Sage Advocacy

Submission to the Commission on Care

November 2024

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Introduction

Sage Advocacy very much welcomes the establishment of the Commission on Care and is firmly of the view that the Commission provides a significant opportunity to look critically at the current architecture of care for older persons in Ireland. The Commission provides a much-needed opportunity to radically re-shape the way that care and support services are conceptualized funded and delivered. As in many other areas of economic and social development, the time is opportune for innovation.

This Submission draws on a range of sources:

1) Ten years of advocacy casework and related identification and analysis of issues arising,

2) A series of reports published by Sage Advocacy in recent years, in particular, *Choice Matters*[1], *Report of the Forum on Long-term Care*[2] and *A New Deal;*[3]

3) A one-day workshop held in February 2024 on the theme, *Responding to the challenges and opportunities of an ageing population*:

    a. Attended by 80 people, including researchers and academics, health and social care professionals, two former Taoisigh, a former Minister for Justice and the Chair of the Sláintecare Oireachtas Committee;

    b. Consisting of inputs by, *inter alia,* health care practitioners, academics, a lawyer and an economist

4) A Red C public opinion poll carried out for Sage Advocacy in October 2023 (see Appendix);[4]

5) The COVID-19 Nursing Homes Expert Panel Report;[5]

6) A report of an analysis of data from The Irish Longitudinal Study on Ageing (TILDA)[6]

A new model of care and support for older persons

Based on the insights gained from the above reports, discussions, reflection and analysis, Sage Advocacy believes firmly that a different model and organisational framework is required where services are developed collaboratively at local level in a manner which optimises the potential of the public, private and NGO sectors in each local area.

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[1] choicematters2020.pdf (sageadvocacy.ie)
[2] report_of_forum_on_ltc_for_older_people_final.pdf (sageadvocacy.ie)
[3] https://sageadvocacy.ie/wp-content/uploads/2024/03/A-New-Deal-Discussion-Document-on-Funding-Long-Term-Care-Sa7ac8.pdf
[4] https://sageadvocacy.ie/wp-content/uploads/2023/11/red-c-poll-sage-advocacy-october-2023.pdfhttps://sageadvocacy.ie/wp-content/uploads/2023/11/red-c-poll-sage-advocacy-october-2023.pdf
[5] https://assets.gov.ie/84889/b636c7a7-a553-47c0-88a5-235750b7625e.pdf
[6] McKeown, K., Pratschke, J. and Haase, T., (2014) 'Individual Needs – Collective Responses: The Potential of Social Enterprise to Provide Supports & Services for Older People', http://trutzhaase.eu/wp/wp-content/uploads/R-2014-Individual-Needs-Collective-Responses.pdf

This model would have a number of underlying organisational concepts:

- ✓ Use of the HSE Integrated Healthcare Areas (IHAs) (within the 6 new health regions) as catchment areas to develop an innovative and collaborative model of service delivery;
- ✓ All services for older persons, irrespective of delivery sector, provided in the community and shaped by the community;
- ✓ Appropriate housing as the first and essential stage in a continuum of support;
- ✓ A target of having all 24/7 congregated residential (nursing home) care integrated into local service hubs and as part of a broad continuum of care and support;
- ✓ An individual needs assessment approach based on a person's right to have their voice heard and to be supported in the decision-making process;
- ✓ The need in the medium-term to move from the current over-reliance on the private sector to deliver both congregated nursing home care and home-based care;
- ✓ A need for a strong spine of public provision in housing, home care, transport and residential care in the context of a mixed model of service provision involving the State, NGOs and the private sector;

Factors that should inform the Commission

The need to focus more strongly on older persons' well-being

A report of an analysis of data from The Irish Longitudinal Study on Ageing (TILDA)[7] stated that 'The purpose of services for older people is to improve well-being and these services are more likely to be effective if aligned with the known determinants of well-being'. Detailed analysis of TILDA data presented in the report indicated that the largest and most significant direct determinants of personal well-being among older people involve social connections; notably the quality of relationships with partners, children, relatives and friends as well as an active participative lifestyle. On the basis of this analysis the report suggested that 'services for older people, as currently funded by the HSE … may not adequately reflect all, or even the most important, risk and protective factors affecting personal well-being'. The report also suggested that 'while hospital and residential services to meet the needs of older people are important, they may have assumed disproportionate importance relative to the social connections which sustain the well-being of older people in their home environment. This critically important point should underpin all of the Commission's deliberations.

