services, and acute and long-term care, as well as physical and mental health services and social care, to meet the multiple needs/problems of an individual or category of persons with similar needs/problems.

Inter-agency Collaboration

This refers to two or more agencies working together to achieve mutually agreed goals for an individual or group. It may involve joint planning and a pooling of resources for specific projects

Legal Capacity

Legal Capacity means the capacity to have rights and the power to exercise those rights. Article 12 of the UN Convention on the Rights of Persons with Disabilities guarantees that persons with disabilities have a right to legal capacity, which means that the law should recognise their capacity to be the bearers of rights, and their capacity to act. (In other words, persons who have a disability have the same legal rights as persons who have no disability). (See also Capacity; Supported Decision-making).

Long-stay residential care

Public, private and voluntary services providing care to people usually on a permanent basis outside of their own home in an institutional setting. Long-stay residential care for older persons in Ireland tends to be synonymous with nursing home care.

Long-term Support and Care

Long-term support and care is understood here as the processes that society puts in place to enhance the quality of life and well-being of people who, because of failing health or reduced physical or cognitive functioning require help from others. These processes include (but are not

limited to) medical and social services designed to support the needs of people living with chronic health problems that affect their ability to perform everyday activities

Mainstream Housing

Housing not specifically designed for a particular user group.

Model of service

The way a service is delivered – the term can be applied to a single service unit, to an organisation or to a national service.

Multidisciplinary

An approach to the planning of treatment and the delivery of care for a service user by a team of healthcare professionals who work together to provide integrated care.

National Treatment purchase Fund (NTPF)

The NTPF is a statutory body designated by the Minister for Health to negotiate with proprietors of registered private and voluntary nursing homes to negotiate and reach agreement in relation to the maximum price(s) that will be charged for the provision of long-term residential care services to Nursing Homes Support Scheme residents.

Nursing Home

This is long-term residential care facility which is provided by a private business, by a voluntary organisation or as a public service by the HSE (see Residential Care Services).

Nursing Homes Support Scheme (NHSS)/'Fair Deal'

The Nursing Home Support Scheme (NHSS) (also known as the 'Fair Deal' scheme) provides financial support towards the cost of the standard components of nursing home care – nursing and personal care, bed and board and basic aids and appliances necessary to assist the person with the activities of daily living. Under the NHSS, the person makes a contribution towards the cost of his/her care in the nursing home (the level of which is determined in accordance with the criteria laid down in law) and the State pays the balance of the cost.

Older Persons

The term 'older person' is used to refer to a person

who has reached a certain chronological age. This age varies among countries but is often associated with the age of normal retirement. Dependency in old age can sometimes be influenced by the social roles a person occupies as well as by a person's level of physical or cognitive ability (see also Vulnerable Adult).

Outcomes

Outcomes broadly refer to changes in health status and well-being which result from the provision of social and health services and interventions. The methods for measuring outcomes are quite varied among providers and there is much debate regarding the appropriate or best measurement tools to be used.

Occupational Therapy (OT)

Therapy designed to help individuals improve their independence in daily living activities through rehabilitation, exercises and the use of assistive devices. In addition, OT provides activities to enhance self-fulfilment and self-esteem.

Person-centred

Person-centred is an approach to the provision of care and support based on individual right to self-determination, mutual respect and understanding. When services and supports are person-centred, the service provider ensures that the person is involved, participates and is truly listened to. The choices that the individual makes are respected and services and supports are tailored around those choices. A person-centred approach also involves helping the individual to manage challenges and risk (see also Care and Support Plan).

Personal Social Service

Assistance with the activities of daily life (e.g., personal care) delivered by a care attendant, home help or social worker and aimed at supporting people who experience difficulties in functioning.

Physiotherapy

The treatment of pain, disease or injury by physical means. Physiotherapists are concerned with promotion of health, prevention of physical disabilities, assessment and rehabilitation of persons affected by pain, disease or injury.

Policy

This is the written operational statement of intended outcomes to guide staff actions on particular aspects of the service and in particular circumstances.

Quality of Life

This refers to the outcome of the interplay between social, health, economic and environmental conditions which affect human and social development. It is a broad-ranging concept, incorporating a person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to their living environment. As people age, their quality of life is largely determined by their social connections, their ability to access needed resources and to maintain autonomy and independence.

