

Towards a
Continuum of
Support and Care
for Older People

Choice Matters



Time to Act

The Covid-19 public health emergency has shown some of the great strengths of Irish society. It has also shown weaknesses in our systems of health and social care. We have a two-tier healthcare system which means that those who can afford it get health care ahead of those who cannot and we have a siloed approach to the long-term support and care of older people which is biased towards congregated settings. We owe it to ourselves, and to those who have sacrificed so much, to do better. It is time to 'shed a tier' and set about building Sláintecare; a single tier national health service with an integrated system of social care focused on home.

The Covid-19 pandemic provides an opportunity like no other to address the dangerous architecture on which our current system of care in congregated settings for older people is built. It also provides an opportunity to review and then act on decades of policy development which has stressed the need for older people to be supported, and cared for where necessary, in the place of their choice which, for the great majority of people, is home.

It may be tempting to leave long-term reform until 'after the crisis' but the Covid-19 Nursing Homes Expert Panel has made a clear recommendation: *'Review and as appropriate following review develop policy and underpinning legislation, as necessary, for the introduction of a single integrated system of long-term support and care, spanning all care situations with a single source of funding'*. They recommend that *'Planning for the review should commence in line with the Commission on Care process'*.

The Programme for Government 2020 has made a clear commitment to establish a Commission on Care for older people. This discussion document is being published to inform the work of the proposed Commission and set out a simple framework for the development of a single tier support and care system. It takes into account the experience to date of the Covid-19 pandemic and the experience and perspective of Sage Advocacy personnel. It is a document that adds another dimension to the Report of the Covid-19 Nursing Homes Expert Panel and the Interim Report of the Oireachtas Special Committee on Covid-19 and it should contribute to the ongoing work of the Department of Health, the HSE and HIQA in developing a rights-based, safe and high quality continuum of support and care for older people.

Over three decades ago, in 1988, *The Years Ahead: A Policy for the Elderly* (a seminal Report of an Inter-Departmental Working Group on Services for the Elderly) was published. The Commission for Care, when established, must quickly review the great body of policy work to date and then set out an implementation plan for the development of a social support and care system which ensures that Ireland is recognised as one of the best places in the world in which to grow old.

The Discussion Document was prepared for Sage Advocacy by Dr Michael Browne

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Foreword

Aunt Alice had already chosen her nursing home. All her life she made hard decisions and stuck to them. But not this morning. I was staying with her because she hadn't been well and when I went in to say goodbye before work, she fixed me with a beady eye. 'I don't think I'll go into that nursing home' she announced 'It's full of old people.' Fair point, I thought.

'Your mother said that if I wanted to, I could come and live with her in Borris. You ring her now and ask her.' I did and my mother said she would speak to my father and she rang me back. 'Your father says you're to tell Alice she is as welcome as the flowers of May'. I still remember the little smile on her face as she bossily waved me out the door.

So till she died, Alice lived in our house. Ramshackle and noisy though it often was, there was always one of us eight children to run errands for her, always a cup of tea on the go and a visitor in the kitchen with local gossip, and always my mother whom she loved.

I'm an old person now and I know that nursing homes suit some people and not others. But Alice had got it in one when she said nursing homes are full of old people. If we didn't know already the dangers of having so many vulnerable people in a congregational setting, Covid 19 has taught us in the cruellest way possible. For years, Sage Advocacy has been calling for a rethink of services for us older ones. This timely discussion paper raises not only the flaws in our nursing home system exposed by the pandemic but also the weakness of a model of services which depends so heavily on nursing home care. Modern life may not allow for the family solution available to my Aunt Alice but we know most of us older people, given supports, would prefer to stay in our community and at home. So why do we do nothing to plan for it or fund it? Yes, it will cost money to give older people choices about where and how we live our lives. It may mean that we don't have as much money to hand on to the next generation. But what gives a family or a society greater pride than that their older people, all our Aunt Alices, live full lives to the end?



Olivia O'Leary
Journalist & Broadcaster

Choice Matters: Summary of Main Points

What we learned from Covid-19

The experience of Covid-19 showed beyond doubt that our current two-tiered long-term support and care system with its high reliance on residential nursing homes was totally inadequate to safeguard vulnerable older people. These concerns are broader than the challenges faced in responding to Covid-19 or to any future pandemic.

The experience of Covid-19 showed that we can do things well, including the marshalling of significant voluntary support for older people living in the community, collaboration between the HSE and Local Authorities and the putting in place of adequate Home Care Packages to enable quick discharge of older people from acute hospitals.

- We need to reflect on and learn from these experiences as has already happened through the work of both the Expert Panel on Nursing Home Care and the Oireachtas Special Committee on Covid-19. Because of the broad consensus across society that nursing home residents were not well safeguarded during the pandemic
- The time was never more opportune to act and to put in place and implement a new vision for long-term support and care based on best international practice and underpinned by rights principles, protection of liberty and safeguarding vulnerable adults. Facilitating individual choice and supported decision-making in respect of care options must be at the very core of this vision.

What we already know

- We know that our health and social care system, as currently designed, cannot meet the growing demands for long-term care in an ageing society.
- Despite the enormous strides in keeping people healthier for longer, the reality is that there will be growing number of people who may require some level of additional care for a period of 20 years or more of their lives. Increased demand for palliative care services and quality end-of life care present new challenges for the health services.
- While substantial levels of funding are provided for long-term health and social care, these will not be enough to deal with future demand – Ireland, like many other countries, needs to urgently address the question of the sustainability of long-term care funding.
- New collaborative models between the State, the private sector and NGOs are required with a particular emphasis on developing local support and care hubs which would include nursing home units built to scale and with organic links to the local community. Social enterprises have a potentially important role to play in such initiatives.

What we need to do

- In the context of the Covid-19 pandemic, and of ongoing efforts to address the many challenges arising from it, there is now both a necessity and an opportunity to progress the development of long-term support and care as an integral part of building an equitable and quality driven national health and social care system through Sláintecare.
 - ▷ We need to move beyond statements of intent and aspirational policy as to how long-term care should be delivered which has been stated in policy documents for over 30 years and about which there is broad agreement in society.
 - ▷ We need to find sustainable, creative and more humane ways to care for people with long-term support and care needs.
 - ▷ We need a much wider range of personalised options beyond the current two-tiered models underpinned by a profit agenda and sectional interests.
 - ▷ We need to identify sustainable methods of funding social and health care in later years at the level to which we all aspire to.
 - ▷ Responsibilities, resources, and risks need to be more evenly and transparently shared.
 - ▷ All of society – citizens, front line services, and government – need to act together to achieve this vision.

Why we need a new vision for long-term health and social care

- Since there have been numerous policy statements on how social and health care in later years should be delivered and there is broad consensus on what needs to be done, it is reasonable to suggest that radical change to the system will only happen through the creation of a new vision coupled with a radical departure from the existing system.
- There is growing consensus that long-term care services should look beyond a purely medical model of 'care'. Instead, they should take a broader, more holistic view in which older people's well-being and quality of life and their preferences regarding support and care are central to the design of services, in line with existing human rights standards.
- 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 part of a continuum of support and care.
- Ireland can and should aspire to a model of long-term support and care (e.g., Denmark) where the emphasis is on publicly funded long-term support and care provided for the most part in community-based settings.
- The current two-tier system (separate provisions for community-based care and residential nursing home care) is no longer acceptable. It does not allow for the right care, in the right place, at the right time.
- Demographic changes and population ageing will require growing levels of public expenditure on long-term support and care. Delivering quality care in people's own homes is not cheap (despite the significant and frequently necessary contribution of family carers) and must be funded to a sustainable level.

Vision for long-term health and social care

The components of a vision for long-term support and care are outlined which, it is suggested, should underpin the deliberations of the Commission on Care, the establishment of which is contained in the current Programme for Government.

The primary task of the proposed Commission on Care should be to address the putting in place of an integrated framework to deliver policies and programmes about which there is broad agreement rather than a restatement of these policies and aspirations. This requires setting out a vision which includes an outline of an integrated model of long-term care and clear implementation benchmarking. Failure to do this can reasonably be viewed as a failure to take seriously the lessons of Covid-19 and its impact on a high-risk and very vulnerable group of older people.



Introduction

The purpose of this Discussion Document is to inform ongoing debate and dialogue on issues arising from the experience of Covid-19 with specific reference to how a better system for long-term support and care can be put in place. This document seeks to draw out the learning and the systemic issues arising from Covid-19 that will help shape the agenda for the future and contribute a reasoned and evidence-based perspective to any inquiries that may be established. Equally important is the need to move beyond Covid-19 and to explore in an imaginative way how our long-term support and care systems can be transformed to make them more fit for purpose for an ageing and more dependent population. It is hoped that the document will inform the deliberations of the Care Commission to be established under a commitment in the current Programme for Government.

Sage Advocacy is a support and advocacy service for vulnerable adults, older people and healthcare patients. Its mission is to promote, protect and defend the rights and dignity of vulnerable adults, older people and healthcare patients. In 2019, there were 1,570 referrals for advocacy and 3,964 requests for information and support. Almost half of Sage Advocacy work in 2019 related to people living in the community, 27% related to nursing homes and 23% to acute hospitals. Much of Sage Advocacy work involves people whose decision-making capacity is to a greater or lesser degree compromised.

The document is based primarily on an analysis of feedback from and reflections by Sage Advocacy frontline personnel on the experience of Covid-19. This feedback was based on their engagement with clients, service delivery personnel and members of the public as well as on requests for advocacy support during the period March–mid-June 2020. As the Covid-19 pandemic evolved and as significant issues began to emerge about the manner in which our health and social care system responded to the crisis, Sage Advocacy embarked on a process of identifying and assessing responses to this unprecedented crisis. Sage advocates, because of their involvement with vulnerable adults throughout the support and care process, are well placed to have a good insight into what was happening and why. They are also independent of the health and social care system. It is, of course, acknowledged that this is but one perspective on the Covid-19 experience and on its implications for the way we provide long-term support and care.

As an initial step, all Sage Advocacy personnel were asked to engage in a process of reflection under a series of thematic headings and to record their observations and experiences accordingly. This feedback was analysed by a researcher and located within the broader context of the response to the crisis and the challenges arising from the model of long-term support and care that currently exists in Ireland.

Outline of Document

Section One sets out the key issues arising from the manner in which Covid-19 impacted on vulnerable older people and raises some questions about the adequacy of our current model of care in congregated settings to respond to a pandemic such as Covid-19. It makes the case for a radical change to our long-term support and care architecture and sets out an alternative vision for this.

Section Two outlines the views and perspectives of Sage Advocacy personnel under a series of thematic headings relating to how Covid-19 impacted on long-term support and care infrastructures in both nursing homes and community settings.

Section Three identifies issues relating to long-term support and care for vulnerable adults arising from the analysis of feedback from Sage advocates.

Section Four sets out a series of policy recommendations for addressing some of the support and care issues that were highlighted during Covid-19. This includes specific proposals for improving medical and nursing care in nursing homes. It also provides a roadmap for delivering change with particular reference to the role of the proposed Commission on Care.

Section Five sets out some final observations and conclusions.

Section One

Long-term Support and care: Current Reality and Future Vision

1.1 Introduction

It has become widely acknowledged that the long-term support and care architecture in Ireland with a high reliance on residential nursing home care presented major difficulties in responding to the challenges of Covid-19. Many of these difficulties have been identified, including by the Oireachtas Special Committee on Covid-19 Response¹, by the Covid-19 Nursing Homes Expert Panel², by HIQA³, by various government and health service personnel and by policy commentators.

The issues identified to date include, in particular, inadequate clinical oversight in private nursing homes, a total lack of any protocols between the HSE and the private nursing home sector and the continued use of multi-occupancy rooms and outmoded premises in some nursing homes. Also, the regulations governing nursing homes are regarded by HIQA as outdated and in need of revision to make them fit for purpose, particularly in relation to governance, staffing numbers, skill-mix, and infection prevention and control.⁴

While these initiatives, investigations and insights are necessary and critically important, it is essential that we do not lose sight of the need to reform in a fundamental way the broader architecture of long-term support and care in Ireland and to develop a new vision to achieve this transformation. Arising from the significant impact that Covid-19 has had on nursing home residents, the need for new models of nursing home care and for an integrated continuum of support and care have been highlighted.

The need to evolve from nursing homes to cost-effective, stay-at-home alternatives is not something new and has been consistently and regularly referenced in policy documents and reports since *The Years Ahead* Report⁵ published in 1988. It has been noted that such stay-at-home models have been in existence across Europe since the late 1980s.⁶ For example, in 1987, Denmark passed new legislation suspending all institutional care for older people and in 1992, in Sweden, residential care was replaced with special housing in various forms. In 2010, the Dutch government introduced an

¹ https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/special_committee_on_covid_19_response/reports/2020/2020-07-31_interim-report-on-covid-19-in-nursing-homes_en.pdf

² <https://www.gov.ie/en/publication/3af5a-covid-19-nursing-homes-expert-panel-final-report/>

³ https://www.hiqa.ie/sites/default/files/2020-07/The-impact-of-COVID-19-on-nursing-homes-in-Ireland_O.pdf

⁴ <https://www.hiqa.ie/hiqa-news-updates/hiqa-report-highlights-experiences-nursing-home-residents-during-covid-19>

⁵ *The Years Ahead*, <https://www.lenus.ie/bitstream/handle/10147/46365/1305.pdf?sequence=1&isAllowed=y>

⁶ Suzanne Cahill, <https://www.irishtimes.com/opinion/better-care-models-for-elderly-must-not-be-derailed-by-covid-19-1.4309064#.Xxair6A1aQM.twitter>

innovative programme for aged care facilities focusing on small-scale domestic dwellings, choice, autonomy, meaningful activities, preservation of personhood and facilitative relationships.⁷ Ireland urgently needs to catch up and put a more ambitious and respectful long-term support and care infrastructure in place.

1.2 A new vision for long-term care

As an overarching societal goal, the nursing home model as it currently exists must be made a thing of the past.⁸ Older people who require support and care have a basic human right to live in the community and to be free of strictures and deprivation of liberty and choice frequently associated with nursing homes as institutions. The important point has been made that living in these places makes it intrinsically difficult to physically distance oneself and that “living with any concentration of people categorised as ‘vulnerable’ to the disease [Covid-19] was a disaster waiting to happen.”⁹

Since the late 1960s, research and policy documents in Ireland have continually stated the primacy of community or home-based care over residential care. The 2016 Forum on Long-term Care for Older People report¹⁰ raised the critical 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 referred to the need to develop a vision for long-term support and care which is entirely focused on outcomes related to the will and preferences of those receiving support. In terms which are as applicable to 2020 as to 2016, the Forum Report stated that ‘Far from the money following the patient, the patient has to follow the silo where the money is’.