Red C 2023 poll

A Red C Poll, carried out for Sage Advocacy in 2023 (see Appendix 1 Infographic) showed that around four in five people:

[7] McKeown, K., Pratschke, J. and Haase, T., (2014) 'Individual Needs – Collective Responses: The Potential of Social Enterprise to Provide Supports & Services for Older People', http://trutzhaase.eu/wp/wp-content/uploads/R-2014-Individual-Needs-Collective-Responses.pdf

- Believe home care and nursing home care now is overly concentrated in the hands of private providers;

- Support the idea of a national not- for-profit organization to be set up as a 'GAA for Care' (with the local community/county being the focus) to help meet the challenges of an ageing society;

- Agree that there should be a legal entitlement for people to have access to an independent advocate;

The Poll also showed that 61% believe that older people should be able to directly employ care workers with more than half (58%) stating that the State should allocate personal budgets for this purpose. Very importantly, the Poll found that almost three quarters of over-55s (73%) believe that that there should be a right to assessment of care needs in the form of a Care Act.

The impact of reliance on the nursing home model of care

It is widely acknowledged that, in contrast to some other countries (e.g., Denmark), where there is a wide range of care alternatives, in Ireland we too easily opt for congregated care in nursing homes (mostly private) simply because of a lack of alternatives.

This institutional model of residential care with its drift, either by intention or lack of coherent policy, towards larger and larger, publicly funded, primarily out-sourced private provision, is a cause for serious concern. Well documented closures of rural smaller homes, and the creation of homogenised care systems arguably focused on meeting reductive regulatory requirements (as distinct from concerns such as community connectedness, personal well-being, maintaining strong inter-personal relationships and choice) exist alongside the stated policy to support older people who have very high support needs to continue to have meaningful, fulfilling life experiences within their own communities.

Notwithstanding the urgent need to move quickly to an alternative community-based model of long-term care and support for older people, it is realistic to acknowledge that in the short to medium term, the current nursing home model will continue to operate and that the private sector will continue to play a central, if increasingly questioned, role.

The current DOHC *Draft Residential Care Design Guidelines* (2023), which propose a move towards small scale households of no more than 12 individuals are a welcome development. The Draft Design Guidelines represent a shift in thinking towards the provision of high quality environments that promote privacy, dignity and respect. They acknowledge the need to halt the drift towards larger and larger buildings that can be disabling and inevitably lead to the exclusion of older people from their own social networks. This reflects a more progressive approach to enabling older people who need continuous support to live their lives according to their will and preferences and aligns with the provisions of the Assisted Decision Making (Capacity) Act 2015.

A need for well-trained and appropriately remunerated care workforce

The importance of a well-trained and appropriately remunerated care workforce in both the community and in residential care settings has long been acknowledged and cannot be overstated. The Report of the Strategic Workforce Advisory Group on Home Carers and Nursing Home Healthcare Assistants

(September 2022)[8] identified the acute shortage of care-workers against a background of rising demand for care. Issues relating to pay and conditions, recruitment and retention were noted. A critically important point noted was that given the increasing complexity of care required by service-users, the rate of pay for care-workers is too low. The report highlighted the need to address the issue of poor terms and conditions within the private home support and nursing home sectors in order to attract talented carers to work in the field

There is a clear need to address the typical pay differentials and working conditions between care workers in the public sector and those in the private sector and NGO Section 39 agencies. The clear focus in the medium to long-term should be to build a fully funded and supported direct public employment system for all care workers. This will be an important consideration in the context of implementing the long-promised Statutory Home Support Scheme and the re-orientation of care into the community to which the Government is committed to under Sláintecare. In the shorter term, the issue of pay differentials between the private home support and nursing home sectors and the public sector needs to be addressed. As a first step, the Minister for Enterprise Trade and Employment should request the Labour Court to establish a Joint Labour Committee (JLC) for the sector. It is suggested that the Commission on Care should recommend that the Government does this.