Residential Care Services

Accommodation for people who can no longer live at home which provides care and support, including help with performing daily tasks (moving around, dressing, personal hygiene, eating) and medical care (various levels of nursing care and therapy services).

Respite Care

Services provided in the home, at a day care centre or by temporary placement in a nursing home or other residential care service to people with a disability or frail individuals in order to provide occasional or systematic relief to family carers.

Rights Safeguarding

This is ensuring that people's rights are protected in all cases but especially in cases where a person because of reduced capacity is unable to assert his/her rights and/or to give informed consent (see also Consent and Informed Consent).

Risk Assessment

Risk assessment refers to the process of identifying the chance of something happening or not happening that may have an impact on an individual or group and to identifying ways of eliminating or managing such risks. Risk assessment may be specific to a particular instance/situation, for example, the impact of going into residential care, family conflict, the potential impact of not providing support and services where it is unclear whether or not a person can give consent.

Self-determination

Self-determination refers to being able to make a personal decision to do something or think a certain way without external compulsion. It is similar to the concept of autonomous decision-making.

Service Provider

Person(s) or organisations that provide services – this includes staff and management that are employed, self-employed, visiting, temporary, volunteers, contracted or anyone who is responsible or accountable to the organisation when providing a service.

Sheltered/Supported Housing

Purpose-built or adapted accommodation providing varying levels of support for people who require assistance to live independently or semi-independently. Different kinds of sheltered housing provide different levels of support and care which typically involves a warden and an emergency alarm system, the provision of some services, such as a daily meal with other tenants and some communal areas, such as a dining room and lounge. Sometimes, where there is a high level of support provided, facilities are referred to as 'very sheltered housing' (see also Assisted Living Housing).

Single Assessment Tool (SAT)

The process whereby a person is assessed for care needs using one form/mechanism so that agencies do not duplicate each other's assessment. Such a mechanism is currently being rolled out in Ireland by the HSE.

Social Support

Emotional, instrumental and financial assistance obtained from an individual's social network. Social support provided by family, friends and neighbours is referred to as 'informal support', whereas social support provided by formal service agencies is called 'formal support'.

Social Enterprise

Social enterprise is a business model that puts people and community first, ahead of private or personal gain, while operating in a commercially viable and sustainable way. Social Enterprises are organisations or businesses set up to tackle social, economic or environmental issues. Driven

primarily by social and/or environmental motives, they engage in trading or commercial activities to pursue these objectives and produce social and community gain. Ownership of the enterprise is within a community, or amongst people with a shared interest.

Social Work

An intervention designed to enhance an individual's physical, mental and social functioning through improved coping skills and use of social supports and community health care services. There are many different types, specialties and grades of social work. Those who specialize in care of older adults are often referred to as geriatric or gerontological social workers.

Speech Therapy

This refers to the treatment by a trained professional of speech and communication difficulties affecting an individual.

Standard

A quality, measure or reference point established as a rule or model by authorities, by custom or by general consent, against which practice can be evaluated and should conform. In Ireland, the Health Information and Quality Authority (HIQA) has responsibility for developing and implementing Standards related to health and social care.

Supported Decision-making

Supported decision-making is a process in which adults who need assistance with decision-making, e.g., people with an intellectual disability or cognitive impairment, receive the help they need and want to understand the situations and choices they face, so they can make decisions for themselves. The concept of supported decision-making is based on Article 12 of the UN Convention on the Rights of Persons with Disabilities:

- Everyone has the right to make their own decisions – known as autonomous decision-making; and
- Everyone has the right to receive adequate support to do so – known as supported decision-making (see also Assisted Decision-making (Capacity) Act 2015; Capacity; Legal Capacity).

'Think Ahead'

This is an initiative which encourages people to plan and record their wishes in the event of an emergency, serious illness or death. Developed by the Forum on End of Life in Ireland, a project of the Irish Hospice Foundation, (IHF), Think Ahead urges people to Think, Talk, Tell, and record and review their personal preferences for future medical, financial and personal care.

Vulnerable Adult

The term refers to a person who, because of physical or mental disability, is unable to take care of him/herself without assistance or unable to protect him/herself against abuse or exploitation. It includes adults with physical, sensory and mental impairments which have been there since birth or which have arisen due to advancing age.

