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Responding to the Challenges and Opportunities of an Ageing Population: How long-term care and support is currently provided in Ireland

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Introduction

This paper provides an overview and some commentary on how long-term care and support is currently provided in Ireland – both the service and support options available to older people to stay in their own homes and the provisions for nursing home care and the provisions for hospice care. It also explores some alternative care and support options which to date in Ireland have remain relatively underdeveloped.

At the outset, I want to say a little bit about the context in which discussions on long-term care and support need to take place. The first, and probably the most significant, point is that older persons are a segment of the population with significant insight and wisdom who have the potential to make an enormous contribution to society. Not only are they significant consumers of services and products and have considerable buying power but, also, they perform key integrative functions by, for example, providing care for dependent others (e.g., spouses and partners), voluntary work in the community and child-minding. I suggest that recognising and developing the potential of this valuable human and societal resource is at the core of how we respond to the challenges and opportunities of an ageing population.

Secondly, some people in their later years are ill and/or have a disability (most disability is acquired over the life-cycle) and are thus dependent on the health, social care and welfare system. The latter group are often seen as a significant drain on scarce resources and, as a result, may be afforded a negative social status with a related lessening of respect.

The next relevant factor is that older people clearly have equal rights with the rest of the population to protection in accordance with citizenship and with international human rights conventions – in particular, the right to liberty and security (Article 5 of the European Convention on Human Rights) and the provisions of the UN Convention on the Rights of Persons with Disabilities, including right to autonomy and self-determination, the right to freedom of movement and the right to receive appropriate support in taking decisions and exercising legal capacity .

The Assisted Decision-making (Capacity) Act 2015 (not yet fully implemented) is particularly relevant to older people with reduced decision-making capacity as a

result of dementia or other cognitive impairment in that, *inter alia,* it includes provisions for supports to enable people to assert their will and preferences.

The fourth factor is the obvious question that needs to be addressed in an open and forthright manner:

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?

There is broad consensus on the direction that our approach to supporting older people who need support and care should take. This includes enabling people to stay at home and in their own communities for as long as possible and the need to provide high quality residential care when and if this is needed. It has been widely acknowledged in policy statements and Government strategies for almost 50 years (going back to the 1968 *Care of the Aged Report*) that community-based care should be prioritised over residential (nursing home care). Findings from the significant body of research in Ireland[1] relating to long-term support and care also reflect this view.

Since we already have a lot of research evidence and related policy statements and strategies[2], we do not need to 're-invent the wheel' but rather to remind ourselves what we aspire to and to compare this with current realities. We know what needs to be done but actually doing it requires new thinking, innovative approaches and the availability of a wider mix of accommodation choices than what is currently available in order to enable progression as support and care needs change over the life-cycle.

Long-term Care and Support

I now want to refer in a general way to three support and care options currently available to older persons requiring care and to refer to some of their shortcomings.[3]

1) The Nursing Home Support Scheme
2) Home Care Packages
3) End-of-life care provisions

I then want to look at the potential role of assisted Living/supported housing as an alternative approach to nursing home care which remains relatively underdeveloped in Ireland.

[1] Such research has been carried out by the NCAOP during the 1990s and early 2000s, by the Law Reform Commission, by NESC, NESF, third-level colleges and medical/nursing organisations and by government departments.

[2] See the Appendix for a selected list of documents relating directly or indirectly to long-term care and support.

[3] Many of the issues around long-term care and support were referenced in the 2016 Forum on Long-term Care – see *Responding to the Support & Care Needs of our Older Population: Shaping an Agenda for Future Action,* http://www.thirdageireland.ie/assets/site/files/pr/Report_of_Forum_on_Long-Term_Care_for_Older_People_FINAL.pdf

Nursing Home Support Scheme

The Nursing Home Support Scheme (NHSS) was established under the Nursing Homes Support Scheme Act 2009 to provide equitable access to nursing homes for older people of all financial means.[4] Under the legislation, 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. In effect, under the NHSS, long-term residential care is financed via a combination of direct State support and a contribution from residents based on their means. Under the scheme, a person makes a contribution towards the cost of his/her care in the nursing home (the level of which is determined in accordance with means-test criteria laid down in legislation) and the State pays the balance of the cost.[5] The average contribution for nursing home residents is approximately 25% of the cost of care.

The NHSS 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

Crucially, the fee negotiation process with nursing homes in respect of the NHSS, carried out by the National Treatment Purchase Fund (NTPF) on behalf of the State, makes no provision for some core aspects of care and support (see below).