The current Programme for Government contains a commitment to establish a commission to examine support and cares for older people and to expand community-based care to bring it closer to home, in line with the Sláintecare Implementation Plan. While this will be an important initiative, if it is to be realistic, it must address in a meaningful way blockages that are endemic in the system and which are already well identified. Merely restating policy aspirations will be a lost opportunity to address a major blot on Irish society which came very much to the fore as a result of the Covid-19 pandemic.

The Oireachtas Special Committee on Covid-19 Response in its Interim Report¹¹ identified a number of structural issues with our current long-term care system.

- The overall model of care for older people is not adequately integrated with the rest of the healthcare system and is deeply flawed.
- The lack of policy integration between home care and residential care continues to put people directly at risk. The current statutory right to nursing home care only can drive people to enter nursing homes earlier than needed due to inability to access adequate home care support.
- There is a need for a change in housing policy to enable older people to live either independently at home or in housing units with supports provided.
- There is a need for a continuum of care ranging from home care, split housing and boarding out

⁷ *Ibid.*

⁸ <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1748-3743.2012.00320.x>

⁹ G. Quinn and A. Campbell <https://www.irishtimes.com/opinion/nursing-homes-must-be-made-a-thing-of-the-past-1.4257422>

¹⁰ https://www.sageadvocacy.ie/media/1124/report_of_forum_on_ltc_for_older_people.pdf

¹¹ https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/special_committee_on_covid_19_response/reports/2020/2020-07-31_interim-report-on-covid-19-in-nursing-homes_en.pdf

to supported housing and including patient focused and clinically appropriate nursing home care.

- Long-term support and care management across the HSE's community service areas should be closely aligned to the principles and goals articulated within Sláintecare – supporting people in or as close to their own homes as possible.

The HIQA report, *The impact of COVID-19 on nursing homes in Ireland*¹² noted that the current system predominately directs people into a single model of residential care when other options may be more suitable and suggested that alternative services such as assisted-living and homecare would enhance the experience of many older people in the later stages of their lives. In May 2020, the then Taoiseach questioned whether the current policy focus on building nursing homes (albeit with all single rooms and high quality environments) was the right approach and whether a focus on enabling people to stay at home for much longer through living in smaller communities may be a better option.¹³ The HSE Director-General has stated¹⁴ that nursing homes, and particularly congregated settings, are not the environment in which people can be protected in a pandemic and that the future of nursing homes in the care system was a matter that needed to be looked at.

The Oireachtas Special Committee on Covid-19¹⁵ has recommended that the Department of Health develop an integrated system of long-term support and care spanning all care situations with a single source of funding (Recommendation 9). The Covid-19 Nursing Homes Expert Panel Report¹⁶ recommended that the integration of private nursing homes into the wider framework of public health and social care should be advanced and should be pursued as a key component of the work of the intended Commission on Care (Recommendation 15.1). The Expert Panel also called for the development of policy and underpinning legislation, as necessary, for the introduction of a single integrated system of long-term support and care with a single source of funding (Recommendation 15.9).

1.3 Envisaging a new model of long-term support and care

A more integrated and community-oriented model of long-term support and care is necessary in order to ensure that all citizens are safeguarded and receive services appropriate to their needs. A comprehensive system like this requires adequate provision of each care option along a continuum, allowing people to select the appropriate support and care option as their needs change. If there are gaps at different points, then there is no real choice and people's ability to select the appropriate care is seriously hampered. At present, such a continuum simply does not exist or exists only in theory. What we have is a piecemeal, *ad hoc* response to needs which leaves older people living in very insecure, vulnerable and precarious positions, some of them socially excluded and some not well safeguarded, with little sense of entitlement or right.

The development of a continuum of support and care presents challenges for all of us, individually and collectively. As a fundamental question, we need to ask whether as a society we make the well-being of vulnerable older people requiring support and care centre-stage in our policy development or whether it is regarded as somewhat marginal in the overall scheme of things. The Covid-19 public health emergency has shown some of the great strengths of Irish society. It has also shown alarming weaknesses in our systems of health and social care pertaining to vulnerable older people. Side by

¹² https://www.hiqa.ie/sites/default/files/2020-07/The-impact-of-COVID-19-on-nursing-homes-in-Ireland_0.pdf

¹³ <https://www.youtube.com/watch?v=HgRqeSEBkAI>

¹⁴ <https://www.breakingnews.ie/ireland/hse-chief-says-ireland-may-not-build-nursing-homes-in-future-1012027.html>

¹⁵ https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/special_committee_on_covid_19_response/reports/2020/2020-07-31_interim-report-on-covid-19-in-nursing-homes_en.pdf

¹⁶ <https://www.gov.ie/en/publication/3af5a-covid-19-nursing-homes-expert-panel-final-report/>

side with a two-tier healthcare system, we have a siloed approach to long-term care which, despite repeated policy aspirations, continues to be biased towards congregated settings.

Now is the time for us to shift the discourse and to fashion a new policy and vision for long-term support and care which will also address the interests and concerns of all citizens. A comprehensive and inclusive long-term support and care policy has the potential to create a more cohesive, co-operative and inclusive society. This has to do with all of us because such a policy needs to be formulated and put in place by all of society and with some urgency. This will require a basic re-thinking of our values and attitudes and how we approach the matter of financing the long-term support and care¹⁷ required by some people in their later years. It also raises critical questions about the extent that we as a society privilege inter-generational transfer of private wealth over paying for long-term care individually and collectively.¹⁸

1.4 Two models of care contrasted

Figure 1.1 outlines the main features and outcomes of both the current model of long-term support and care and an envisaged alternative model. In juxtaposing these models, it becomes clear that different values underpin each model. The existing model is rigid, two-tiered and lacking in fluidity. It is not conducive to supporting people's legal and human rights and does not allow for a seamless continuum of provision. Its inherent bias towards nursing home care runs totally contrary to the wishes and preferences of the vast majority of Irish people. The heavy and growing reliance by the State on the private sector to deliver care in both nursing homes and in the community results in a massive transfer of public resources to the private sector, a dismantling of public services and a considerable loss of social capital. The outcomes for people of this approach may be such that people with significant support and care needs do not receive the quality of care conducive to health and well-being.

While arguments in favour of the current model regularly cite efficient use of resources, there is inadequate attention afforded to other more important factors such as choice, safeguarding vulnerable older people, well-being and quality of life in later years. "To enter our long-term health and care systems is to pass through an entrance which may open as rarely – and shut as resoundingly behind you – as any workhouse or asylum door".¹⁹

¹⁷ See Sage Advocacy (2019), Financing Long-term Care in an Ageing Society: The Challenge Facing Ireland, https://www.sageadvocacy.ie/media/1538/sage-advocacy_summary-financing-long-term-care-in-ireland_2002019.pdf

¹⁸ This matter is discussed in detail in a forthcoming Safeguarding Ireland Working Paper, Safeguarding Vulnerable Older People: Sharing the Cost Fairly.

¹⁹ Alex Fox (2018), *A new health and care system: Escaping the invisible asylum*, <https://www.researchgate.net/publication/323527338>

Figure 1.1: Changing the architecture of long-term support and care

	Existing model	Model envisaged
Features	<p>A 2-tier system;</p> <p>A privatised model;</p> <p>25,000 supported by NHSS;</p> <p>54,000 Home Care Packages;</p> <p>Home care supports underdeveloped;</p> <p>Little integration between health and social care supports and housing;</p> <p>Absence of community connectedness by nursing homes;</p> <p>Poor liaison between the HSE and the private nursing home sector;</p> <p>Statutory entitlement to State support for nursing home care/not for home care;</p> <p>Funded from taxation and co-payment by users (NHSS);</p> <p>Precarious public financing structures;</p> <p>Inadequate remuneration, training and supports for care workers;</p> <p>Waiting periods for HCPs and NHSS.</p>	<p>All people requiring LTC living at home or in a place which feels like home;</p> <p>State-supported housing options that support ageing in place;</p> <p>All services and supports grounded in a strong community connectedness;</p> <p>Multi-purpose community-based hubs providing a continuum of supports, including nursing care;</p> <p>Appropriate remuneration, training and support for care workers and LTC nurses;</p> <p>Meaningful supports for families caring for people with LTC needs;</p> <p>Strong clinical oversight in services providing medical and nursing care;</p> <p>Timely access to supports required;</p> <p>A guaranteed funding system for LTC (not subject to market vagaries which impact on revenue available);</p> <p>Innovative partnerships involving the public, community and voluntary sectors</p>
Underlying aspects	<p>People's rights poorly protected;</p> <p>Growing reliance on private sector;</p> <p>State involvement decreasing;</p> <p>Lack of integration between community care and nursing homes;</p> <p>Linkages between acute hospitals and nursing homes underdeveloped;</p> <p>Poor clinical governance in some private nursing homes;</p> <p>Limited LTC options for individuals;</p>	<p>People's legal and human rights protected;</p> <p>People supported to live at home;</p> <p>A continuum of support and care options available;</p> <p>The 'voice' of people enshrined in decisions;</p> <p>Community connectedness central in all service delivery;</p> <p>People with reduced capacity receive appropriate supports</p>

	Existing model	Model envisaged
Cost	<p>NHSS - €1billion</p> <p>Home Care- €936</p>	<p>New cost and funding structure developed and a sustainable LTC financing model</p>
Outputs	<p>People inappropriately 'put into' nursing homes;</p> <p>Insufficient Home Care Packages;</p> <p>Waiting periods for approval for both HCPs and NHSS;</p> <p>Unnecessary admissions to acute hospitals;</p> <p>Delayed discharges from acute hospitals;</p>	<p>A range of LTC options available;</p> <p>Local multi-purpose hubs to include supported housing and provision for nursing care;</p> <p>Social enterprises providing a range of community-based support and care options;</p> <p>LTC care workers and nurses adequately remunerated, trained and supported;</p> <p>Strong clinical oversight in all LTC services;</p> <p>Timely discharges from acute hospitals;</p> <p>Reduced need for hospital admissions;</p>
Outcomes	<p>Little choice for people with complex care needs</p> <p>People institutionalised in unsafe environments;</p> <p>People isolated from their communities;</p> <p>People living at home in at-risk situations;</p> <p>Family carers under stress and not adequately supported;</p>	<p>People more in control of their situation;</p> <p>Enhanced community connectedness and less social isolation;</p> <p>More resource efficiencies;</p> <p>Better quality of life and well-being;</p> <p>Vulnerable older people better protected and safeguarded;</p> <p>A stronger social partnership approach;</p> <p>Building social capital in local communities;</p>

Our current system rests on familiar assumptions about the divide between community-based citizens and nursing home residents rather than on removing that divide. The dehumanising effects of the 'total institution' have been long since highlighted²⁰ with some institutions run for profit, rather than for the benefit of their inhabitants. Having to spend time (however short) inside institutionally organised buildings and systems continues to be an experience of living apart from the real life of family and community. This by its very nature, irrespective of the quality of care provided, frequently diminishes personhood and agency and undermines independence. The problem becomes all the more acute when nursing home care is contracted out to private providers who have little track record of helping people to build and maintain relationships, sustain family life or become active in their community.

²⁰ Goffman, E. (1961). Asylums: Essays on the social situation of mental patient and other inmates. New York: Anchor Books.

The alternative model envisaged is underpinned by the core principle of enabling people to live at home or in a place which feels like home. Congregated settings are totally at odds with this principle. Essential underpinning principles of the alternative model are:

- ✓ All services and supports grounded in the concept of strong community connectedness
- ✓ People provided with the kinds of support which most closely resemble what communities do 'naturally'
- ✓ Formal support in the community in the form of multi-purpose hubs with sheltered housing options that support ageing in place²¹ and 24-hour nursing units
- ✓ Meaningful and realistic guaranteed supports for families caring for older persons with support needs
- ✓ People with reduced decision-making capacity facilitated to make choice and to assert their will and preferences
- ✓ High levels of clinical governance and medical support in facilities where nursing care is provided
- ✓ A social enterprise approach which stimulates and supports local initiatives and builds social capital
- ✓ Private sector involvement based on a different model where partnerships with the State and with local social enterprises are embedded in provision.

1.5 Critical role of supported housing

In order to make community living work, we need many more sheltered and supported housing options as well as a range of in-house and community support services targeted and individually-tailored. In early 2019, the government published an important policy statement addressing a range of housing options for older people.²² The purpose of the statement was to provide 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".²³ 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".²⁴ 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,²⁵ 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

²¹ <https://alone.ie/wp-content/uploads/2018/07/Housing-Choices-for-Older-People-in-Ireland-Time-for-Action-1.pdf>

²² <https://assets.gov.ie/9398/ca553fa753b64f14b20e4a8dcf9a46ab.pdf>

²³ *Ibid.* p.25

²⁴ *Ibid.*

²⁵ https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/home_from_home_full_report.pdf

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.

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.

A Housing with Support Demonstration prototype is currently being implemented by Dublin City Council in collaboration with a number of statutory bodies and NGOs.²⁶ The 'Housing with Support' model is structured around three pillars.²⁷

- 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.

1.6 Commission on Care: Need to articulate a new vision

The proposed 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. Figure 1.2 provides an overview of the strands that need to be addressed by the Commission – integrated needs assessment, a continuum of provision, a single integrated support and care system, supported housing as the fulcrum of the system, local multi-purpose support and care 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.

The need for integrated needs assessment for people requiring long-term support and care has long since been acknowledged as is the need to provide equitable access to services in accordance with needs that will operate consistently and fairly across the country. Needs assessment criteria should be such as to enable the choice of the best and most appropriate long-term support and care option for individuals and include the following essential components:

- The level of dependency and/or needs of individuals in respect health, housing, social care and transport needs
- Establishing the will and preferences of individuals as to how the support and care they require should be provided

²⁶ These include the Department of Housing, Planning and Local Government as well as the Department of Health, HSE, Age Friendly Ireland and the Irish Council for Social Housing and ALONE.