Appendix One

The Eden Alternative in Care Communities

(Source: <http://www.edenalt.org/>)

TRANSFORMING RESIDENTIAL CARE ENVIRONMENTS

By moving away from top-down, departmental approaches to management and moving decision-making closer to the Elders themselves, The Eden Alternative helps nursing homes, short-term rehabilitation, and assisted living communities create a vibrant, empowered existence for the Elders they serve and the people who work closely with them, as care partners.

Implementation of The Eden Alternative impacts the organizational structure, physical environment, and relational interactions of residential care. When identifying goals for personal and organizational growth, organizations must consider how to best live out each of the Eden Alternative Ten Principles for the benefit of the Elders and their care partners, as well as the community as a whole.

Eden at Home

TRANSFORMING HOME & COMMUNITY-BASED CARE...

Eden at Home applies the Eden Alternative Philosophy to improving quality of life for Elder(s) living at home and their care partners. Working together, empowered care partner teams, composed of families, care professionals, and the Elder herself, ensure the independence, dignity, and continued growth and development of the whole team by eliminating loneliness, helplessness, and boredom for all.

Aging-in-community requires creative grassroots solutions. Thus, Eden at Home engages adult day services, hospice, independent living communities, senior centers and non-profit, faith-based, and home care/home health organizations. Designed to bring different stakeholders together within a single learning environment, Eden at Home creates a shared language for all members of the care partner team.

Eden LifeLong Living

CREATING QUALITY OF LIFE FOR THOSE LIVING WITH DEVELOPMENTAL, COGNITIVE, PSYCHOLOGICAL, AND PHYSICAL CHALLENGES

The Eden Alternative also enhances the lives of those living with developmental, cognitive, psychological, and physical challenges. While society tends to describe the needs of these individuals in terms of “disability,” the Eden Alternative Philosophy builds on strengths.

By focusing on the unique ways our “different abilities” hold the promise of possibility, we are better prepared to highlight what we each have to offer our communities.

Meaning, empowerment, and growth are essential parts of living, no matter who we are. The Ten Principles of The Eden Alternative foster transformation in residential care communities designed to meet the needs of those living with different abilities. When environments support a life worth living rich with purpose, everyone wins!

Through education, consultation, and outreach The Eden Alternative® promotes quality of life for Elders and their care partners, wherever they may live.

When it comes to creating a life worth living, we all have different needs and different roles. The following resources will help you learn more about us, answer challenging questions, find support that reflects our unique approach to care, and help others understand why a culture of care that puts the person first is essential. While the first column offers information for consumers and providers alike, the second column offers a more focused list of options most likely of interest to providers

“Well-being is a much larger idea than either quality of life or customer satisfaction. It is based on a holistic understanding of human needs and capacities. Well-being is elusive, highly subjective, and the most valuable of all human possessions.”

Dr. Bill Thomas, What Are Old People For

Well-being is the path to a life worth living. It is the ultimate outcome of a human life. Through a grant-funded collaborative effort, The Eden Alternative brought together a task force of culture change experts in 2004 and identified seven primary Domains of Well-Being. Together, they serve as a simple framework for asking thoughtful questions that help identify the unmet needs of those we care for:



- **IDENTITY** – being well-known; having personhood; individuality; having a history
- **GROWTH** – development; enrichment; expanding; evolving
- **AUTONOMY** – liberty; self-determination; choice; freedom
- **SECURITY** – freedom from doubt, anxiety, or fear; safety; privacy; dignity; respect
- **CONNECTEDNESS** – belonging; engaged; involved; connected to time, place, and nature
- **MEANING** – significance; heart; hope; value; purpose; sacredness
- **JOY** – happiness; pleasure; delight; contentment; enjoyment

Appendix Two

The image shows the front cover of a report. On the left is a dark red vertical band with the 'amárach research' logo at the top, the date 'May 2016' in the middle, the acronym 'SR' below it, and the report number 'S16-132' at the bottom. The main white area on the right contains the title 'Forum on Long-Term Care for Older People' and the date 'June 15th 2016'. Below the title are logos for 'sage' (Support & Advocacy Service for Older People), 'third age' (Responding to the opportunities and challenges of ageing in Ireland), 'Family Carers Ireland' (Framework for Carers), and 'ALONE' (Helping older people in need).