Essential role of housing with support in the health and social care continuum

In order to make community living for older persons work, we need many more sheltered and supported housing options as well as a range of in-home and community support services. In early 2019, the Government published an important policy statement addressing a range of housing options for older people.[9] The purpose of the Statement was stated as providing a policy framework "to support our ageing population in a way that will increase the accommodation options available to them and give them meaningful choice in how and where they choose to live".[10] There was a focus on increasing the options available to older people and on facilitating the integration of supports, particularly between the housing and health sectors, with a view to facilitating people to live at home and in their communities, independently, for longer. While the policy statement identifies a programme of 40 strategic actions to further progress housing options for older people, it is unclear to what extent these strategic actions have been progressed to date.

A 2019 report on the continuum of care for people with dementia,[11] prepared for the HSE National Dementia Office, highlighted the fact that for most people with dementia, there are only two choices in relation to care setting – home care or nursing home care. It also re-iterated the well-established fact that the current funding system supports the residential care option ahead of all other choices and noted that, in Ireland, there are only a very small number of housing with care schemes that are capable of addressing the complex needs of people with dementia.

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[8] 237210_448892b3-36b4-4b7a-a41e-90368ff2345c.pdf would address the issue of poor terms and conditions within the private home support and nursing home sectors; and contribute to attracting talented carers to work in the field.

[9] https://assets.gov.ie/9398/ca553fa753b64f14b20e4a8dcf9a46ab.pdf

[10] *Ibid.* p.25

[11] https://www.understandtogether.ie/Training-resources/Helpful-Resources/Publications/The-Continuum-of-Care-for-People-with-Dementia-in-Ireland-2019-.pdf

The need to take account of the potential of new residential models, including housing with care is referenced in the National Dementia Strategy and in the Report on the Review of the Nursing Home Support Scheme (NHSS). 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 the development of appropriate pilot projects by Local Authorities.

The three pillars around which a Housing with Support Demonstration prototype is currently being implemented by Dublin City Council in collaboration with a number of statutory bodies and NGOs are relevant.[12]

- The creation of a 'village' feel and sense of place through the provision of communal facilities that promote and encourage social interaction and engagement;
- The availability of a range of services, supports and amenities, designed to facilitate independence and autonomy;
- An integrated approach to building mixed tenure and vibrant, mixed communities.

Great care is required to ensure that any such initiatives are centrally located and integrated into local communities in order to avoid any form of ghettoisation or social marginalisation.

The current position is that the provision of housing with supports as part of an integrated care and support package is mainly reliant on once-off initiatives, personal champions and relationships rather than a mandated way of working, for example, between the Department of Environment and Department of Health and the HSE and Local Authorities. There is a clear need for an emphasis in practice as well as in policy aspirations on facilitating the integration of supports, particularly between the housing and health sectors in order to realise the full potential of supported housing as a fundamental and essential part of continuum of care and support. There is also a need to ensure that all housing planning applications are assessed in terms of how they fit with stated policy on integrated housing.

[12] https://www.housing.gov.ie/housing/minister-damien-english-announces-eu15million-housing-support-demonstrator-project-st

KEY MESSAGES AS TO WHAT IS REQUIRED

A new system of financing home-based care to include co-payments by the State and families (related to ability to pay)

An explicit focus on housing as being at the very core of the social support and health care infrastructure for older persons

A strong regulatory framework for home care that is monitored and evaluated to ensure that it does not prioritise systems over person-centredness

All services and supports grounded in the concept of strong **community connectedness** and a need in some instances to reinforce or build community connectedness where it has become fragile

People provided with the kinds of support that most closely resemble what communities do 'naturally'

Services for older persons developed in a mainstream social environment to avoid social marginalisation and potential ghettoisation

Formal support in the community in the form of **multi-purpose community-based hubs with supported housing options** that support ageing in place and 24-hour nursing units