²⁷ <https://www.housing.gov.ie/housing/minister-damien-english-announces-eu15million-housing-support-demonstration-project-st>

Figure 1.2: Components of a vision for long-term support and care



- Establishing the least restrictive means of providing support and care
- Establishing in a realistic and transparent manner the respective potential contribution of family members, community/neighbourhood networks and voluntary/community organisations
- Allowing for choice of provider where the services required are being purchased from private providers to enable people to choose those that best suit their preferences
- Establishing how best to link into statutory entitlement to public services

Critically, the HSE Single Assessment Tool (SAT)²⁸ must refer to all support and care options and must be extended to housing with a particular emphasis on people's supported housing needs to enable them to live in the community.

A continuum of provision²⁹ would include:

- Home support service in an older person's home e.g., Home Care Package commensurate with need
- Home sharing with registered and vetted tenants who provide basic support
- Co-located housing with 2-3 generations onsite in different units
- Foster families for older people who have no suitable family supports
- Supported independent living in dedicated housing units with 24/7 support and care available
- Care villages involving clusters of age friendly housing with strong supports for social interaction
- Cooperative housing and housing mutuals, where groups of older people pool resources and are able to share home support and care services
- Small communities of older people living in shared facilities with an element of shared services across a campus
- Residential nursing units located in multi-purpose hubs

The problems with the current two-tier system of care – one for nursing home care and one for care in the community – are obvious. For older people in Ireland, long-term support and care is divided up into a regulated statutory system (Nursing Home Support Scheme) for nursing homes for which co-payment is required and an unregulated non-statutory Home Support Service system which is currently free of charge. This distinction between care in the community and nursing home care is detrimental to the development of a continuum of support and care and must be eradicated.

As stated above, the role of supported housing in enabling people to age in place is critical and must be at the core of the new vision for long-term support and care.

There is growing consensus that long-term care services should look beyond a purely medical model of 'care'.³⁰ Instead, they should take a broader, more holistic view in which older people's well-being and quality of life and their preferences regarding support and care are central to the design of services in line with existing human rights standards. The development of local multi-purpose support and care hubs (with supported housing) as an integral part of town and village development should, therefore, be enshrined in a long-term support and care vision.

²⁸ <https://www.hse.ie/eng/services/list/4/olderpeople/sat/>

²⁹ Sage Advocacy Submission to COVID-19 Nursing Home Expert Panel <https://www.sageadvocacy.ie/media/1902/sa4dd3-1.pdf>
<https://www.sageadvocacy.ie/media/1902/sa4dd3-1.pdf>
Sage Advocacy Submission to the Oireachtas Special Committee on Covid-19 Response <https://www.sageadvocacy.ie/media/1893/submission-to-oireachtas-special-committee-on-covid-19-response-250520.pdf>

³⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5746722/>

A significant opportunity exists to contribute to providing services for older people within the existing budgetary framework and through more innovative configurations of services at local level. If the total amount of money available for different kinds of care for older people, within a distinct geographical area, was available for tendering by social enterprises, this would create an entirely different dynamic and would likely provide a stimulus for innovation and more effective use of resources. Social enterprise can build on four principles³¹ that are widely recognised as constituting the essence of quality in all public services:

- 1) Individualisation of support and care according to individual needs and preferences
- 2) Integrated networks of support and care in defined geographical areas
- 3) Innovation with regard to the nature and methods of service delivery
- 4) Ensuring accountability in the best use of resources and in delivering the best possible outcomes for citizens

The role of the family in providing long-term support and care is critical in Ireland as is the case in many other countries. In the context of the clear need to optimise the community support and caring infrastructure, further policy reforms should be introduced to reduce the financial and emotional pressures on carers. In particular, these should focus on addressing the stresses (financial, physical and emotional) experienced by many carers and their families alongside increasing the provision of respite care for carers and for those for whom they care. In this context, the 24-hour responsibilities of carers should be a central consideration.

The need for sustainability in long-term support and care financing is a crucial consideration in that delivering a continuum of care is not cheap despite the significant and frequently necessary contribution of family carers. As already stated, a new model of long-term care will require a basic re-thinking of how we approach its financing. Putting in place a sustainable long-term support and care financing system must form part of a new vision and requires active consideration by the Commission on Care. The basic question to be addressed is where and how is Ireland to find the money to pay for long-term support and care in an ageing society. This matter was addressed by Sage Advocacy in 2019 in a Discussion Document, *A New Deal*.³² This document argued that Ireland can and should aspire to a model of long-term support and care (e.g., Denmark) where the emphasis is on publicly funded long-term support and care provided for the most part in community-based settings. Building on international and Irish research, a number of possible options were set out in that document which require detailed and actuarial examination. 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.

³¹ Citizens Information Board Submission to Consultation on Draft National Social Enterprise Policy for Ireland 2019-2022 https://www.citizensinformationboard.ie/downloads/social_policy/submissions2019/National_Social_Enterprise_Policy_CIB%20Submission.pdf

³² https://www.sageadvocacy.ie/media/1538/sage-advocacy_summary-financing-long-term-care-in-ireland_2002019.pdf

An integrated response by health and local authorities to address the housing and support needs of older people should not be left to local initiatives or NGOs but should form a core component of Government policy. Innovative ways must be found to overcome the inbuilt blockages arising from silo funding by individual Departments. A critical question refers to the interface between housing need and health and social care support needs. There are many instances where making a distinction between the two in terms of resource allocation fails to acknowledge the multi-faceted support and care needs of the individual involved which cannot be compartmentalised.

The long-term support and care system should be deliberately biased towards home which is where the vast majority of people want to live, and to die. This is patently not the case at present. There is strong evidence, both anecdotally and from Sage advocates, that there are substantial numbers of people inappropriately placed in nursing homes against their will because of a lack of community-based alternatives. Nothing short of a single tier integrated system of support and care will prevent this and ensure that every older person who requires support and care gets it at a level appropriate to need and in accordance with their will and preferences. Most importantly, an integrated system is required to ensure that vulnerable older people are safeguarded irrespective of where they live.

The primary task of the proposed Commission on Care is to address the putting in place of an integrated framework to deliver policies and programmes about which there is broad agreement rather than a restatement of these policies and aspirations. This requires setting out a vision which includes an outline of an integrated model of long-term support and care and clear implementation benchmarking. Failure to do this can reasonably be viewed as a failure to take seriously the lessons of Covid-19 and its impact on vulnerable older people.

Section Two

Lessons for Long-Term Care from Covid-19: The Experience and Perspectives of Sage Advocates

2.1 Introduction

Sage Advocacy continued to provide services during the pandemic in the form of telephone and email contact with clients and services. Nursing homes and community care professionals were contacted to make them aware of this. For the most part, both nursing home and community care personnel continued to engage with Sage advocates around particular case issues as required. Sage Advocacy personnel also continued to engage with acute hospitals in relation to both individuals and matters around patient discharge and access for people with non Covid-19 health care needs.

At the end of April, Sage advocates were asked to record their experiences in their particular region during the Covid-19 pandemic from its onset and to continue to do this until the end of May. They were asked to outline their perspectives under the following headings:

- The response of public bodies with responsibility for managing Covid-19
- Nursing homes and other residential care facilities
- Community and home care
- Acute hospital care
- Media and reporting
- Access to independent advocacy
- Safeguarding matters
- The long-term support and care system

Responses were received from 20 Sage Advocacy personnel. While not all responses included information under all headings, the composite information provided overall was comprehensive and wide-ranging. However, it should be noted that there is an inherent data limitation in that the information provided by third parties was not reported directly to the researcher but was conveyed via Sage advocates. Notwithstanding this limitation, the data provides a rich and valuable information source. Importantly, the data is provided by people [Sage advocates] who are independent of the health and social care system. Sage advocates are also in a unique position of being able to follow a

person all through their support and care journey which enhances their perspectives regarding what unfolded during the pandemic.

The responses were returned by email and were analysed thematically by a researcher. This section of the Discussion Document presents the findings of this analysis under a number of general headings and sub-headings.

2.2 Nursing Home Care: Perspectives of Sage advocates

2.2.1 General observations by Sage advocates

Sage advocates noted that there was a clear perception that nursing home staff felt that nursing homes were forgotten at the outset of the pandemic.³³ The major focus by Government, the HSE and the Department of Health at the outset was seen as having been on preparing hospitals and Intensive Care Units, with nursing homes and the residential care sector generally being largely forgotten. The delay in testing in nursing homes was seen as a critical issue. Many private nursing homes had difficulty initially in getting PPE and nursing home staff were frustrated at a lack of clarity as to where responsibility for providing the equipment lay. Sage advocates reported receiving information about staffing issues from a number of nursing homes which subsequently reported that many of these were subsequently addressed by the HSE. Some nursing homes reported 'losing staff to the HSE'. Many nursing home staff contacted by Sage Advocacy reported being concerned and apprehensive about the future and the long term implications of the Covid-19 experience for both nursing home residents and staff.

2.2.2 Visitor restrictions

Many private nursing homes put in place visiting restrictions from early March. This had been recommended by Nursing Homes Ireland (NHI) on 6th March and was subsequently adopted as HSE and Government policy about a week later. The general consensus among Sage advocates was that nursing home residents were facilitated to remain in contact with relatives via video chats and proactive weekly updates from the nursing home.

While the need for visitor restrictions was clear, this presented major difficulties for nursing home residents, particularly those with reduced decision-making capacity, and their relatives. (Some two-thirds of nursing home residents are deemed to have some degree of dementia).³⁴ Sage advocates noted that Skype, Face Time and communicating through windows were simply inappropriate for many nursing home residents and, for some people, likely to add to their confusion, anxiety and distress.

2.2.3 Communication and information

Most nursing homes continued to liaise with and provide information to Sage advocates but some were reluctant to do so. In some nursing homes, staff stressed how busy they were but took the time to discuss Sage Advocacy clients. Other nursing homes were experienced as being more reluctant to engage in discussion about the broader challenges facing the nursing home. Sage advocates reported finding it increasingly difficult to get through to a small number of nursing homes. As the number of positive Covid-19 clusters in nursing homes rose, nursing homes were perceived by Sage advocates to have become more closed off with calls not being returned. This was seen as being related to a fear of, and perhaps anxiety, about sharing information. The point was also made that pressures on staff almost certainly resulted in phones being unanswered in some nursing homes.

³³ This perception referred principally to private nursing homes and it is not clear whether or not it was an issue in public nursing homes.

³⁴ https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/home_from_home_full_report.pdf

Nursing homes with websites (which many do not have) were reported as having varying levels of Covid-19 information available with links to the HSE website. Some nursing homes set up a group text messaging service for families of residents and advocates with ongoing cases in these nursing homes which provided updates on developments. Other nursing homes had pre-recorded voice messages with updates on Covid-19.

Overall, a mixed response by nursing homes to offers of support from Sage Advocacy was reported – some indicating the major difficulties they were facing on a daily basis, some not answering their phone and some saying that everything was fine and that they did not have any problems.

While the majority of nursing homes contacted by Sage advocates were very approachable and willing to engage, some nursing homes were less so once there were positive Covid-19 cases in the nursing home. Since nursing homes have no statutory obligation to engage with Sage Advocacy (or any other independent advocacy provider), a reluctance to communicate is a choice. In the Covid-19 crisis, it appears that contact with Sage Advocacy was curtailed by some nursing homes where such contact would normally have been acceptable and welcome.

The following additional points relating to communication with and information from nursing homes were identified by Sage advocates:

- It was difficult to find out which nursing homes had positive cases and some nursing homes appeared to want to keep information related to any positive cases quiet in order to avoid attracting public and media attention;
- There was a poor level of communication with relatives by some nursing homes regarding the status of the virus in the home – one case referred to Sage Advocacy was of a person seeking support to challenge a nursing home's lack of communication regarding the status of the virus in the home;
- There was a lack of clarity about which nursing homes were taking new residents and providing respite care;
- Nursing homes that did not have prior close connections with Sage Advocacy were difficult to reach at this time and Sage advocates felt that Sage Advocacy may have been perceived as being prying and intrusive rather than supportive.

Some nursing homes reported to Sage Advocacy being themselves unsure about whether or not families of residents in the nursing home should be notified that there were Covid-19 positive cases in the home and sought guidance from the HSE on the matter. [It is not known whether this reported requirement to seek clarity up the line from the HSE pertained to public nursing homes as well]. The Covid-19 Nursing Homes Expert Panel has recommended that meaningful communications with residents and families should take place regularly in relation to visiting protocols, changes in processes and explanations relating to same (Recommendation 13.1).

2.2.4 Personal Protective Equipment (PPE)

Shortage of PPE was reported to Sage advocates as an issue during the initial period of the pandemic with a divergence of views as to who was responsible for providing PPE – in other words a belief on the part of the HSE that private nursing homes should procure their own PPE and a view on the part of Nursing Homes Ireland that they were unable to do so without support from the HSE. Private nursing home staff reported being caught in the middle of this debate. The shortage of PPE affected some services much more than others and the distribution of PPE appeared to Sage advocates to be inconsistent. Some home care workers told Sage Advocacy that they had sufficient PPE while one DoN told a Sage advocate that they were told at one stage that they were not

regarded as a priority for PPE because they did not have any positive Covid-19 cases. While all areas of the broader health and social care sector suffered from a shortage of PPE in the initial period, it was not clear who had responsibility for supplying PPE to private nursing homes. As with staffing, there would seem to have been competition for resources before *ad hoc* collaboration between public health services and private nursing homes became the norm (see 2.2.10 below).

2.2.5 End-of-life care

End-of-life care in nursing homes presented additional difficulties during Covid-19 especially in relation to relatives not being able to visit. This was particularly difficult for families who were not able to have quality time with a loved one who was dying and who did not have Covid-19. Some families expressed concern to Sage advocates about how well pain was managed when they were not able to be present to monitor it. There was also a lack of clarity as to what was permitted in terms of being with a loved one at end of life.

Case Example: End-of-life care

A client with a dementia related illness died in a nursing home. The family are not happy as they were denied access to their loved one at end of life. Confusion took place in the communication to the family as to when and how many family members could visit at any one time. The nursing home had a death from Covid-19 the day before and stated that they were under pressure trying to protect both their residents and the family of the dying resident. The matter has resulted in a detailed complaint. “The family have asked that Sage Advocacy be involved in supporting improvements in the situation for other nursing home residents at end of life” (Sage Advocate).

On the positive side, webinars on end-of-life care organised by the Irish Hospice Foundation³⁵ were regarded by Sage advocates as very positive and helpful.