Two types of financial support are available under the NHSS to people who are assessed as needing nursing home care:

(a) State Support
(b) A Nursing Home Loan (referred to as Ancillary State Support)

A person's eligibility for the NHSS is based on an assessment of his/her care needs carried out by a HSE multidisciplinary team which focuses on abilities to carry out activities of daily living. A Standardised Assessment Tool is used to carry out the assessment.[6]

People are assessed financially on the basis of both income and assets[7] and their personal contribution to their nursing home care is comprised of 80% of their

[4] Approximately 22,000 are currently in receipt of assistance under the scheme.
[5] See http://www.citizensinformation.ie/en/health/health_services_for_older_people/nursing_homes_support_scheme_1.html
[6] https://www.hse.ie/eng/services/list/4/olderpeople/nhss/CSARGuidanceDocument.pdf
[7] Where a person is deemed to lack decision-making capacity, s/he is appointed a Care Representative by the Circuit Court.

assessable income and 7.5% of the value of their assets per annum. A person's 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.

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.

There are a number of safeguards built into the NHSS to protect both the person entering long-term nursing home care 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 a nursing home
- 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.

The advantages of the NHSS are:

- It provides access to nursing homes for older people of all financial means;
- It has a legislative basis which guarantees entitlement to state support for people in nursing homes on a means-tested basis – funding must be provided for the scheme;
- Access to the NHSS is based on an assessment of need for nursing home care;
- The amount an individual has to contribute under the scheme is based on their individual means.

There are, however, a number of significant shortcomings to the NHSS:

- The fee negotiated by the State with nursing homes provides only for 'bed and board';
- There is a 'one-size fits all' approach with little focus on the support and care needs of individuals or on facilitating people's will and preferences;
- There is no provision under the scheme for therapies or specialised equipment (e.g., chairs) and anecdotal evidence suggests strongly that people living in the community are prioritised by the HSE in the provision of therapies and specialised equipment;
- People have to sign legally binding contracts and frequently may not understand what is involved;
- The HSE which funds the scheme is not party to the fee negotiation process between nursing homes and the NTPF;
- There are no formal linkages between the Health and Information Quality Authority (HIQA) which is responsible for quality standards and monitoring in nursing homes and the price negotiation system;
- The complexity and challenging nature of the care required by people with complex care and support needs, particularly people with dementia, is not adequately taken into account;
- There are additional charges on residents in most private nursing homes for social activities – this leaves people whose only income is the Non-Contributory Pension with little or no disposable income to cover expenses, for example, relating to personal care, specialised equipment, family gifts, mobile phone.

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.

Home Care Packages

In recent years, there has been much debate and discussion both at policy and political level about the role of Home Care Packages and the need for legislation to provide equal access to supports for care in the community as to nursing home care and, thereby, redress the current prioritisation of nursing home care. As you are no doubt aware, a public consultation process on the matter has been mooted – this will keep the matter in the public domain. There would appear to be universal consensus that there is an essential need for Government to re-orientate the health service to give far greater priority to home care supports and community supports. This is

necessary in order to deal with:

a) The situation of people being unable to leave hospital because they do not have home care packages in place or because they are waiting for ramps or different aids to be provided in their homes (due to the long waiting lists in the local authorities)

b) People having to go into a nursing home because appropriate community and housing supports are not available in a timely manner

A Home Care Package (HCP) typically provides supports such as therapy, respite care and home help based on an individual Care Needs Assessment.[8] In December 2016, 45,956 people were in receipt of HSE funded home help services, 16,351 people got Home Care Packages (HCPs) and 180 got intensive HCPs, the vast majority of whom also get a home help service. The average weekly hours for home help are 4.3 hours. Currently, around 16,450 currently have a Home Care Package. Many people also pay out of pocket for private homecare services.

There are many positive aspects to Home Care Packages:

- Funded by the HSE and free of charge as part of the public health service
- Important in enhancing the quality of life for people with a high level of dependency living in the community;
- Those who succeed in getting a Home Care Package are usually satisfied

The shortcomings of present provisions for Home Care Packages[9] have been well documented, including, in particular:

- Absence of legislative entitlement
- Only limited access due to under-funding
- Entitlement arbitrary in the sense that eligibility is not clear
- The absence to date of formal national quality standards[10]

[8] It should be noted that a Single Assessment Tool (SAT) to uniformly assess dependency levels is being introduced. The HSE's National Service Plan 2016[8] refers to a phased implementation of SAT 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.

9 See, for example, NESC, 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

[10] See Law Reform Commission (2011), *Legal Aspects of Professional Home Care*, http://www.lawreform.ie/_fileupload/Reports/r105.htm

- Little or no focus on outcomes

The recently published Committee on the Future of Healthcare Sláintecare Report[11] proposes an expansion of home care over a five-year period.