Very high levels of clinical governance and medical support in facilities where nursing care is provided

Easy and timely access to GPs and Advance Nurse Practitioners irrespective of geographical location

Meaningful and realistic guaranteed supports for families caring for older persons with support needs, in particular access to adequate **in-home care, respite care and therapies**

A social enterprise approach which stimulates and supports local initiatives and ensures linkages between social and economic objectives

Private sector involvement based on a different model where partnerships with the State and with local social enterprises are embedded in provision

Identifying optimal spatial planning areas for integrated HSE and Local Authority planning for older persons' services

Developing the potential to harness area-based partnership structures as a means of mobilising local actors

A **statutory innovation fund** to stimulate local integrated & collaborative developments (in the order of multiple millions over a five-year period) in order to assist in the emergence of new models of care which have been regularly called for

Legislation in relation to protection of liberty, adult safeguarding and independent advocacy

An overarching long-term care governance structure which would replace, over time, the existing patchwork of legislation, policy and service delivery with its embedded binary choices

A mechanism to identify the **optimum spatial planning areas** required to develop and sustain outcome focused innovation, taking into account current HSE and Local Authority operational areas

Ring-fenced accelerated hospital avoidance programmes to include community-based geriatrician led teams, including GPs & advanced nurse practitioners

A Care Act along the lines of the UK Care Act 2014

A Commissioner for Older Persons in order to better protect and promote the human and legal rights of older persons in Ireland

Addressing the systemic barriers to and impact of current funding mechanisms on integrated working between health and housing in respect of integrated social care for older persons

An **analysis of measurable outcomes** for older persons in the context of the cost of 'Fair Deal' (€1.12bn in 2023) and expenditure on home care services €723 million. In 2023) and Social Return on Investment (SROI)

Personalised and individualised care and wellbeing to be at the heart of all health and social care systems

A central focus on outcomes as distinct from promoting better coordination between existing players

Overarching considerations

Changing the architecture of long-term care in Ireland

We need to fundamentally change the architecture of long-term care and support in Ireland and replace it with a new structure underpinned by the core principle of enabling people to live at home or in a place which feels like home. This means a new long-term care vision and policy consisting of an overarching integrated strategic plan, clear leadership structures, and a framework for implementation and monitoring. This would include, *inter alia*:

- A fully integrated care and support system with an inbuilt default to care in the community by the community;
- A focus on local social enterprise responses;
- Provision for individualised/personalised care and support budgets;
- The establishment of a dedicated Transformation Team established to drive a modernisation programme for long-term care;

Enhancing collaboration between NGOs at local level

Since many NGOs are deeply embedded in their communities delivering key services such as day centres, meals and wheels, supported housing, volunteer driving groups, care and repair, there is strong potential to bring these services together to reimagine their work and collaborate in the interests of putting older people in their communities first and minimise inappropriate and unnecessary duplication in service provision.

Timely access to acute hospital care

The provision of acute medical care for vulnerable older people, as reported on a worryingly regular basis in the media, is of particular concern. In particular the narrative of long waiting times for important elective procedures and have understandably caused alarm amongst the public and older people who fear becoming ill and having to navigate the Accident and Emergency System. Timely access to rehabilitation and reablement for older people following acute and chronic illness remains underdeveloped despite the well-known economic and personal benefits of such programmes.

Need for a long-term care innovation fund

There is a strong argument that the Government should provide an innovation fund to promote integrated development at local level.[13] Factors to be considered in determining innovation areas would include, *inter alia*:

- ✓ New regional and sub-regional structures of the HSE and readiness to engage during a time of internal change;
- ✓ Quality of leadership and sustainability of wider public sector involvement;
- ✓ Strength of local government commitment to age-friendly objectives;
- ✓ Potential for philanthropic and private sector engagement with the process and capacity to make social and economic investments of reasonable scale;

[13] Sage Advocacy has identified one such local area and has begun engaging with key stakeholders to explore the concept.