2.2.6 Isolation

The isolation of residents in their rooms was regarded by Sage advocates as giving rise to serious concerns in relation to residents with reduced decision-making capacity who did not understand the need to isolate and why they should be confined to their rooms which was not their normal experience. Isolation was seen as a particular concern for many smaller nursing homes, especially older homes with few single rooms and where residents had died from the virus. One nursing home reported that, while they had no Covid-19 cases to date, the GP had isolated a number of residents due to their regular respiratory condition. Staff in this nursing home reported to Sage Advocacy that they found this situation very difficult to manage.

Some nursing homes highlighted to Sage advocates the potential after-effects of restrictive practices – keeping residents in their rooms during the lockdown and exclusion of visitors. The risk of pressure sores and the decreased immunity they might have were highlighted as particular concerns. Also the mental health effects of being kept in one room for months could be enormous (see below), particularly for those with dementia. Some nursing home staff expressed worries to Sage advocates about the human rights of residents in situations where they were being confined to their rooms.

³⁵ <https://hospicefoundation.ie/wp-content/uploads/2020/06/IHF-Bereavement-and-COVID-19-Webinar-26th-May-2020.pdf>

2.2.7 Nursing home staffing and resource issues

A major issue reported to Sage advocates related to widespread staff shortages, especially once testing came in for both residents and staff. This resulted in many staff needing to self-isolate at home and nursing homes having to recruit agency staff. This was seen as compounding an already difficult situation as some of these agency staff worked in a number of different places of care in any given week. In addition, the use of agency staff was reported as creating additional stress and being disruptive for residents because of not personally knowing who was going to be caring for them on any given day or night. In practice and in order to meet HIQA requirements and to manage continuity of care, there were no alternative options available to nursing homes.

Private nursing homes also highlighted difficulties in attracting temporary staff citing the fact that HSE pay was higher than the nursing homes could afford. While the Covid-19 social welfare payment was a very positive and necessary move to support people who became unemployed, the question was raised by some Sage advocates as to what extent the payment contributed to low paid staff in the nursing home sector, e.g., care assistants and cleaning and catering staff, deciding to stay off work and apply for the payment.

A number of nursing homes reported to Sage advocates that during the initial phase of the pandemic, there was little or no support from the HSE in relation to staffing. Indeed, an observation made by some nursing homes was that the HSE had offered jobs to nursing home staff who had applied for positions previously, thus 'poaching' them from private nursing homes.³⁶ (It should be noted that the HSE stated that in the main private nursing homes were not a target for recruitment by the HSE).³⁷

The importance of not having to take in any staff from "outside" the nursing home was highlighted to Sage Advocacy by some nursing homes. In this regard, the Covid-19 Nursing Homes Expert Panel recommended that nursing homes should have a clear written back-up plan when regular staff cannot work or fail to turn up for work and that this should be incorporated into the nursing home's preparedness plan for review by HIQA (Recommendation 5.2). The Expert Panel also recommended that for the next 18 months (or until the declaration of the end of the Global pandemic by the WHO), staff employed by a nursing home should be precluded from working across multiple sites and adequate single-site employment contracts should be put in place to support this (Recommendation 5.6).

Pressures on nursing home staff

Some Directors of Nursing in private nursing homes who engaged in information-sharing with Sage advocates stated that they felt isolated and alone and without clear direction. They also became overwhelmed with additional paper work (NHI guidance information, HIQA reporting, applications for grants for PPE). Sage advocates had a sense of nursing home staff becoming exhausted because of the additional workload due to staff shortages. There was also the fact that staff were becoming increasingly anxious and worried about themselves, the people in their care and their families and were on high alert coming to work every day. Some DoNs reported being very fearful at times as they struggled to protect residents and staff and to reassure relatives. "I got the impression that they were just about keeping their heads above water" (Sage Advocate). One DoN was quoted by a Sage Advocate as stating that the workload on DoNs working over 12-hour shifts regularly was simply not sustainable going forward.

³⁶ See also https://data.oireachtas.ie/ie/oireachtas/debateRecord/special_committee_on_covid-19_response/2020-05-26/debate/mul@/main.pdf p.29

³⁷ *Ibid.*

2.2.8 Good practice in nursing homes

While there were many issues and difficulties that arose in nursing homes because of the pandemic, there were also good stories. Indeed, some nursing homes told Sage advocates that they were receiving good support from the HSE and local GPs in the care of residents. Some Sage advocates reported having conversations with residents in nursing homes who were very happy with the care that they received during the crisis. There were a number of examples of good practice in nursing homes reported to Sage Advocacy:

- A rapid access team was set up in one nursing home to react to a Covid-19 confirmed case in the home.
- Three separate dining rooms (for its 20 residents) were set up in one nursing home to facilitate social distancing
- Existing rooms were converted to ensure that each resident had their own room by making use of, for example, an office, a chapel and a hairdresser's room as additional bedrooms.
- Another nursing home instigated a Covid-19 testing system for a staff panel that they might need to draw on as the pandemic evolved.
- Good practice was reported in an instance where in the case of death of a resident from a non Covid-19 complication, a room was set up downstairs where the family could have access without needing to enter the rest of nursing home.

2.2.9 Poor practice in nursing homes

Some instances of poor practice were brought to the attention of Sage Advocacy, as illustrated in the Case Example which follows. This case has also been reported in the media.³⁸

This case was seen by Sage Advocacy as disturbing and as highlighting very poor practice and as begging the question as to whether there are similar instances in other nursing homes. It is not clear how much of the failure in this instance was related to pressures arising from dealing with Covid-19 and associated deaths in the nursing home. However, notwithstanding the need to 'make allowances' for some shortcomings which might follow such pressures, this case was seen by Sage Advocacy as raising fundamental issues of great concern, including:

- The quality of care provided and the effective neglect of residents
- The lack of clear clinical governance in and oversight of nursing homes and the inability of the HSE to directly intervene, either through safeguarding or clinical approaches
- The lack of regular assessment and early attention to specific needs which would have prevented deterioration and stimulated referral to ameliorative services
- The inability of the regulator to engage directly in a timely manner with the serious issues presented

³⁸ <https://www.irishtimes.com/news/health/covid-19-tragedy-of-terrible-dimensions-as-woman-loses-husband-and-son-1.4296757>

Case Example: Concerns regarding the care of two nursing home residents

The case of two nursing home residents (since late 2018/early 2019) was brought to the attention of Sage Advocacy by Person M.³⁹ The two residents are a father (Person U) and step-son (Person A) (both now deceased) who were sharing a room. The father was 79 years old with severe dementia and a recent diagnosis of facial cancer and his son was 52 years old, had Down's Syndrome and also had dementia.

The issues identified in this case which are of concern are:

1. Person A was sent to an acute hospital with pneumonia in mid-March, tested negative for Covid-19 and was returned to the room he shared with his father in the nursing home. This was a matter of serious concern as the nursing home already had a cluster of suspected Covid-19 cases and A, having pneumonia, was then displaying symptoms of Covid-19. It is clear that precautions should have been taken to isolate Person A from other residents, especially his father who has dementia and with whom he shared a room. The nursing home involved clarified to the local HIQA inspector that they had no other choice but to put the resident back into the shared room as there was no other room available. When A returned to hospital on 27th of March, he was seriously ill and tested positive for Covid-19. He died on 31st March.
2. The Sage advocate involved was aware of reports of Person U 'wandering the halls' of the nursing home for weeks after his son's death in hospital while awaiting the results of his Covid test, which also proved positive.
3. It took two weeks to have Person U assessed by a GP and this only after sustained pressure by his wife, Sage Advocacy and a HSE social worker (The nursing home claims that the GP visited Person U 6 days after the initial complaint was made by Person M).
4. Person U was admitted to an acute hospital (where he subsequently died from sepsis) with seriously infected (and infested) head wounds relating to his condition. Pictures of U's face which evidenced neglect and inadequate personal care, were shown to Sage Advocacy by U's wife and, also, to HSE Primary Care Social Work and to the HSE Safeguarding & Protection Team.
5. Person M told Sage Advocacy that prior to the above, she had wished to make a complaint about the care her husband and son were receiving in the nursing home but had been discouraged after a staff member told her directly that they hoped that she was not going to make a complaint against them. She had also been advised by the Director of Nursing that both residents could be asked to leave the nursing home if she continued to make complaints.

The following further aspects of the above case were highlighted by Sage Advocacy:

- Delay in having a GP assessment carried out
- The lack of regular assessment of Person U to recognise the impact of his behaviours in creating and exacerbating wound complications
- Poor communication by the nursing home management to both Person M and to Sage Advocacy

³⁹ This case was reported to Sage Advocacy by the older resident's wife who expressed a wish to Sage Advocacy that the issues around the way both of her relatives were treated by the nursing home be put into the public domain.

- Concerns formally escalated to HIQA by Sage Advocacy on four separate occasions regarding poor practice and the extreme neglect of Person U not resulting in any action that led to person U receiving prompt and adequate treatment
- Poor protocols between the nursing home and the acute hospital
- Concerns about this case previously flagged by the HSE Safeguarding and Protection Team to HIQA not fully addressed in a timely manner
- The need for more effective collaboration and liaison between safeguarding services, nursing homes and acute hospitals
- The limitations of HIQA to investigate any individual case in a nursing home and the fact that effectively there is no formal existing channel for this purpose.

In a statement to the media⁴⁰ relating to the case, the nursing home extended their sincere condolences to the family on the deaths and stated that it was not appropriate to go into clinical detail relating to any resident or their treatment. The nursing home stated that they had submitted a report to HIQA and were awaiting the outcome of a further review. The statement noted that the nursing home, like many others, had been under acute pressure in the midst of the pandemic and its managers and staff had worked extremely hard to deliver the best care for all of its residents and continue to do so. Matters and issues relating to this case are the subject of ongoing review and discussion.

2.2.10 Private nursing homes in the overall long-term care system

Sage advocates through their work and through media reports became aware early on in the pandemic of the tension between private nursing homes and the HSE particularly regarding the role of the HSE as a provider of PPE to private nursing homes and in addressing the clear shortages of staff in these homes. The nursing homes were represented as 'for profit' bodies who should look after their own PPE while NHI believed that the HSE was negligent in not providing PPE to private nursing homes. It should be noted that the issue of PPE availability was largely impacted on by the fact that the market was emptied of supply and that the HSE as a bulk buyer could command priority purchasing.

According to Nursing Homes Ireland (NHI), nursing homes did not get the support that they had been looking for and, if they had, they would not be in the position they were in.⁴¹ An alternative view expressed by Sage advocates was that, had private nursing homes the proper care, good management and planning in place, they would not have found themselves in this situation. However, it should be noted that apart from countries who learned from SARS, having the required bulk of PPE in place to deal with Covid-19 was a common issue globally, particularly at the beginning of the pandemic.

The initial unilateral decision taken by NHI to restrict visitors was seen by Sage advocates as giving the impression that private nursing homes had a plan and were in control of the situation. This clearly turned out not to be the case. While nursing homes were not in a position to go it alone, on the other hand, as it emerged, the Department of Health and HSE did/do not have sufficient linkages with the sector. This was regarded as a critical factor.

A key question raised by Sage advocates was who held the public health responsibility for nursing homes. Not having a direct link with nursing homes, the HSE and the Department of Health relied on HIQA which, while having an important regulatory and inspection role in respect of nursing homes, may not have the in-depth insight as to what the shortfalls would be in the event of a pandemic such as Covid-19.⁴²

⁴⁰ <https://www.irishtimes.com/news/health/covid-19-tragedy-of-terrible-dimensions-as-woman-loses-husband-and-son-1.4296757>

⁴¹ https://data.oireachtas.ie/ie/oireachtas/debateRecord/special_committee_on_covid-19_response/2020-05-26/debate/mul@/main.pdf

⁴² *Ibid.*

It would appear that prior to Covid-19, HIQA did not have a public health responsibility in relation to nursing homes. While this was clearly a sharp learning curve for all involved, the view of some Sage advocates was that Directors of Public Health Nursing who manage community services within a defined geographical area would have been much better placed to provide practical and clinical support to the nursing homes in their patch and, thereby, discharge the public health responsibility more effectively than was the case.

There was a perception on the part of Sage advocates that, at least initially, the promise of support staff from HSE was not adequately delivered. There was a sense that during the early stages of the pandemic the HSE provided oversight from its medical advisors but did provide care assistants or replacements for the latter when they became ill or took time off work to reduce the risk of infection.

2.2.11 Reported reaction to HIQA Checklist for preparedness of nursing homes

Sage advocates reported that the HIQA self-assessment⁴³ and protocol guidelines for residential settings initiative was perceived negatively by some nursing homes in that they saw HIQA's regulatory and inspection role as not lending itself to taking on a supportive role. While some nursing homes found the HIQA Checklist useful, the view, as reported to Sage advocates, was that it came much too late. HIQA's intervention was regarded as reactive rather than proactive since it was April 18th before HIQA was designated as the body responsible for assessing nursing homes' readiness to deal with the pandemic and April 21st before the Checklist was issued. This was six weeks after the decision to restrict visitors to nursing homes was introduced. Sage advocates also reported that some nursing homes considered this as another paper-based requirement in an already stressed workplace.

While it was acknowledged that HIQA plays an important role in monitoring standards in nursing homes, some nursing homes told Sage advocates that without immediate resources to put in place HIQA recommendations, its usefulness in the Covid-19 crisis was somewhat limited. On the positive side, Sage advocates noted that in instances where they brought issues to HIQA's attention, HIQA staff encouraged families of nursing home residents to contact them with any questions or concerns.

2.3 Discharges from hospital: Perspectives of Sage advocates

The overall perception of Sage advocates was that a cohesive response was put in place by acute hospitals in response to the crisis. This resulted in significant efforts to make as many safe discharges of patients as possible in preparation for an expected influx of Covid-19 patients. However, it was felt that in the absence of a robust testing system, it is most likely that there would have been some transfers of Covid-19 positive patients back to the community as well as to nursing homes. The asymptomatic nature of Covid-19 in vulnerable older people was not understood in the early stages of the pandemic. This point was highlighted by the Oireachtas Special Committee on Covid-19.⁴⁴ It should also be noted also that there is some commentary about a higher than normal false negative in Covid-19 testing.⁴⁵ The Covid-19 Nursing Homes Expert Panel recommended that all new nursing home residents coming from the community or proposed transfers from hospitals should be tested for Covid-19 prior to admission (Recommendation 4.1).