End-of -life care

The Council of Europe Statement on the Rights of Older Persons[12] requires Member States to 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. There has been a consistent commitment by successive governments, the Department of Health and the HSE to deliver equal access to hospice services. While much progress has been made in this regard in recent years, provision for hospice and palliative care is not uniform across the country. A 2013 Irish Hospice Foundation (IHF) Report [13] estimated that because of regional inequity in resource allocation, approximately 2,470 people were being denied admission to hospice beds in Ireland each year.

While some two-thirds of Irish people express a preference to die at home, in reality only 26% of the circa 28,000 deaths that occur in Ireland each year take place in the home. The IHF 2013 report noted that many of the deaths (perhaps a quarter) that occurred in acute hospitals could have taken place at home if the necessary supports were in place since the patients did not have medical needs requiring hospital treatment and therefore could have been cared for elsewhere. This strongly suggests that more could be done to facilitate people to die where they would wish.

It is also the case that there are different practices and outcomes in different parts of the country. For example, it has been noted that, in comparison with Ireland as a whole, Donegal has significantly less deaths in hospital and significantly more deaths at home.[14]

Maximising the role of housing in long-term support and care

There is universal acknowledgement that enabling people to age at home is a desirable social goal. Older persons in need of care and support who wish to remain at home clearly require a range of accommodation, care, nursing and medical responses and a continuum of delivery and intensity. Where people cannot continue

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

12 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).

[13] http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf

[14] McKeown, K. (2012), *End-of-Life Care in Donegal*, A report commissioned by: Donegal Hospice Committee, Health Services Executive and Irish Hospice Foundation.

to live in their own homes, the potential of supported housing in the community should be the first alternative option explored.

Meeting the health and quality of life needs of older people who need support and care requires strong linkages in the continuum of support and care – between housing, community support, acute hospital care and long stay residential care. This is necessary in order to ensure that housing-related factors that can potentially exacerbate deteriorating health and affect wellbeing are identified and addressed. This will, of course, require better partnership between housing, health and social and health care providers and strong and visible planning leadership across the sectors.

Enabling people to stay in their homes
At a basic level, we need to address the issue of older people living in accommodation that does not meet their needs as they age and particularly as their mobility decreases. For example, if people's housing requires adaptations to enable them to return home after a hospital stay, carrying out such adaptations should be a matter of priority. The Housing Adaptation Grant (available from Local Authorities) can be a crucially important support in enabling people with an acquired disability or mobility problems to remain living in their own homes – however, as it currently operates, it falls far short of what is required due to both its limited funding and long processing time-frame.

Enabling older people to stay in their homes as their needs change requires intervention at multiple 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, for example, opportunities for active social engagement; access to therapies; transport to GPs and out-patient clinics; and day support services.

3) There is evidence of significant fuel poverty among older person households which require to be addressed both through energy efficiency measures and through the social welfare system.

4) Assessment of housing needs and housing-related support services should be a core aspect of integrated needs assessment – this may not always be the case at present.

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.[15]

Assisted living housing/housing with care

Not everyone can continue to live indefinitely in mainstream housing and it may not be possible to meet people's housing and support needs in their current dwelling and, in such instances, people need some form of supported housing. Sheltered housing has long been promoted as having the potential to bridge the gap between living independently at home and residential care. *The Years Ahead* (the 1988 inter-departmental seminal report) 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.

The need to take account of the potential of new residential models, including housing with care is referenced in the National Dementia Strategy. The Report on the Review of the Nursing Home Support Scheme (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 2016 Action Plan for Housing and Homelessness, *Rebuilding Ireland,* notes that older persons have specific housing requirements such as being in proximity to their family and social networks and the need for access to public and other essential services, recreation and amenities and refers to a new cross-Departmental/inter-agency approach including a the development of appropriate pilot projects by Local Authorities.

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).[16] Data from a

[15] Cluid (2015), *A Home for Life, https://www.cluid.ie/wp-content/uploads/2015/10/A-HOME-FOR-LIFE-FINAL-28-10-15.pdf*

[16] 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,

2011 ICSH Survey[17] shows that there was a total of 4,432 sheltered housing units provided by voluntary housing associations. The survey highlighted an almost constant (though varying) level of support to tenants either through the availability of staff and volunteers or through services accessible to tenants. However, the survey also found that that the majority of respondent housing associations provided units for older people capable of independent living. Specific high level care services, which are indicative of tenants with higher needs, were the least provided services. The main services provided to tenants were "passive supports" which did not necessarily provide or demand direct interaction with tenants and were available to but not mandatory or even necessary for tenants to engage with, e.g., alarm/security systems, laundry, communal areas and activities, day centres. The least provided services were the more care intense services (nursing, personal care) where the tenants required one on one interaction or engagement in response to an increase in their needs and a decrease in their ability to live independently.