- ✓ Willingness and capacity of voluntary and community sectors to engage and collaborate effectively;
- ✓ Potential to focus nationally organised NGOs on area-based outcome focused work;
- ✓ Potential to achieve greater congruence through a whole of society approach including public, private and civil society elements;
- ✓ Potential to harness area-based partnership structures as a means of mobilising local players;
- ✓ Potential for government to champion the initiatives and to provide necessary innovation funds to attract the attention of a range of sectoral players, including private sector players, to address new models of community-based support and care informed by the learning from the Covid 19 pandemic;
- ✓ The optimum size of geographic and demographic area consistent with being able to build a baseline of data necessary to demonstrate progress;
- ✓ The potential for involvement by appropriate academic institutions to assist with research and analysis;
- ✓ How best to develop an integrated continuum of care and support – from independent living to 24-hour residential nursing care for those who require it, and including various forms of supported housing;
- ✓ A focus on integrated social and healthcare support hubs developed within 'natural' socio-economic hinterlands;
- ✓ Risks associated with the current model;

Additional questions that need consideration

- ✓ How can clinical governance be strengthened through more active engagement of community-based medical professionals – GPs, Geriatricians and Advanced Nurse Practitioners and oversight by regional and sub-regional health structures?
- ✓ How can the current disconnect between nursing homes and normal community life and social interactions be remedied?
- ✓ How can local communities (including health and social care professionals and NGOs) forge stronger links with nursing homes in their area?
- ✓ How can a flexible system of moving in and out of residential nursing care units as needs determine be implemented?
- ✓ What are the optimum components of transitional care, taking into account clinical, rehabilitation, people's right to choose, safeguarding and financial issues?
- ✓ How can older persons be better faciltated to assert their legal and human reights, especially in relation to giving full effect to their will and preferences as provided for in the assisted decision-making legislation, in all health care settings?

Some concluding comments

There is a need for an overarching long-term care governance process which would replace, over time, the existing inadequate patchwork of legislation, policy and service delivery with the resultant binary choices between home care and nursing home that do not acknowledge the individual circumstances of each older citizen.

There is a need for a programme of clear legislative and policy instruments which addresses cohesive access to funding and services and the safeguarding and inclusion of older citizens who require ongoing supports. This has been developed in other jurisdictions through legislation such as the Care Act 2014 in the UK which has been put in place specifically to address the rights of citizens who require support to live their lives as independently as possible.

It is essential that we rethink current strategies and consider possible alternative models which focus on better solutions for workers, older people and families alike. One promising model is the provision of Care Co-operatives located within empowered and resourced communities and driven by community development principles.[14]

As part of an overall long-term care policy development, consideration should be given to undertaking an analysis of the existing home support delivery model in the context of overarching vision, procurement model, incentives and governance taking into account a 2021 HIQA report.[15]

There must be a recognition that in order to realise socially ambitious objectives, we need public, private, philanthropic and community resources organised around a strong vision of health and social care for older persons and a recognition of the need to create new models of delivery as part of that process.

The Commission on Care must become a point of significant departure which sets out a clear alternative vision of what needs to be done and how – integrated needs assessment, a continuum of provision, a single integrated care and support system, supported housing as the fulcrum of the system, local multi-purpose care and support hubs, statutory/private partnerships, a social enterprise approach, building a strong partnership between the State, NGOs and family carers, and, crucially, a sustainable funding model.

Finally, the Commission should give serious consideration to the need for a significant innovation fund to ensure that the necessary infrastructure and supports are in place to enable the development of more effective locally-based responses to the needs of an ageing population.