Sage Advocacy became aware of Home Care Packages being allocated where previously there had been difficulties and blockages. Also, people were transferred to nursing homes on transitional

⁴³ <https://www.hiqa.ie/sites/default/files/2020-04/Assessment-framework-DCOP-covid19-preparedness.pdf>

⁴⁴ https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/special_committee_on_covid_19_response/reports/2020/2020-07-31_interim-report-on-covid-19-in-nursing-homes_en.pdf

⁴⁵ <https://www.npr.org/sections/health-shots/2020/04/21/838794281/study-raises-questions-about-false-negatives-from-quick-covid-19-test?t=1594981639899&t=1600698895063>

funding without an NHSS application being completed. The typical 'delayed discharge' cases associated with waiting for a HCP or nursing home funding was no longer an issue. Sage advocates suggested that this flexible discharge approach should be looked at in more depth after the crisis and some learning gained from it. The question was raised as to whether patients actually needed to remain in hospital until the NHSS application process was fully completed.

2.4 Home care supports: Perspectives of Sage advocates

Sage advocates reported finding it difficult to get a full picture of what was happening in relation to home care supports. On the one hand, there were instances of people being discharged from acute hospitals with Home Care Packages (HCP) that were adequate. For example, one person known to Sage Advocacy received a HCP of 27 hours a week which was unprecedented in the area, the normal cap previously being 14 hours. On the other hand, there were instances where home care was either significantly reduced or withdrawn.

Some home care providers indicated to Sage Advocacy that they lost a significant proportion of their carers (25% in one case) due to people opting out of work because of the Covid-19 Payment (€350 a week) or child care issues or both. Another instance reported to Sage Advocacy was home help having to be refused to new applicants due to home helps being out sick, on leave due to fear of picking up Covid-19 themselves or infecting family members with underlying conditions

Case example: Withdrawal of home care

A family reported that their older parents were having homecare withdrawn after their GP suspected the father of having Covid-19 and referred him for testing. His wife also had her care withdrawn as a result. The homecare company contracted by the HSE to provide the care told the relatives that care was withdrawn because no agreement had been reached with the HSE in respect of personal protective equipment, indemnity and training. This was brought to the attention of the NPHE Vulnerable People Subgroup where it was decided that the Department of Health members of the general NPHE would follow up on the matter. The father subsequently received a negative result for his COVID-19 test and care was then restored to him and his wife. "The family still want to have contact with NPHE to share their experience but we do not know whether this has happened or not" (Sage Advocate).

The overall impression of Sage advocates was that home support services remained in place for people who had medium to high needs, including those who had suspected or confirmed Covid-19. However, in some other situations, people with low support needs had some services reduced or withdrawn. This was usually done after consultation with the person and their family. Alternative supports were provided to many people in that situation through the Local Authorities and other voluntary supports. It was noted (as also highlighted in the media) that in many areas community services came together and set up systems for checking in with older and vulnerable people in the community who in some instances would not have been in receipt of any services. However, Sage advocates became aware of some instances where this did not happen and there were a number of referrals to Sage Advocacy in respect of families who had not been linked into any community services prior to Covid-19 and not known to the PHN in the area but who now needed assistance.

Some home care providers indicated to Sage Advocacy that people had requested that the number of calls to their home be reduced or the package suspended entirely due to Covid-19 concerns. In some such cases, family members took on the role of providing the support required. However, it was also brought to the attention of Sage Advocacy that this cancelling of the home care occurred in some instances without any prior discussion with the person receiving the support and without

their consent. This was regarded by Sage advocates as a serious matter and an effective denial of a person's right to choose.

Some Sage Advocacy clients who had returned home from hospital against advice to go to a nursing home reported that they were most grateful that they are in their own environment where they felt safe. They stated that they felt that the support they were receiving had improved during the Covid-19 crisis and expressed the hope that this would remain the case into the future.

Case Example: Level of Home Care Package provided

Sally was advised that she needed 24/7 care for a safe discharge from an acute hospital. This requirement was reduced to 2 carers x 1 hr x 4 times a day x 7 days a week (8hrs x 7 days = 56hrs a week) along with the support from the family. It was not at all clear that the level of family support required could be sustained long-term which raised the prospect of nursing home care becoming the only option available in the future.

While many positive initiatives were put in place, there was a general perception by Sage advocates that supporting people living at home could have been done much better. Engagement with families by home care providers in exploring options, while satisfactory in some instances, was less so or non-existent in other cases. Home care providers, regardless of whether HSE or private, should, according to Sage advocates, have been able to assure families that they could meet all the health and safety and PPE requirements. This did not always happen and some families were left uncertain, frightened and forced into making decisions to carry out care that in some cases was beyond their capacity and impacted negatively on the wellbeing and mental and physical health of the whole household.

Poor quality home care was also brought to the attention of Sage Advocacy. Some home carers indicated to Sage advocates that they had 30 calls in a week to different houses but had only 1 face mask and were told to save it for anybody that had Covid-19 symptoms.

Case Example: Poor practice in home care provision

Helen moved out of a nursing home at the start of the pandemic to be cared for at home by her daughter. The daughter reported to Sage Advocacy that in 3 weeks she had 7 different carers. They were not wearing face masks. One arrived in a dirty uniform. She made a complaint to the provider and this did not happen again.

Some people working from home or who were off work and providing care to a relative told Sage advocates that they were worried that the HCP would be taken away if it was indicated that outside carers were not needed in the short-term. "Therefore, some families were asking carers to call but not to enter house" (Sage Advocate). Sage advocates noted that this may have had the unintended consequence of further isolating the person receiving the support.

While in many instances, families took over the provision of support and care because of fear of bringing infection into the home, Sage advocates highlighted a major concern as to what would happen as family members return to work, experience burn-out or tensions arise between family members not usually spending so much time in a caring role.

The Covid-19 experience was perceived by Sage advocates as further highlighting the inherent deficiencies in the community care infrastructure. It was pointed out that many nursing home residents (at increased risk of exposure to the virus) would not have been in that situation if there

had been realistic support and care options available to them in their own homes. The impact of the pandemic in nursing homes should reinforce the point that more people should and could be cared for and supported in either their own homes or in local-based small-scale sheltered/supported housing complexes.

2.4.1 Key points relating to home care identified by Sage advocates

- ✓ While there was some evidence of families taking their relative out of nursing home to be cared for at home during Covid-19, there was also evidence of family members blocking discharge home due to Covid-19 concerns.
- ✓ There was some evidence of families refusing access to home carers because of fear that they might be carrying the virus but be asymptomatic.
- ✓ Many home carers were not working because of fear of contacting the virus -- this made it difficult to have a consistent service.
- ✓ There was an additional difficulty for some people arising from having multiple carers, many of whom were not previously known to them.
- ✓ The non-availability of respite/day services put enormous stress on families and further isolated vulnerable older persons.
- ✓ Home Care Coordinators prioritised the allocation of care assistants to those who did not have any family support.
- ✓ The need to replace formal home care with phone contact presented a major difficulty for people with an intellectual disability who did not understand the need for social distancing.

2.5 Public Health Nurses during Covid-19: Perspectives of Sage Advocates

The potential role of public health nurses (PHN) in responding to the crisis at community level was perceived by Sage advocates to have been undermined by the redeployment of some PHNs to testing centres. PHNs were asked to review their caseloads, close cases where possible, reassess individuals' needs and to reduce direct contact with people in their homes. It was noted that PHNs could also volunteer to be redeployed to public nursing homes, in order to allow the staff in public nursing homes to assist in private nursing homes. It was also confirmed to Sage Advocacy that in one area the PHN team was down a number of staff members due to Covid-19. PHNs continued to provide telephone support to patients. However, they were, as far as possible, avoiding face to face meetings with patients and keeping essential visits as short as possible which was sometimes very difficult when a person had complex nursing care needs.

The majority of PHNs who were in contact with Sage Advocacy were perceived by Sage advocates as being overly stretched with some stating this explicitly. Others were less inclined to engage with Sage advocates. A critical issue for PHNs during the early stages of the pandemic highlighted to Sage Advocacy was their inability to source PPE for themselves or for their patients who needed it.

Case Example: Impact of insufficient PPE

Two people returned to the community and PHN and home care support was provided. However, staff did not have sufficient PPE, no testing had been done prior to discharge and one person tested positive for Covid-19 after returning home. This in turn resulted in a loss of home care workers and PHN who had to go into isolation for 2 weeks.

Based on feedback from PHNs, the following were identified by Sage advocates as matters which impacted on PHNs:

- The majority seemed to be overstretched with some stating explicitly that to be the case;
- Some PHNs only visited homes in respect of 'urgent issues' – palliative care patients, people who need wound attention and mothers with new babies;
- There were reports of PHNs lacking adequate PPE;
- PHNs were not allowed to spend more than 15 minutes in a person's home – this meant, for example, that a HCP assessment could not be properly conducted.
- Some PHNs expressed concern about individuals returning to community from hospital without having been tested for Covid-19.

2.6 Media and reporting: Perspectives of Sage advocates

Some nursing home staff told Sage Advocacy that they were very concerned about their nursing home being caught up in the media frenzy and being on 'front pages of the papers' where the message might go out that they were non-compliant and failing to deal adequately with the Covid-19 threat even though they had no cases and were managing the challenge well. The media was seen by some nursing home staff consulted by Sage Advocacy as not being helpful in that it tended to focus on the negative rather than the positive. While it was acknowledged that the unpreparedness of nursing homes should be highlighted, there was also a need to highlight the fact that some nursing homes dealt with the challenge well. Also, some nursing homes told Sage Advocacy that, while they floundered initially, they soon got on top of the situation and that this was not reflected in media coverage.

A concern was also expressed by Sage advocates that the focus on Intensive Care Units and available hospital beds in the daily media reporting was almost certainly likely to have resulted in people with conditions that needed medical intervention putting off going to a hospital. This may have had significant consequences for older people who, as reported to Sage advocates, decided that there was no point in going to a hospital and/or that it was unsafe to do so. The initial media focus on inadequate PPE and the daily news reporting was seen by Sage advocates as having created or amplified people's fears about the dangers of going to their GP or to a hospital. The media focus may have inadvertently communicated a message of GP surgeries and hospitals being places to be avoided. This happened despite counter-messages coming from Government that people should contact their GP and/or hospital if they had specific symptoms or conditions that concerned them.

The widespread speculation in the media that large numbers of patients were discharged from acute hospitals to nursing homes to prepare for the Covid-19 surge almost certainly resulted in adding to the already negative image of nursing homes and a perception that they were being made 'warehouses' for Covid-19 patients with all the associated risks. Media reports of nursing homes being short staffed due to workers moving to the HSE for better pay, while, perhaps, factually correct, put further stress on relatives of nursing home residents.

Some Sage advocates expressed concern about a line of reporting which, perhaps unintentionally, communicated a message that may have had a very negative effect. Typically, figures for the number of deaths that occurred on any given day were accompanied by the statement that the median age of those who had died was late 70s or 80s and/or that many had an underlying condition. This additional information, while almost certainly being a source of solace for the vast majority of the population who are fit and well and below that median age, may, according to Sage advocates, have subliminally sent out a message about how we view our older people or those who have an underlying condition. "Many people with disabilities have underlying conditions and have felt very strongly about this almost 'throw away comment'" (Sage Advocate).

2.7 Mental health issues arising from Covid-19: Perspectives of Sage advocates

Sage advocates highlighted the significant challenges faced by people with mental health difficulties during the pandemic. Their situation was compounded by the fact that normal support and counselling services for those living in the community had to be put in abeyance. People with dementia understandably were becoming more and more agitated due to lack of social interaction and routine. In addition, vulnerable adults generally who were 'locked down' during Covid-19 were seen as almost certainly experiencing heightened anxiety coupled with fear of infection. The increased burden of care on many families arising from the suspension of home care provided by outsiders, the non-availability of day care centres and other respite services was undoubtedly stressful for these families. Since people were not availing of GP services as regularly as before there was, according to Sage advocates, a strong possibility that many vulnerable people were not seeking or receiving the support that they needed to deal with this new situation.

From an early stage in the pandemic, some relatives of people in nursing homes reported to Sage Advocacy that they struggled to cope with not being able to visit their loved ones. This, coupled with the fear of losing a loved one or a close relative being left to die alone added to their level of stress.

The potential mental health impact on health care professionals working in Covid-19 environment was also highlighted by Sage advocates.

While information booklets were distributed to every household that provided contact numbers for mental health support services, some people were unaware of these booklets. The Mental Health Commission reported⁴⁶ that it was in contact with the 65 approved in-patient mental health units since the beginning of March in relation to plans to deal with the virus. The Commission reported that it was supporting the HSE by identifying risks at these facilities, so that, where necessary, immediate and effective action can be taken. Sage advocates had little awareness of whether or not, or to what extent, these initiatives had outreach to the community.

Mental health difficulties and possible post-traumatic stress disorder were seen by Sage advocates as potentially being a huge issue in nursing homes following the pandemic – for residents, nursing home staff and families. There was a clear need for additional counselling supports going forward for people in residential care facilities, health care staff generally as well as families in dealing with grief and coming to terms with what for many was a horrific experience. It was suggested that there was a particular need to focus on nursing homes (public and private) that had been identified in HIQA inspection reports as carrying significant risks.

⁴⁶ https://www.mhcirl.ie/About_Us/Covid-19/Covid-19.html

2.8 Safeguarding issues

Sage advocates highlighted some safeguarding issues related to Covid-19. For example, a case brought to the attention of Sage Advocacy referred to a family who did not want their relative to come home, citing Covid-19 risk as a reason to stay in a nursing home. This was despite the risks of infection being higher in the nursing home. The nursing home feared a Covid-19 outbreak and was trying to encourage people who could go home to do so.

Sage advocates expressed the view that the HSE Safeguarding and Protection Teams were not as vocal as they might have been in relation to the safeguarding of vulnerable adults in the current crisis. This was seen as especially relevant where families were taking on additional caring roles and where there was less engagement by outside professionals and more involvement by volunteers not all of whom would have gone through a vetting process. Some of the Safeguarding and Protection Teams told Sage Advocacy that they only had skeletal staff (e.g., one social worker in each county) and that there were a high number of referrals coming in. Some of these were reported as referring to situations where no outside carers were coming into the home. The Safeguarding Teams were only working on most urgent priority cases, working over the phone and other cases were being put on a waiting list.