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Methodology

- ▶ Interviewing was conducted via Amáarach's online omnibus, which interviews a nationally representative sample of 1,000 adults aged 16 + years each month.
- ▶ Combination of quota controls and weighting is used to ensure the final sample is aligned to the population in terms of gender, age, social class and region.
- ▶ Fieldwork for this research took place between the 9th – 13th of May 2016.

B. Sample Profile




(Base: All Irish adults 16+)

Sex	Age	Social Class	Region
Male: 49%	16-24: 17%	ABC1 F50+: 46%	Dublin: 28%
Female: 51%	25-34: 22%	C2DE F50-: 54%	ROL: 27%
	35-44: 19%		Munster: 28%
	45-55: 16%		Conn/Ulster: 18%
	55+: 27%		

Quotas were set to ensure that the sample attained is aligned to the Irish population, any sampling error is corrected with minor data weighting.

Long Term Care - Funding

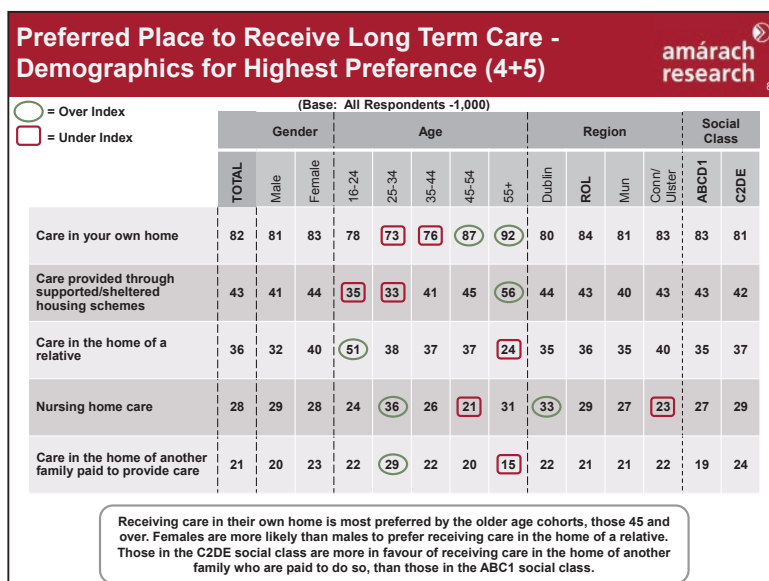
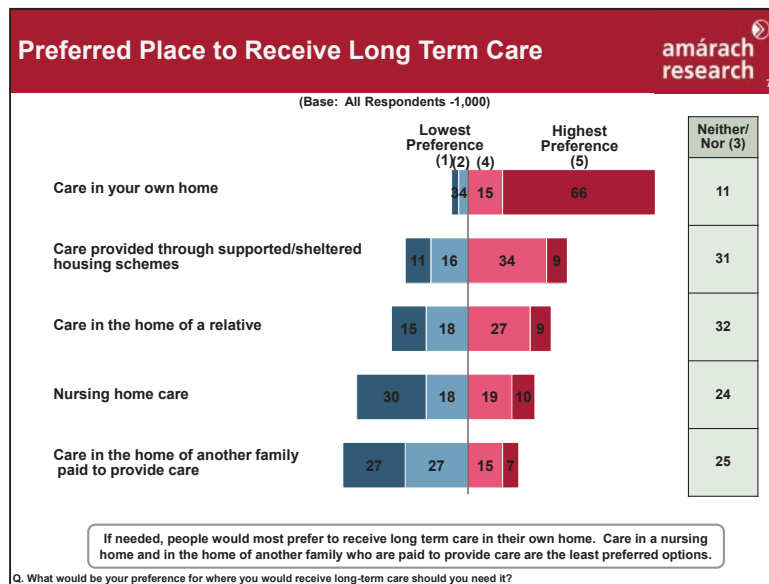
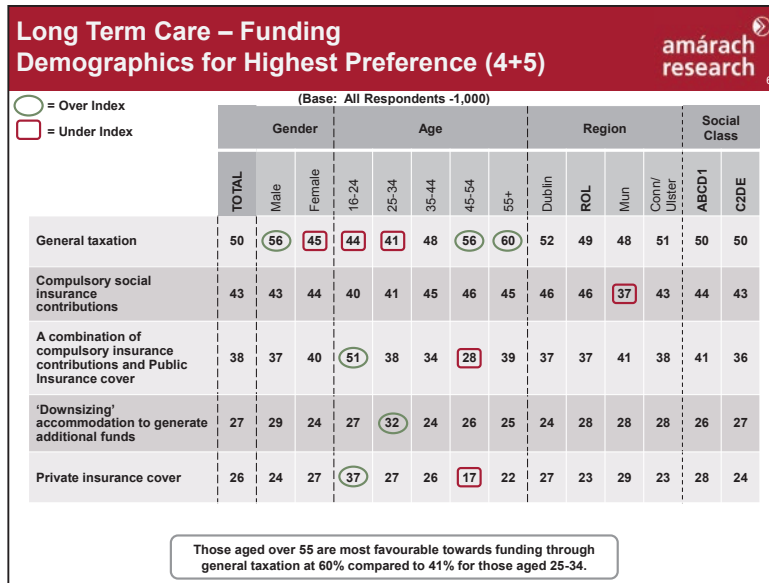