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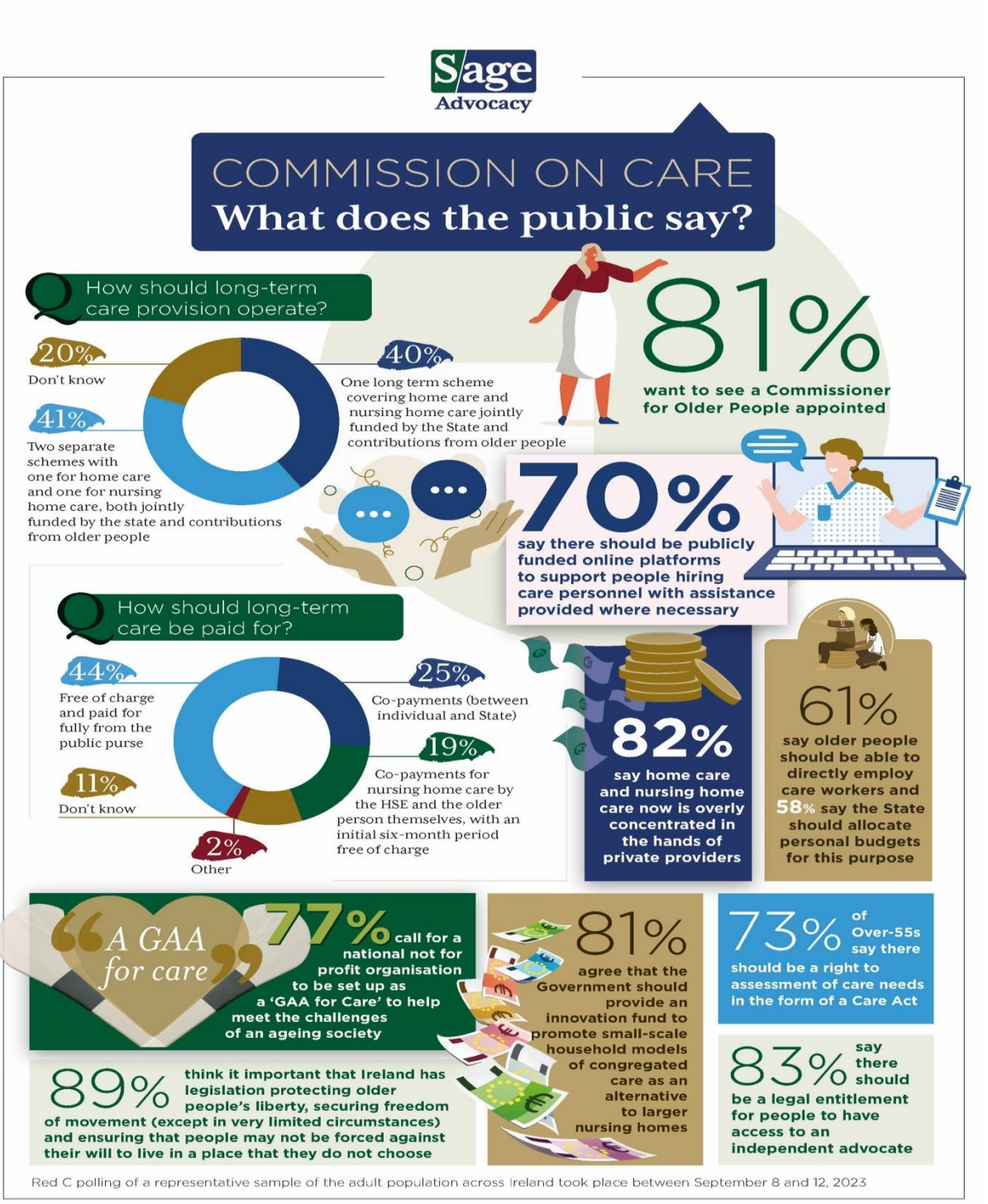
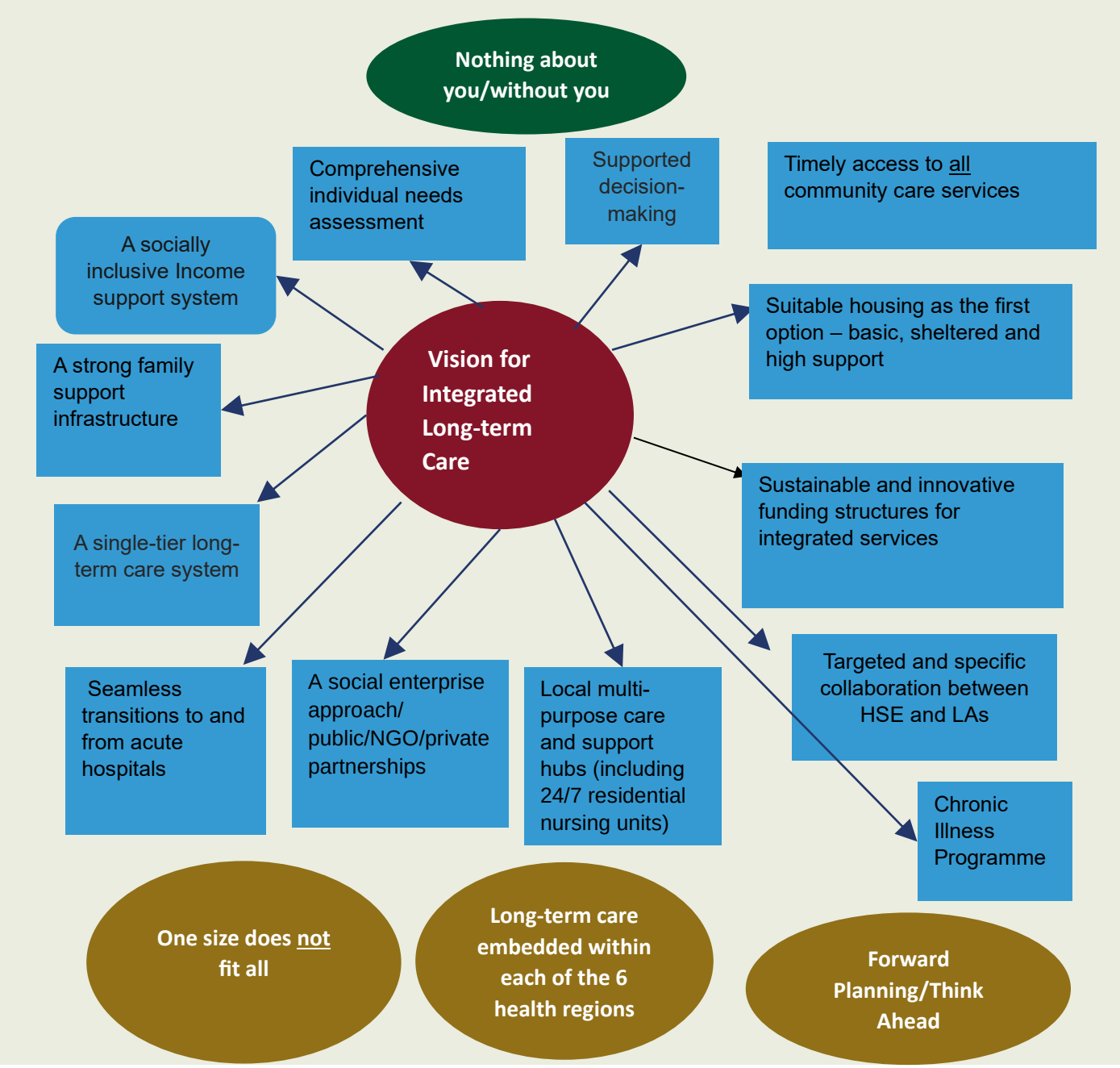
14 https://static1.squarespace.com/static/60794fe9b05e0b4b67aebfc7/t/640b3d57888e09131aa61798/1678458286043/CareVisions+CP+CC+presentation+.pdf