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 care and support intensive sheltered housing. Of critical importance here is the availability not only of communal facilities and services but, also, homecare packages and easy access to medical and nursing care as required.

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 care. A UK Department of Health funded evaluation of "extra care" housing schemes found "similar or lower costs" than residential care but better outcomes.

The NGO sector in Ireland, 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.

There is scope for much more development of assisted living/housing with care models. A public initiative aimed at increasing this type of provision is required, having regard to the need to develop models of intermediate forms of care – between home care and full nursing home care. Such a development on the scale required would be likely to require, *inter alia,*

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alarm systems, and a laundry.
http://www.icsh.ie/sites/default/files/attach/publication/358/reportonshelteredandgrouphousing.pdf
[17]

https://www.icsh.ie/sites/default/files/attach/publication/435/theprovisionofhousingandservicesfortheelderlyinthevoluntaryhousingsector.pdf

- 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 HSE financing or directly providing the health care and social services needed to enable the assisted-living programme to operate.

Integrated housing provision: a longer-term approach

In the longer-term, the concept of 'sustainable communities' outlined in a 2007 Government Statement on Housing Policy, *Delivering Homes, Sustaining Communities*[18], 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 three macro-level questions will need to be addressed by Government and across Departments:

1) How can the building of more lifetime adaptable and accessible housing be provided by the private sector and how might this be progressed?

2) How can the separate components (design/building and social supports) of sheltered/supported housing be better conceptualised as an integrated package and with appropriate integrated funding?

3) What needs to be done to develop new models of assisted living housing building on the experience to date in both Ireland and other jurisdictions?

Need for stronger inter-agency collaboration

There has been much discussion over the past three decades on matters relating to partnership, coordinated services, networking, inter-agency co-operation and service integration.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 older people's support needs. In this context, a 2013 Council of Europe has stated that Ireland does not have enough constitutional

[18] http://www.environ.ie/sites/default/files/migrated-files/en/Publications/DevelopmentandHousing/Housing/FileDownLoad,2091,en.pdf

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. 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.[19]

A related and equally important consideration is the fact that there is no overall national strategic framework for meeting a range of different care and support 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 Housing, Planning, Community and Local Government and local authorities. It is clear that 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, *viz.,* enable people to age with confidence, security and dignity in their own homes and communities for as long as possible.

Exploring the potential of a social enterprise model

A social enterprise[20] model has been proposed[21] to develop innovative responses to the needs of older people. This model would seek to integrate current separate and disparate initiatives and provide for easier access to services by older people who need support. The model would, *inter alia,* include:

- Facilitating the development of legal mechanisms to enable people to opt in and out of shared resources, partnerships and mutual arrangements
- Community navigators to advise and support on accessing services
- Re-visioning traditional services such as meals-on-wheels, day centres and respite
- Micro-working systems to manage paid, bartered and donated time
- Organising volunteers
- Transport
- Greater use of assistive technology
- Group-purchasing schemes to reduce the cost of heating or respite breaks
- Befriending service
- Telephone contact and support services
- Urgent adaptations to a person's home to enable return from hospital

[19] https://wcd.coe.int/ViewDoc.jsp?p=&id=2113703&direct=true

[20] The proposed social enterprise would be likely to require a different legal status to a public or private body. It would trade commercially but with a social rather than a private purpose and its surplus would be re-invested in this social purpose.

[21] 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.

- Care and repair for home and garden
- Advice and assistance with financial and legal matters
- Emergency response in situations where home-based supports are threatened or the family is unable to cope
- Advance planning when the end of life is known to be approaching.

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.[22]

Quality of life is broadly-based and includes a range of aspects, including physical health, psychological and emotional well-being, 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:[23]

- The opportunity to perform activities of daily living (ADL)
- The opportunity to engage in meaningful use of time
- Enriching social interactions
- 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.[24]

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.[25] The role of the visual arts, music and entertainment in enhancing care environments is increasingly appreciated.The importance of having specified standards of accommodation in residential care facilities, e.g., own room with an *en-suite*

[22] http://apps.who.int/iris/bitstream/10665/206411/1/B4966.pdf

[23] 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

[24] http://retirement.berkeley.edu/pdf/Sexuality%20and%20Intimacy.pdf

[25] 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

bathroom and a physical and social environment to fulfil recreation, social interaction and stimulation needs has been emphasised.[26]

The HIQA National Standards for Residential Care Settings for Older People in Ireland[27] 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 as is 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.