2.9 Additional observations on practice during Covid-19 made by Sage advocates

Some specific positive responses during the crisis were identified by Sage advocates:

- ✓ Additional nurses and midwives were rapidly added to the nurses' register;
- ✓ Some Sage Advocacy clients aged over 70 years living in the community reported receiving calls from their GP to check in on them;
- ✓ Notwithstanding the bigger systemic issues, many social and health care personnel worked assiduously to find solutions and appropriate responses for individuals;
- ✓ Hospitals worked on getting communication right in order to minimise stress on families;
- ✓ Hospitals worked on getting communication right in order to minimise stress on families;
- ✓ There was an increased interest in and a growing awareness among service providers of the limited role of 'next of kin;'

There were also some specific shortcomings identified by Sage advocates:

- Shortage of administrative staff in some hospitals resulting in delays in important letters being sent out;
- Social workers finding it difficult to have proper conversations with people because of having to wear PPE;
- Poor communication by hospitals with relatives in some instances which heightened anxiety among families through not knowing how their relative was.

2.10 Overview of Sage advocates' perspectives

While Sage advocates had some difficulty in capturing the total picture in their catchment areas and while there were notable divergences in practice between different CHO areas, the main picture that emerged from the feedback was that there were positive elements in the response of health and social care services and, especially, by local communities. The major focus on the role of the acute hospital in responding to the pandemic put pressure on hospitals to discharge patients/older persons back home or to nursing homes. In contrast to the situation prior to Covid-19, funding for such discharges was easily accessible throughout the pandemic.

The extent of the virus and related deaths in nursing homes was seen as a major shortcoming in our long-term support and care system. Issues at the beginning with PPE provision undermined the care system in both nursing homes and in the community. There were issues around people refusing home care services due to concern that home care workers would bring the infection into their home. The inability of Government to find a solution to the child care needs of frontline health and social care staff (mostly women) exasperated an already very stressful situation.

The hope was expressed by Sage advocates that the 'thinking outside the box' type of support that underpinned much of the Covid-19 response to home care would continue following the crisis, in particular, how simple measures such as having someone to collect prescriptions and drop off groceries can make all the difference in keeping someone living at home.

There was a perception that preparation by the nursing home sector (public and private) for what was well known at the outset to be a very infectious disease was inadequate.

- ✓ Additional nurses and midwives were rapidly added to the nurses' register;
- ✓ The fact that the HSE does not normally have a direct relationship with private nursing homes was seen as a matter of huge concern which needs to be addressed.
- ✓ There was a significant underestimation of the potential effects of Covid-19 on nursing home residents.
- ✓ Concerns were identified in respect of vulnerable adults who were at home with family members full-time where there was no external oversight and which could potentially give rise to safeguarding issues.
- ✓ Some people were discharged to a home environment that was not conducive to their care in that their family was not supportive because they feared that this arrangement would become long-term and that they could not sustain it.
- ✓ The lack of childcare for essential health care workers was identified as an ongoing issue which put further stress on individuals and resulted in some people having to opt out of essential frontline work.
- ✓ The pandemic highlighted a major flaw in the current safeguarding and protection system where safeguarding and protection teams have no right of entry to private nursing homes.

- ✓ The lack of right of access by independent advocates to nursing homes meant that Sage advocates were unable to offer any support to residents in some nursing homes who had been referred.
- ✓ There were concerns about situations where home care had been put in place as part of protection and safeguarding measures and where families had now stopped home care workers going into the home.
- ✓ There were situations reported where family members had asked the home carers to cease visiting without any consultation with the older person who was the care recipient.
- ✓ Some nursing home residents were particularly affected where the design of buildings was not conducive to respectful social isolation.
- ✓ The isolation, lack of physical contact with relatives and friends coupled with fear and anxiety almost certainly impacted on the mental health and well-being of many nursing home residents.
- ✓ The fact that the majority of medical appointments were cancelled or suspended, e.g. cancer treatments, diabetic retinopathy, was regarded by Sage advocates as having potential long-term effects on people.
- ✓ The understandable fear that people had of going to an acute hospital led to uncertainty and anxiety as they continued to live with conditions that they knew required hospital intervention.

Finally, it is noted that many of the issues identified by Sage advocates have been highlighted in the Oireachtas Special Covid-19 Interim Report and in the Covid-19 Nursing Homes Expert Panel Report.

Section Three

Sage Advocates Perspectives: Synthesis of Long-term Care Issues Identified

3.1 Introduction

This section draws on the feedback from Sage advocates to identify a number of overarching factors relating to both the policy response to Covid-19 and the overall long-term support and care infrastructure which came under the microscope during the pandemic. Sage advocates are well placed to have a good insight into the landscape within which long-term support and care policy has operated to date and its inherent shortcomings. The Sage Advocacy experience over the years has been one where gaps in the long-term support and care infrastructure have regularly undermined people's access to quality long-term support and care of choice. The Covid-19 experience clearly points to the need to put a different shape on the architecture of long-term support and care policy going forward. It showed the dire consequences of our over-reliance on nursing homes while at the same time highlighting the clear advantages of easier access to home care for people heretofore trapped in acute hospitals.

3.2 The 'architecture' of long-term care

Sage advocates highlighted the fact that Covid-19 placed significant additional pressures on a long-term care system that was already under stress. Private nursing homes were under-staffed, lacking in clear clinical governance and without adequate oversight. While the view of Sage advocates was that some nursing homes coped adequately with the crisis, others were perceived as not having done so for the various reasons outlined earlier.

The growing reliance on the 'for profit' sector for nursing home care has been highlighted by both politicians and the media during the Covid-19 pandemic. A centrally important question highlighted by Sage advocates is the pressure on private nursing home operators to cut costs, increase profits, pass on charges and employ a low-paid work force. At a more basic level, however, the important point was made by Sage advocates that the current architecture for long-term support and care (with its high reliance on residential nursing home care) is basically flawed.

A key question raised by Sage advocates related to people in nursing homes being in a high Covid-19 risk environment when they would not have been there in the first place if there was a comprehensive and integrated home support system in place. The Covid-19 experience brought this reality to a head and points to the need for a fundamental review of the current system.

The lack of funding for HCPs prior to Covid-19 was contrasted with the approach adopted at the onset of the pandemic. Recipients and families, while welcoming this in most instances, were apprehensive as to whether this level of support would continue post Covid-19 and feared that they would be back to the drawing board and having to 'fight' again for services.

3.3 Adequacy of policy response

The extent and quality of the support provided in different CHO areas is difficult to assess. Feedback from Sage advocates indicated that at the beginning of the pandemic, in some instances, the HSE had difficulty in getting staff on the ground into nursing homes which was clearly required from the very start. While management support and supervision was available and extremely important, it was not the type of immediate response required in some instances as staff had to go off sick and ratios were down. This was seen as putting the wellbeing, safety, health and ultimately the lives of people at even further risk. Despite such shortcomings, it is clear that the HSE support initiative had a lot of positive aspects and that these should act as a template for the provision of integrated supports to nursing homes in the future. The Oireachtas Special Committee on Covid-19 concluded that the formation of Covid-19 response teams had a positive impact in supporting nursing homes staff and residents⁴⁷ and the Covid-19 Nursing Homes Expert Panel found that these teams have been critical and must remain in place and be standardised in terms of operation and composition (Recommendation 1.2).

Many health and social care workers clearly worked hard in difficult circumstances both at the frontline and working from home in various support roles. However, this response needs to be juxtaposed with the overall response at the systemic level. In particular, the single focus at the outset on making space available in acute hospitals to treat Covid-19 cases almost certainly resulted in extremely vulnerable people being discharged to the community without adequate planning and others being transferred to nursing homes contrary to their will and preferences. As one Sage advocate reported in relation to two people discharged back into the community, "There was no planning, community care social work said they couldn't take it on and safeguarding [HSE Safeguarding and Protection Team] have picked up the pieces and liaised with Sage Advocacy as required".

It quickly emerged during the response to the crisis in nursing homes that it was not at all clear who was ultimately responsible for clinical care in nursing homes. There are no HIQA standards with regard to the levels and skills required for nursing home staff and the level of medical cover required in nursing homes. Staff pay and living conditions may be an important barrier to effective infection controls, particularly if staff do not have access to sick pay or need to work in multiple facilities, or live in shared or crowded or accommodation.

The lack of legislative entitlement to or regulatory framework for home care services and the inadequate supply of Home Care Packages resulted in a situation where people were already unnecessarily in a nursing home or transferred there at the outset of the pandemic. This put people at a higher risk from Covid-19.

3.4 Impact on families taking on additional care responsibilities

Home care providers, regardless of whether HSE or private, should have been able to assure families that they could meet all health and safety and PPE recommendations. Without this, families were left uncertain, frightened and forced into making decisions to carry out care that in some cases was beyond their capacity and impacted on the wellbeing and mental and physical health of others in the family.

⁴⁷ https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/special_committee_on_covid-19_response/reports/2020/2020-07-31_interim-report-on-covid-19-in-nursing-homes_en.pdf p.37.

During Covid-19, many families took on additional responsibilities for providing support and care to relatives who required support and care. As people return to work, much of this support may not be sustainable. It is also very likely that some people will have experienced stress and burn-out from taking on this caring role and would not feel able to continue with it. It is crucially important, therefore, that an appropriate level of home care support is restored as soon as it is practicable and safe. Also, it is abundantly clear that more resources for home care are required.

3.5 People with disabilities

Many people with disabilities will inevitably have experienced great difficulty during the pandemic arising from, for example, being locked down; people not having access to day care; people in residential care not been able to have physical and personal contact with their loved ones; people with intellectual disability having to grapple with the concept of social distancing; reduced or no access to therapies and personal assistance essential for people's well-being. The outcomes of all of these factors on the well-being of people with disabilities need to be identified and addressed with some urgency by service providers. It is likely that some additional state funding will be required to ensure that this happens.

The matter of people with disabilities continuing to be accommodated in congregated settings, including nursing homes is of particular concern both during the pandemic and on an ongoing basis. The fact that there are 1,300 people with disabilities living in nursing homes⁴⁸ needs to be addressed and those who wish to move out need to be enabled and supported to do so. This must include community-based supports relative to their needs. Many are in nursing homes because there was no alternative option available to them. Others are there because the congregated setting they used to call home was de-congregated based on government policy as recommended in *Time to Move On*. Since this policy was not resourced to its requirements, many ended up in a nursing home – another congregated setting and one totally unsuited to meeting the needs of many of those so placed.

3.6 People with mental health difficulties

During the pandemic, significant challenges were faced by people with mental health difficulties. This was almost certainly exacerbated by limited access to counselling services. While the Mental Health Commission put in place protocols for managing Covid-19 in psychiatric units, these supports may not have extended to the community to a sufficient degree. There was also the potential mental health damage that "cocooning" could have had on some older people and people with disabilities. Additional mental health challenges would have been experienced by some people as a result of fears of infection, not been able to get urgently needed hospital appointments and scans; concerns about relatives living in nursing homes; and, for some, the burden of caring for relatives. Some people with dementia or other intellectual disability would undoubtedly have become more stressed due to lack of social interaction and routine. Since people were not able to avail of GP services at the same level as prior to Covid-19, there is a strong possibility that many people did not seek or receive the support and medical advice that they would have needed. There is also the issue of helping bereaved families to come to terms with what for some was undoubtedly a troubling and stressful experience. The stresses experienced by frontline health and social care staff is also a matter that needs acknowledgement as we move forward. There will also be mental health challenges for people living in over-indebted households arising from Covid-19. All of the above point to a vital need for a comprehensive and targeted approach to the provision of additional counselling and support services. This is a matter that Government must address.

⁴⁸ https://www.disability-federation.ie/assets/files/pdf/dfi_rr_2018_web.pdf

3.7 End-of-life care

Sage advocates noted that end-of-life care presented major challenges for people in hospitals and for nursing home residents as well as for relatives because of both the need to isolate, pressures on staff, the need for health and social care staff to wear PPE, restricted visiting and, very importantly, the absence of the supportive presence of loved ones. There were also issues arising out of the absence of clear guidelines during the early stages of the pandemic as to who and how many could be present at the end-of-life stage. There were also reports of contradictory messages having been given by different staff as to what was permitted. The Irish Hospice Foundation issued a statement⁴⁹ on dying alone in hospitals and care settings at the beginning of April which made three important recommendations:

- A) One family member to be allowed with every person who is dying;
- B) Hospitals and care settings to provide as much detail as possible on where, how and when visiting can be allowed and facilitated in order to alleviate distress for families;
- C) Where there is a no-visiting policy for infection control reasons, proactive measures are put in place to ensure that people who are dying are not left alone;

In order to focus specifically on end-of-life care in the Covid-19 context, it is useful to restate the four overarching standards set out in the Quality Standards for End-of-Life Care in Hospitals⁵⁰ developed by the Irish Hospice Foundation in conjunction with the Hospice Friendly Hospitals Programme. These are:

- 1) The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients;
- 2) Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care;
- 3) Each patient receives high quality end-of-life care that is appropriate to his/her needs and wishes;
- 4) Family members are provided with compassionate support and, subject to the patient's consent, given information before, during, and after the patient's death.

A question arises as to how well these standards were implemented or, indeed, formed part of the discourse, in the pressurised Covid-19 environment, particularly in nursing homes. It is reasonable to suggest that these standards were either not adhered to or only minimally because of system pressures and over-worked staff. This is regrettable given that dying, death and bereavement can be the most troubling aspects of our human existence. The Standards provide a benchmark against which practice relating to end-of-life care should be measured. A key question yet to be addressed is the extent to which these standards were or were not adhered to. Clearly, additional research is required to examine this fundamentally important question. The Covid-19 Nursing Homes Expert Panel recommended that a joint HSE-IHF collaborative national programme on palliative, end-of-life and bereavement care for the nursing home sector should be initiated along the same lines as the HSE-IHF Hospice Friendly Hospitals Programme (Recommendation 11.3).