15 HIQA (2021), Regulation of Homecare: Research Report, https://www.hiqa.ie/sites/default/files/2021-12/Regulation-of-Homecare-Research-Report-Long-version.pdf

Appendix 1: Sage Advocacy Red C Poll Infographic



Appendix 2: Components of an Integrated Care Framework



Appendix 3: Housing options for older persons

Housing Type	Actions	Features	Targeted at	Requirements
Single/ dispersed	Making existing homes more age-friendly	Enabling people to age in their existing homes	People who wish to and are able to remain in their homes	House adaptations; Retrofitting; Maintenance; Technology; Security; Future accessibility proofing
	Downsizing	Accessible smaller houses/ apartments	People whose existing homes are too big/too difficult to manage;	Purpose-built housing (private and public) to facilitate choice, and downsizing;
Shared housing in the community	Home sharing	Enabling people to benefit from having someone else living with them;	Older people who would be willing to share their homes; Younger people with a housing need;	Incentives and provision for appropriate contractual templates (rights, responsibilities and termination);
	Split housing	Supporting people to live adjacent to relatives	People who could and wish to live in self-contained units with relatives	Some grant incentivisation where such provision lessens need for other long-term support accommodation;
	Boarding Out	People who require support move into other people's homes on a paid basis.	People who are no longer able to live on their own but would like to live in a 'family -type, household;	Incentivisation, supervision, ongoing funding and contractual templates;
Dedicated housing for older people	Sheltered housing;	Catering for the needs of people who require easy access to basic supports for independent living;	People with low and medium support needs.	More provision of suitable schemes at local level – directly by Local Authorities, by Hosing Associations and private developers;
	Retirement villages;	Age-friendly communities which promote independence and social interaction;	People who wish to live independently and have opportunities to pursue common interests and shared activities;	Likely to be private sector developments for those who can afford it.
	Older persons' co-housing communities	People living independently as part of a communal facility;	People who wish to live as part of a newly- created community;	Could be provided by private developers by Housing Associations or by means of local social enterprises;
High support	High support sheltered housing	Housing with24/7 on-site support and care	People who require access to 24/7 support but who do not require 24/7 nursing care;	Part of local integrated support hubs
	Residential nursing care units	24/7 nursing care for those who need it	People who require 24/7 nursing care	Community -based and integrated with other local services –social and health care.

Source: Adapted from https://alone.ie/wp-content/uploads/2018/07/Housing-Choices-for-Older-People-in-Ireland-Time-for-Action-1.pdf

Appendix 4: Selected information sources

'Individual Needs – Collective Responses: The Potential of Social Enterprise to Provide Supports & Services for Older People', http://trutzhaase.eu/wp/wp-content/uploads/R-2014-Individual-Needs-Collective-Responses.pdf

ESRI (2024), *Long-term residential care in Ireland, Developments since the onset of the Covid-19 pandemic*, https://www.esri.ie/system/files/publications/RS174.pdf

The Need to Reframe Nursing Homes as Community Hubs
The Need to Reframe Nursing Homes as Community Hubs | Health Policy | JAMA Health Forum | JAMA Network

Exploring the Potential for the Development of Care Co-operatives to Support Older People to Age Well at Home,
https://static1.squarespace.com/static/60794fe9b05e0b4b67aebfc7/t/640b3d57888e09131aa61798/1678458286043/CareVisions+CP+CC+presentation+.pdf

P*ost-Acute Inpatient Rehabilitation Service Provision: A National Overview of HSE Funded Services,*
post-acute-inpatient-rehab-service-provision-a-national-overview-of-hse-funded-services-full-report.pdf

Care Act 2014 (legislation.gov.uk)

Evaluation of the 'Pilot Implementation of the Framework for Safe Nurse Staffing and Skill-Mix in Long-Term Residential Settings for Older People, https://assets.gov.ie/281431/33e2fab8-fd96-4133-b47e-38aa80743fca.pdf

Choice Matters: T*owards a Continuum of Support and Care for Older People* choicematters2020.pdf (sageadvocacy.ie)

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
report_of_forum_on_ltc_for_older_people_final.pdf (sageadvocacy.ie)

'*A New Deal', A discussion document on funding long-term support & care*

https://sageadvocacy.ie/wp-content/uploads/2024/03/A-New-Deal-Discussion-Document-on-Funding-Long-Term-Care-Sa7ac8.pdf

Red C Public Attitudes Poll 2023,
Commission on Care Red C Poll 011123b

COVID-19 Nursing Homes Expert Panel Examination of Measures to 2021,
https://assets.gov.ie/84889/b636c7a7-a553-47c0-88a5-235750b7625e.pdf

Identifying RISKS Sharing RESPONSIBILITIES The Case for a Comprehensive Approach to Safeguarding Vulnerable Adults 6439-Safeguarding-Risks-Resp-Report-FA4_lowres.pdf (safeguardingireland.org)