There is still much to be done to ensure that the design and location of nursing homes caters for key quality of life considerations -- community access, maximising individual capacity and self-expression and individual preferences.

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, [28] 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 and people's inability to access the therapies that they require in order to optimise capacity is hugely problematic – addressing this deficit in provision is clearly possible within existing resources.

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)[29]. "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

[26] 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

[27] http://hiqa.ie/publications/draft-national-standards-residential-care-settings-older-people-ireland-2014

[28] 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.

[29] 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.

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.[30]

Balancing the requirements of care and people's needs to avoid over-care and learned helplessness is an important quality of life consideration and particularly important in residential care settings. 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.

Multi-purpose and integrated community-based developments

All of the research evidence and reflected practice suggests that multi-purpose community-based developments providing a continuum of support and care (social activities, day facilities, sheltered accommodation, nursing units) can contribute enormously to enabling people to live independently or semi-independently.

While we already have some good models in place in Ireland and some being developed, this approach requires additional momentum and more integration with local development. The Integrated Multi-purpose Unit Model should be made an integral part of town planning and the social and economic infrastructure rather than an add-on.

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 and could include space for 'normal' activities associated with daily living, e.g., coffee shop, newsagent, pub, clothes boutique, hairdresser, betting shop.

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[30] 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**;**

In order to make this vision a reality, 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 need to plan for an ageing population and provide for infrastructural development accordingly.

As an initial step, it is suggested that the Government might establish 3/4 pilot projects around the country based on:

1) Developing integrated and sustainable inter-generational communities

2) An integrated funding model (as distinct from the current silo funding model)

3) Provision for all of the activities and engagements required for daily living and social interaction

4) Located within regeneration zones and/or in locations where health and social facilities have been operating but are no longer being provided

5) Basic social care and health services located within the zone

6) Maximising the use of supportive technology – both as social support and health aid but also as a means of enhancing social connectedness

7) A focus on outcomes – people having optimal quality of life in terms of social connectedness and living (and dying) in the place of their choice

Concluding Comments

What we have now is scarcely adequate for Ireland in the 21st century in terms of long-term support and care for an ageing population.

While there is broad acknowledgement of the principle of enabling people to exercise their will and preferences in the way support and care is provided, the reality is that some people who do need to be in a nursing home end up there not by choice but because of a lack of appropriate community-based alternatives.

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.

We need to shift 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) and within the normal social and economic infrastructure. There is a need for Local Authorities to take on much more responsibility for the development of integrated multi-purpose

options that would include provision of sheltered and supported housing as part of such developments.

There is a need to proactively plan for the financing of long-term care of an older population who are living longer and to make decisions about how this is to be funded – a public opinion survey carried out last year [31] for the Forum on Long-term Care found that the greatest overall preference for funding long-term care is through general taxation – this is a matter that needs to be explored further.

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.

Finally, we have a National Positive Ageing Strategy, we have Age Friendly Ireland and we have Age Friendly Strategies in Local Authority areas. We know what people want, we know what the current policies and aspirations are, we know what current practice is and where the gaps are and we know the models that need to be developed. No report on long-term support and care has proposed the current model.

[31] Amárach Research (2016), Presentation to Forum on Long-term Care

Appendix
Selected Research Reports, Policy Documents and Strategies

- Committee on the Future of Healthcare Sláintecare Report (May 2017), http://www.oireachtas.ie/parliament/media/committees/futureofhealthcare/Oireachtas-Committee-on-the-Future-of-Healthcare-Slaintecare-Report-300517.pdf

- Age Friendly Strategy (Various Local Authorities)

- Approaches to the regulation and financing of home care services in four European countries: An evidence review, Health Research Board (2017) http://www.hrb.ie/uploads/tx_hrbpublications/Approaches_to_the_regulation_and_financing_of_home_care_services_in_four_European_countries.pdf

- Report of the Áras Attracta Swinford Review Group (2016)
- Healthy Ireland Strategy, A Framework for Improved Health and Wellbeing 2013 – 2025
- National Council on Ageing and Older People (NCAOP) (Various Reports 1991 -2000)
- 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*
- National Positive Ageing Strategy (2013)
- National Carers Strategy (2012)
- NESC (2012) Quality and Standards in Human Services in Ireland: Home Care for Older People
  NESC (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
- 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)