⁴⁹ <https://hospicefoundation.ie/wp-content/uploads/2020/04/9th-april-Statement-from-IHF-on-dying-Alone-in-hospitals-and-care-settings-FINAL.pdf>

⁵⁰ http://hospicefoundation.ie/wp-content/uploads/2013/04/Quality_Standards_for_End_of_Life_Care_in_Hospitals.pdf

3.8 A human rights perspective

A view expressed by Sage advocates was that there was a total lack of consultation with the people most likely to be impacted upon by policy decisions relating to support and care options generally and specifically in relation to Covid-19. The Covid-19 response was seen by Sage advocates as decisions being made for older and vulnerable people rather than with them. It was pointed out, for example, that consultation with over 70s as part of decisions regarding their protection from this pandemic did not take place on either an individual or collective basis. While the government advice was at the level of 'strong recommendation' for cocooning rather than a mandatory requirement, it may have been understood initially by many as prescriptive in nature. Sage advocates pointed out that the general focus on over-70s in the population totally failed to identify and focus on those at greatest risk in nursing homes. Concerns were also expressed by Sage advocates about the rights of people in psychiatric facilities whose movements were restricted because of Covid-19 and whether this constituted a breach of the right to liberty and freedom of movement.

3.9 Supported decision-making

It is crucially important that the implementation of the Assisted Decision-making (Capacity) Act 2015 Act proceeds apace in order to ensure that people with reduced decision-making capacity are fully supported in exercising their will and preferences. This is particularly important because of the manner in which it would appear transfers to nursing homes from acute hospitals took place at the beginning of the pandemic. While it is unclear as to what level of consultation took place prior to such transfers, it is very likely that many people ended up in nursing homes without choosing to do so. A recent study⁵¹ has shown that almost 28% of patients in acute hospitals in Ireland lacked decision-making capacity. There is also the matter of ensuring that people have a right of access to independent advocates (which is not currently the case). This needs to be addressed with some urgency. The Covid-19 Nursing Homes Expert Panel has recommended that relevant aspects of the Assisted Decision Making (Capacity) Act 2015 in areas such as capacity assessment, recognising each resident's will and the wider use of advanced healthcare directives should be implemented (Recommendation 10.3).

3.10 Long-term support and care: questions arising from Covid-19

Sage advocates raised a number of basic questions relating to long-term support and care arising out of the Covid-19 experience that need to be addressed:

- 1) Why did the spontaneous community response to supporting vulnerable older people that emerged during the pandemic not transfer in any meaningful way into nursing homes?
- 2) How was the virus transmitted into some nursing homes?
- 3) To what extent did discharges from acute hospital settings to nursing homes contribute to the surge of cases in nursing homes?

⁵¹ Ruth Murphy, Sean Fleming, Aoife Curley, Richard M. Duffy & Brendan D. Kelly (2019) Convergence or Divergence? Comparing Mental Capacity Assessments Based on Legal and Clinical Criteria in Medical and Surgical Inpatients, *Journal of Legal Medicine*, 39:3,213-227, <https://www.tandfonline.com/doi/full/10.1080/01947648.2019.1622476?scroll=top&needAccess=true>

- 4) How can we ensure that the positive community support for vulnerable adults that emerged spontaneously during the pandemic will continue?
- 5) How can the increased momentum for home care that emerged during the pandemic be consolidated going forward?
- 6) What else needs to be done to enable all vulnerable adults to live safely and well in their own communities?
- 7) How do we capture and galvanise the undoubted social solidarity which has emerged in many communities during Covid-19?
- 8) How do we create a new contract between the citizen and the state which binds people to a relationship of mutual rights and responsibilities as these relate to vulnerable older persons?
- 9) How do we create a long-term support and care system that safeguards people both generally and, specifically, against future pandemics?
- 10) How in the emerging world of where so much more is now being done online do we harness the true potential of technology to aid better, more person-centred care?
- 10) Did ageist attitudes affect the public and policy responses at the initial stage of Covid-19 and, if so, how can these be left behind?

Section Four

A Policy Action Framework for Long-term Care Outlined

4.1 Introduction

Section One of the document outlined a vision for an alternative model of long-term care towards which we should strive. This section identifies a broad framework for addressing core issues arising from the Covid-19 experience and makes a number of specific recommendations for addressing these issues. It also sets out a roadmap for achieving the changes required to our current system of long-term support and care.

The experience of Covid-19 has highlighted a number of policy issues relating to the provision of long-term support and care that were already well known – the under-funding of long-term support and care, the lack of statutory entitlement to home care, the drift towards the privatisation of long-term support and care both in nursing homes and in the community, inadequate provision for medical care in private nursing homes and different funding models for long-term care and acute hospital care. The Covid-19 experience also brought into a sharper focus two major deficiencies in private nursing home care – the lack of adequate clinical governance and the fact that the HSE, as the provider of last resort, had no direct involvement or oversight in respect of private nursing homes. This section sets out a series of recommendations to address both the issues that were already well known and those that came to public attention because of the pandemic. These recommendations concur broadly with those made by the Covid-19 Nursing Homes Expert Panel and by the Oireachtas Special Committee on Covid-19.

4.2 Suggested Policy Action Framework

Figure 4.1 (below) sets out an overall framework for addressing the policy issues relating to the provision of long-term support and care which includes a series of specific actions relevant to the development of the vision for long-term support and care set out in Section One above.

First and foremost, there is the need to begin to action the process of developing a single tier integrated system of long-term support and care based on a seamless continuum and better integration of the private sector in the planning and delivery of services. Secondly, since the current funding model is not sustainable for an ageing society, the process of further exploring alternative health and social care funding models must begin immediately with a view to developing and implementing concrete and targeted proposals on the matter within a short time-frame.

The case for providing a range of alternative housing options for people who require long-term support and care has been set out in Section One. Existing relevant initiatives, at national and international levels, must be built upon and the appropriate inter-departmental initiatives required embedded in the administrative system.

The development of a wider range of models of health and social care in later years is necessary and can be achieved through public, private and NGO partnerships. A local social enterprise approach supported by Government has significant potential in this regard.

The development of enhanced education and training in gerontology and nursing/medical care of older people is necessary in order to ensure that care is provided at the highest level and that such care is afforded the same status and importance as acute hospital care (see 4.3 below).

Figure 4.1: Suggested Policy Action Framework for Long-term Care

Action	Aim	Outcomes	Priority
Develop a single tier integrated statutory system of long-term support and care	Provide a clear and realistic continuum of support options for people who require long-term support and care	People are able to choose which option best suits their needs at a particular point in time	A long-term support and care system deliberately biased towards supporting people at home
Integrate private nursing homes into the wider framework of health and social care	Ensure statutory oversight in all congregated care facilities for older people at both regional and national level	Standardised quality care provided in all nursing home settings	Arrangements for intervention and re-deployment of relevant staff across sectors in line with future pandemic planning
Explore alternative long-term support and care financing models	Put in place a sustainable long-term support and care financing system	Publicly funded long-term support and care provided for the most part in community-based settings	Analysis of other models of financing long-term support and care other than taxation and co-funding
Provide a range of housing options for people who require long-term support and care	Enable people with high support needs to continue to live in the community; Lessen the need for residential nursing home care	More people supported to live independently or semi-independently and to 'age in place'	Build much more sheltered and supported housing
Develop new models of long-term support and care	Provide a wider range of ownership and partnership models for both homecare and nursing home care	A 'mixed economy' of care in which social enterprise plays a significant role	Promote and stimulate social enterprise at local level in the provision of long-term support and care
Develop enhanced education and training opportunities in gerontology and nursing/medical care of older people;	Provide a more gerontologically-attuned staffing in all long-term support and care services	Health and social care staff better able to deal with conditions associated with old age, frailty and dementia	Initiate and pilot a number of initiatives

Action	Aim	Outcomes	Priority
Review registration of nursing homes legislation and regulations	Strengthen the process of determining if an applicant for registration or re-registration is a 'fit person'	Members of the public or statutory agencies have a right to make a legitimate and bona fide objection to an application	Focus attention on the private nursing home sector
Undertake a review of the resilience of the nursing home sector in a future pandemic	Identify the risk to vulnerable older people and to the State	Better forward planning and anticipation of potential difficulties and identification of ways of dealing with these	Develop strong clinical governance systems in both public and private nursing homes
Identify a suitable platform technology to provide a uniform recruitment and work record for all staff in the long-term support and care sector	Make available for public scrutiny the qualifications and work record of all staff in the long-term support and care sector	A better overview of staff qualifications and experience and skill-sets	Empowering the public health and social care sector to exercise vigilance over care quality at local level
Provide legal recognition, national quality standards and training and equitable funding for independent advocacy	Enable independent advocates to act on behalf of vulnerable adults independent of family, service provider and systems interests	Better protection and safeguarding of vulnerable adults who require long-term support and care	Legal right of access for independent advocates enshrined in legislation
An integrated data collection and reporting system across all public bodies with a role in long-term support and care provision	Ensure that there is a timely information flow between the core public agencies involved in the delivery of long-term care - Department of Health, HSE and HIQA	A fast track approach to identifying people most at risk and prioritising actions accordingly.	Develop a site-specific profile of all nursing home residents in the public and private sectors
Implement in full the Sláintecare recommendations	Provide an integrated long-term support and care system within the overall health and social care system with a strong bias towards care in the community;	People provided with a range of options along a continuum of support and care	Establish mechanism for integrated long-term support and care in each of the new CHO areas;

There is a need for a review of the legislation and regulations for private nursing homes to ensure that a prospective nursing home proprietor is a 'fit person' for the provision of such a vital service to people who are mostly very vulnerable. The position and status of care workers (both in the community and in nursing homes) needs to be looked at in terms of remuneration, training and support commensurate with the role. Action is also required on exploring the resilience of the private nursing home sector in dealing with the ongoing challenges of Covid-19 and with any future pandemics that may emerge.

An integrated data collection and reporting system across all public bodies with a role in long-term support and care provision is required in order to ensure that people receive support at the most appropriate level in relation to their needs irrespective of geographical location. The establishment of a mechanism for integrated long-term support and care in each of the new CHO areas in accordance with the implementation of Sláintecare will be critical in this regard.

In addition, and, very importantly, we need a stronger social support infrastructure for families providing support and care to older relatives and related flexible working and pension arrangements. Such an approach has indeed been demanded by the UN Convention on the Elimination of all Forms of Discrimination Against Women (Article 11 (d)).⁵²

4.3 Training in geriatric care

The need for high quality multi-disciplinary and gerontological training requirements for nurses has been highlighted.⁵³ While all nursing homes are now inspected by HIQA, these inspections may not be frequent enough or specific enough about the training and multidisciplinary team (MDT) clinical practices of care within nursing homes.⁵⁴

While people residing in nursing homes generally have more complex health care needs than the average older person, their experiences of health care services has been found to be of variable quality.⁵⁵ In particular, the provision of primary care to nursing homes is too often reactive, with little proactive or anticipatory care and little in the way of continuity.⁵⁶ As a result, residents sometimes have a poor experience, receive sub-optimal medication and have frequent unplanned admissions to hospital.⁵⁷ It has been noted that concerns persist that nursing home residents receive less organised medical care than their community dwelling counterparts with poorer monitoring of chronic disease and higher rates of unnecessary prescribing. For example, only 12% of European Geriatric Medicine Society (EUGMS) countries have written medical care standards for physicians applicable to nursing home care provided by professional organizations.⁵⁸

The following principles have been identified by the European Geriatric Medicines Society (EUGMS) Long Term Care Special Interest Group⁵⁹ as a basis for European guidelines on the provision of medical care for nursing home residents:

⁵² <https://www.ohchr.org/en/professionalinterest/pages/cedaw.aspx>

⁵³ <https://www.lenus.ie/bitstream/handle/10147/76516/leascross2009.pdf?sequence=1&isAllowed=y>

⁵⁴ Sage Advocacy Submission to Oireachtas Special Committee on Covid-19, <https://www.sageadvocacy.ie/media/1893/submission-to-oireachtas-special-committee-on-covid-19-response-250520.pdf>

⁵⁵ <https://www.nuffieldtrust.org.uk/files/2018-04/transforming-care-report-final-web.pdf>

⁵⁶ Robbins I, Gordon A, Dyas J, Logan P and Gladman J (2013) *Explaining the barriers to and tensions in delivering effective healthcare in UK care homes: a qualitative study*, <https://bmjopen.bmj.com/content/3/7/e003178.full>

⁵⁷ Smith P, Sherlaw-Johnson C, Ariti C and Bardsley M (2015) Focus on: hospital admissions from care homes. The Nuffield Trust and The Health Foundation, https://www.health.org.uk/sites/default/files/QualityWatch_FocusOnHospitalAdmissionsFromCareHomes.pdf

⁵⁸ Desmond O'Neill, Robert Briggs, Iva Holmerova, Finbarr Martin https://www.irishgerontology.com/sites/default/files/basic_page_pdf/IAGG-ER%20th%20Congress%20-%20Abstracts%20Book%20%28Irish%20Ageing%20Studies%20Review%29.pdf p.102

⁵⁹ *Ibid.*

- 1) Nursing home practice viewed as an inter-professional (multi-disciplinary) endeavour that requires a sound theoretical, scientific, and values base in addition to clinical expertise;
- 2) Assessment by a specialist in geriatric medicine or old-age psychiatry prior to consideration for admission;
- 3) Formal competence in geriatric medicine or old age psychiatry mandatory for physicians providing medical care to nursing home residents;
- 4) Clinical partnership with nurses who have gerontological training, including training in dementia and palliative care, and care attendants who have due training in the care of older people;
- 5) Supported by allied health professionals;
- 6) Supported by specialist comprehensive gerontology services, including geriatricians, old age psychiatry and clinical nurse specialists;
- 7) Resident medical and nursing records gerontologically attuned so as to reflect the needs of this group;
- 8) Appropriate schedules maintained for preventive interventions (such as vaccination), monitoring of chronic diseases, and regular clinical review and medication review.

This issue of staff training was raised in a 2020 Sage Advocacy Discussion Document on Medical Care in Nursing Homes⁶⁰ where multi-disciplinary education and training was highlighted as a requirement to improve morale and enhance shared learning and practice. The point was made that nursing home staff may not have the exposure, experience and training available to staff in acute hospitals. It should, of course, be noted that there are many nursing homes that have expertise and staff with relevant skill sets.⁶¹

Areas identified where multi-disciplinary training would be useful were:

- Respective responsibilities of GPs and nurses
- Dementia awareness and care for people with dementia
- End-of-life care
- Advanced Care Directives
- Working with families, particularly around the limited role of next-of-kin
- Implementing the provisions of the ADM (Capacity) Act 2015 with particular reference to Advanced Healthcare Directives and supported decision-making
- Components of quality of life for nursing home residents

In developing a strategy for nursing home care going forward, clinical training of medical, nursing and health and social care professional staff will be a core consideration. It is crucially important to bring the importance of care of older people to a wider interdisciplinary academic and business community. There is currently no educational facility in Ireland for multi-disciplinary training in medical, nursing and social care provision for older people with complex needs. There is potential to address this deficit in the development of new campuses which could reflect the wider educational benefits of age-friendly design and architecture and gerontechnology.