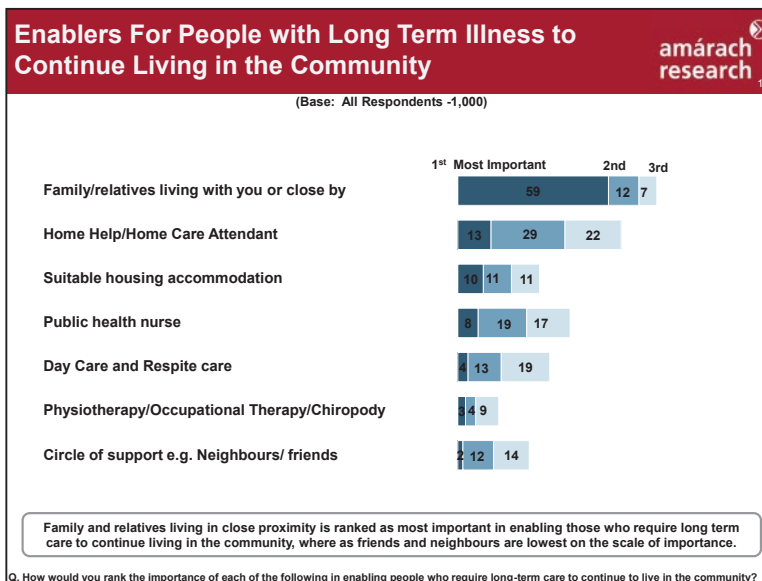
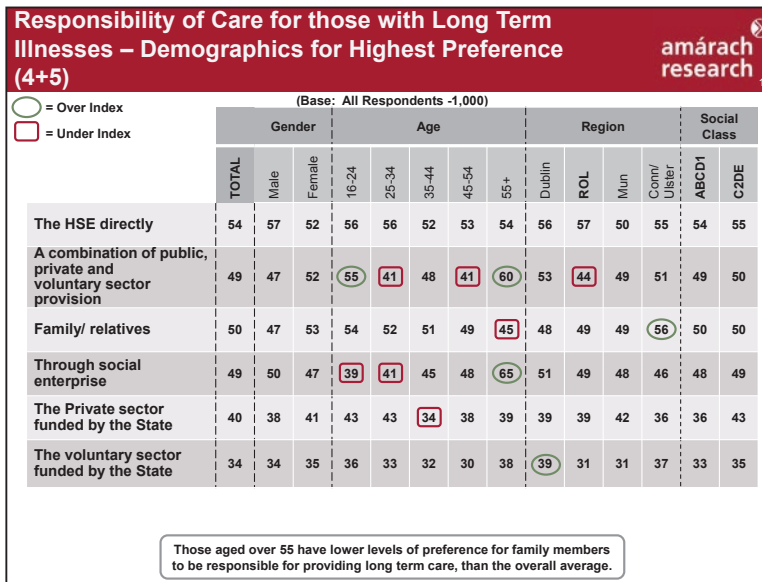
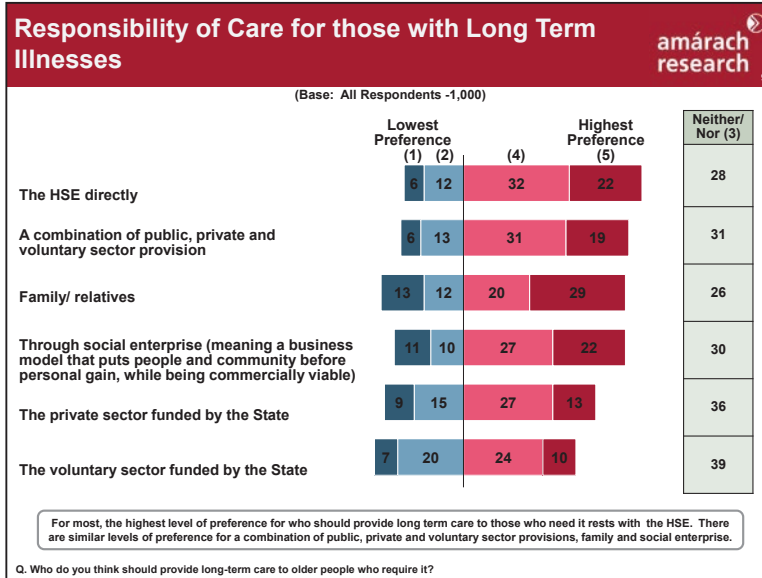
(Base: All Respondents -1,000)


	Lowest Preference (1)	(2)	(4)	Highest Preference (5)	Neither/Nor (3)
General taxation	10	13	22	28	27
Compulsory social insurance contributions	7	17	29	14	33
A combination of compulsory insurance contributions and Public Insurance cover	11	17	23	15	34
'Downsizing' accommodation to generate additional funds	31	18	16	10	25
Private insurance cover	19	21	18	8	34

Funding long-term care for older people through general taxation was rated most favourably by respondents. 'Downsizing' accommodation to generate additional funds rated as the highest least preferred option.

Q. How do you think that long-term care for older people who need it should be funded?






Enablers For People with Long Term Illness to Continue Living in the Community– Demographics- 1st Preference 

(Base: All Respondents -1,000)

○ = Over Index
□ = Under Index

	Gender		Age					Region				Social Class		
	TOTAL	Male	Female	16-24	25-34	35-44	45-54	55+	Dublin	ROL	Mun	Conn/ Ulster	ABC1	C2DE
Family/relatives living with you or close by	59	55	62	57	57	65	64	53	56	59	59	61	56	61
Home Help/Home Care attendant	13	15	11	8	13	11	15	18	14	11	13	15	16	11
Suitable housing accommodation	10	10	10	7	6	11	9	17	12	12	8	8	10	11
Public health nurse	8	10	6	14	13	4	8	4	8	8	7	10	8	8
Day Care and Respite Care	4	5	4	5	4	5	2	6	3	4	8	2	5	4
Physiotherapy/ Occupational Therapy/ Chiropody	3	3	3	4	5	3	1	1	4	2	3	2	4	2
Circle of support e.g. Neighbours/friends	2	2	3	6	2	2	1	2	3	3	2	2	2	3

Those aged over 55 are less likely to select family and relatives as most important in helping those with long term illnesses remain in the community and have a slightly higher, than the overall preference, for a home help/ home care attendant.

- Key Findings** 
- In terms of funding long term care, the greatest overall preference is through general taxation.
 - 'Downsizing' accommodation to generate additional funds is a much less popular option to provide funding. This may have more of a tangible effect on peoples everyday life and a less accessible option overall.
 - 'Funding through general taxation' is preferred more as respondents increase with age from those aged 25-34, this group are possibly entering into a steady career are therefore least in favour of this option.
 - Being cared for in their own home is the most preferred option for respondents if they should ever need long term care.
 - Being cared for by 'another family paid to do so' is least preferred by respondents. Although there is a greater level of preference for this option by those in the C2DE social class compared to those in the ABC1 social class.
 - The second least preferred option is being cared for in nursing home care, despite the fact that there is an entitlement to health service in this case (through the NHSS).
 - Overall, there is greater preference for the HSE to be responsible for providing long term care to older people who require it.
 - 'The Voluntary sector funded by the state' was selected as the lowest preference by the greatest amount of respondents across all options, for who should provide long term care.
 - 'Family and relatives' living close are ranked as most important for enabling those with long term illnesses to remain in the community, this does not appear to extend to neighbours and friends.



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