⁶⁰ <https://www.sageadvocacy.ie/media/1679/6078-report-medical-care-in-nursing-homes-web2.pdf>

⁶¹ Amanda Phelan & Brendan McCormack (2013), *Exploring Nursing Expertise in Residential Care for Older People in Ireland*, <https://www.lenus.ie/bitstream/handle/10147/285717/Finalwithbio.pdf?sequence=1&isAllowed=y>

The Covid-19 Nursing Homes Expert Panel has recommended that:

- HIQA should carry out and publish a detailed audit of existing staffing levels (nursing and care assistant) and qualifications in all nursing homes – public, voluntary and private (Recommendation 9.1);
- All Healthcare Assistants should have a relevant QQI Level 5 qualification or be working towards achieving it (Recommendation 5.3);
- There should be a requirement that senior nursing staff will have undertaken post-graduate gerontological training (Recommendation 10.4).

4.4 Independent advocacy

There is general acknowledgement that some vulnerable 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. People with cognitive impairment in residential care settings may be vulnerable, not only because of their individual needs, but also because historically the system of service provision has tended to be based on a dependency model rather than on an approach that maximises choice, supported decision-making and independence.

Independent advocacy (defined as advocacy that is independent of families, service providers, and systems interests) has a key role to play in enabling such people to have their own ‘voice’.⁶² For many people with dementia, there are likely to be some aspects of their lives where they can make decisions and others where they are unable to do so – recognising these aspects and providing support accordingly is at the very core of advocacy work. In order to reflect the underlying principles of a rights-based approach contained in the Assisted Decision-making (Capacity) Act 2015, a statutory provision for independent advocacy is required. Indeed, the Oireachtas Joint Committee on Health and Children’s Report on the Role of Advocacy in Health and Social Care Services in Ireland (January 2016)⁶³ commented that the lack of statutory powers for advocacy acts as a barrier of access to advocates by vulnerable people.

A strong case has been made for legislation to give recognition in law to the practice of independent advocacy.⁶⁴ In addition to legal recognition, there is also a clear need for national quality standards for independent advocacy, appropriate advocacy training and qualifications and equitable funding for independent advocacy services.⁶⁵ The Covid-19 Nursing Homes Expert Panel recommended that the Department of Health and HIQA should explore introducing a requirement that all nursing home providers promote, facilitate and engage meaningfully with independent advocacy services (Recommendation 15.2).

⁶² <https://www.safeguardingireland.org/wp-content/uploads/2018/10/Advocacy-Scoping-Document-Final-310818.pdf>

⁶³ <https://www.drugsandalcohol.ie/25068/1/JCHC-Report-on-the-Role-of-Advocacy-in-Health-and-Social-Care-Services-in-Ireland.pdf>

⁶⁴ Sage Advocacy Submission to Law Reform Commission Issues Paper, <https://www.sageadvocacy.ie/media/1889/sage-advocacy-submission-to-lrc-200520-final.pdf>

⁶⁵ Browne, M. (2018), Independent Advocacy in Ireland: Current Context and Future Challenge, Safeguarding Ireland, <https://www.safeguardingireland.org/wp-content/uploads/2018/10/Advocacy-Scoping-Document-Final-310818.pdf>

4.5 Addressing shortcomings in nursing home care policy

Figure 4.2: Suggested Policy Action Framework to standardise and enhance the care provided to nursing home residents

Action	Aim	Outcomes
Responsibility for clinical care in all nursing homes in each region assigned to a community-based physician specialising in geriatric medicine	Provide a clear system for clinical oversight in all nursing homes (public, private and voluntary);	Standardised and transparent quality medical and nursing care in all nursing homes
Regional consultants supported by a small team of Advanced Nurse Practitioners (ANPs)	ANP specialists in the care of older people to be linked into the regional public health nursing structures	A consistent focus on primary and community care and avoidance of a hospital centric approach
Develop a network of community teaching hospitals in each health region to provide teaching centres for the Geriatricians and ANPs	Education and training in gerontology with a focus on long-term support and care and a multi-disciplinary approach	Multi-disciplinary training and shared values across all relevant professionals
Develop clear protocols for all interactions between community services and nursing homes	Develop protocols for admission, discharge and transfer from and back to the community and for support and involvement of palliative care teams	Acknowledge different levels of service capability in different nursing homes and allocate patients accordingly
Coordination by the HSE of a National Clinical Programme for the Long-term Support and Care of Older Persons	Identify and address national issues of a systemic nature relating to clinical oversight	A uniform quality clinical governance system in all nursing homes
Establish regional coordination structures for long-term support and care	Provide a Planning Forum to include HSE Safeguarding & Protection Teams, Public Health Nurses, Directors of Services for Older People, Geriatrician, ANPs and HIQA	A more streamlined approach to long-term support and care provision and planning
Develop Guidelines for nursing and medical care in nursing homes	Identify the appropriate ratio of suitably skilled nurses to residents with particular levels of need; Identify the minimum level of medical cover that is required from GP services	Better nursing and medical care; A standardised approach across nursing homes nationwide
GP care in nursing homes provided through a single GP practice to most or all residents in a home	Provide a dedicated Medical Officer for each nursing home, or geographically clustered group of homes	Standardised and enhanced medical care provided to nursing home residents
Multi-disciplinary training and CPD for all nursing home staff and Medical Officers	Provide an integrated medical and nursing care response to all nursing home residents	Access to appropriate staff training and support systems

4.6 A Roadmap for Change

In the context of the Covid-19 pandemic, and the ongoing efforts to address the many challenges arising from it, there is now both an opportunity and a necessity to progress the development of long-term support and care as a core part of building an equitable and quality driven national health and social care system through Sláintecare of which long-term support and care would be an integral part. The Oireachtas Special Covid-19 Committee interim report recommendations and those of the Nursing Home Expert Panel reinforce the consistent policy message of recent decades and, taken together, provide an unprecedented opportunity to develop a single tier integrated system of long term support and care across the life-cycle.

The Oireachtas Special Committee on Covid-19 has recommended that the Department of Health should work closely with the Department of Housing to develop models of independent living, supported housing and sheltered housing to cater for the wide range of housing preferences among older people and that there should be a specific focus on moving care from congregated settings (Recommendation 9). That Committee also recommended the enactment of legislation underpinning the regulation of and statutory provision and regulation of home care and, in the meantime, that additional funding for home care would be increased to clear the current waiting lists (Recommendation 11).

A fully integrated system would:

- Have equity of access;
- Be available to older people with support and care needs and to people with disabilities;
- Recognise the needs of family carers as well as care recipients;
- Maximise opportunities for personalisation of supports and services based on individual will and preferences;
- Cover all care situations including domestic homes, supported living facilities and community hospitals with incentives to maximise care provision in the place of care of choice;
- Be funded through a single social support and care fund based on social insurance payments, inheritance tax and an element of personal payment;
- Have a common system for assessment of need and allocation of resources;
- Be supported by a comprehensive oversight and regulatory approach which blends oversight, quality standards and an ability to intervene and investigate;
- Phase out the Nursing Home Support Scheme and discard plans for a standalone statutory home care scheme.

This Sláintecare Social Care system would be underpinned by specific legislation which would:

- Incorporate a broad definition of long-term support and care and indicate the range of services necessary to support and sustain people at home;
- Integrate health and social care along the lines of, for example, Ontario's Home Care and Community Services Act 1994;⁶⁶

⁶⁶ <https://www.ontario.ca/laws/statute/94l26> -- This Act seeks to integrate community services that are health services with community services that are social services in order to facilitate the provision of a continuum of support and care.

- Set out a comprehensive framework approach which defines clearly the respective responsibility of the State and the family in the provision of long-term support and care;
- Provide for enhanced support for families that are contributing to the long-term support and care of a family member;
- Be sufficiently broad to encompass all potential users of long-term support and care services;
- Enshrine the principles of objectivity, transparency and consistency in the assessment of support and care needs and provide for a credible independent review of needs assessments;
- Provide for the system to support informed choice by care users;
- Provide for a needs based planning framework to ensure adequate service levels;
- Provide for an independent regulatory system to ensure the quality and integrity of the long term support and care system;

4.6.1 Implementation Roadmap

The framework for the development of a single tier Sláintecare Social Care system would be progressed through the proposed Commission on Care referenced in Section One above which should have a broadly based membership. An outline framework of the work modules to be addressed by the Commission on Care is set out below.

The framework locates the development of an integrated model of long-term care clearly within the Sláintecare implementation strategy. It suggests that new legislation should be developed – a Sláintecare Social Care Act – to bring together all the elements of an integrated system in order to ensure that a seamless health and social care service is available to all who need it. In order to emphasise the need for urgent action, the framework sets a target of Q4 2021 for the passage of a Sláintecare Social Care Act. The funding model would be a Single Social Care Fund comprised of long-term care social insurance contributions and/or exchequer funding with the possibility of using Inheritance Tax as co-payment.⁶⁷ This approach would require the merging of the Nursing Home Support Scheme funding for home care and funding for supported housing.

The Framework sets out key underlying principles, important design features, a list of agencies that should be included in a multi-agency approach, the new legislation and regulation required, the need to develop an alternative and sustainable funding model and, finally, what is required in terms of implementing a new model.

⁶⁷ The matter of financing long-term care has been dealt with comprehensively in a previous Sage Advocacy Discussion Document, https://www.sageadvocacy.ie/media/1538/sage-advocacy_summary-financing-long-term-care-in-ireland_2002019.pdf

Framework for Development

PRINCIPLES

- Rights-based
- Supported decision-making
- A life-cycle approach
- Equity of Access
- Continuum of supports & care
- Personalised
- Balanced range of providers

DESIGN

- Schedule of services
- Assessment system(s)
- Oversight & Regulation
- Staffing & training
- Quality & Safety
- Data & Research

MULTI AGENCY

- Dept of Health
- HSE
- Dept of Housing
- Local Authorities
- HIQA
- Social enterprises
- Private sector

LEGISLATION

- Sláintecare Social Care Act
- Integrated Services
- Integrated needs assessment
- Oversight & Regulation
- Quality & Safety
- Five year review periods

FUNDING

- NESC Review
- Single Social Care Fund
- Social Insurance or exchequer funded
- Inheritance Tax as co-payment
- Social Innovation Fund

IMPLEMENTATION

- Merging of NHSS & Social Care Funds
- Assessment & review Process
- Minimum datasets
- Quality outcomes

Section Five

Final Observations and Conclusion

5.1 Caring for an ageing society: Building a new partnership between citizens and the State

For many people, there is a dissonance between what they hope and should expect their experience of support and care will be and the often dreary reality of nursing home care. It may also be the case that people working in those services sometimes find themselves the representatives of systems which can feel as challenging to work in as to live in. The long-term support and care system that we have is primarily a societal failure as people may wrongly assume that Government will always do what is right for all citizens. Therefore, the established infrastructure for long-term support and care remains broadly intact and, indeed, unseen. Its assumptions, its relationships, its power dynamics and the way resources (sometimes scarce) are deployed are regarded as givens and rarely challenged in any fundamental way.

A key question for providers of long-term support and care is how they can build a new partnership with the people they support. This change requires services and the professionals who work within them to have clarity and confidence in what they can achieve and realism about the shortcomings of existing provisions. This is the cultural change that is required – new ways of working alongside people rather than for them. This requires a fundamental shift of power, money and responsibility, without which more humane and relational ways of working lose out to resource efficiency, crude value for money arguments and the profit/corporate ethos.

5.2 Participation and meaningful inclusion

There has been a strong policy emphasis on ‘person centred’ care in recent years. The need for such an approach is clearly self-evident but the fact that it has to be repeatedly stated begs the question about where very significant expenditure on support and care would have been spent in the absence of a person-centred approach. This is an important consideration in long-term support and care which is particularly applicable to the current nursing home model. As a 2016 Journal of Clinical Nursing editorial noted, many nurses (in common with many other care and health professionals) work in contexts and cultures that are inherently unsupportive of person-centredness.⁶⁸ As nursing home care has become more privatised, the individual support needs of people requiring long-term support and care can easily become lost in a profit-driven system. Public residential care facilities clearly also frequently fall short as was evidenced by the experience of Áras Attracta residents.

At the core of the current long-term support and care model is that, while there are regulations and standards in place, people using these services are not able to define in any meaningful way outcomes for themselves or the type of supports they actually want. HIQA regulation and standards, while very necessary and important in themselves, may well be inadequate to assure high quality

⁶⁸ <https://onlinelibrary.wiley.com/doi/full/10.1111/jocn.13681>

individually-tailored care in accordance with people's will and preferences. Quality standards are to a large extent limited to the enforcement of those tangibles of the environment and procedures which can be measured. The intangibles that have to do with a human setting and supportive relationships may frequently elude the controls of the regulatory process. It is also true that regulation deals only with what already exists. In a field as seriously lacking in innovation as the nursing home sector, regulation is still unable to play the role of creator of new models or planner of new systems. It is almost certain that business methods which underpin the private nursing home sector may not always provide what makes a good human environment.

The alternative model based on a rights-based approach and on social inclusion principles would seek to build relationships with and between people and to work wherever possible through partnerships, communities and networks. Nursing care units would be part of a menu of supports and residential homes would not operate as isolated stand-alone entities where frequently residents have little real say and little influence on the structures and ethos that shape these institutions.

5.3 An integrated model of health and social care

Long-term support and care encompasses housing, medical, nursing, social and personal care dimensions, all of which need to be provided for irrespective of where the support and care is provided. Housing and health and social care can no longer remain parallel lines. They must converge. For this to happen we need to focus our energy on housing policy as much as on health and social care policy.

A recent paper⁶⁹ has drawn attention to the interdependency of health and social care and has suggested that the arbitrary distinction between these sectors has resulted in endemic underfunding, failure to integrate needs-based health care paradigms into policy and practice, lack of integration between the public and private sectors, and lack of recognition and regard – all of which are obstacles to good healthcare in care homes. “For each UK example reported in this commentary, there are similar experiences in the Republic of Ireland and the Netherlands and reports from the care home sector internationally suggest that there have been similar experiences in many countries”.⁷⁰ Integrating the housing component into the health and social care interface is also a vital requirement which has been outlined in Section One above.

5.4 Community connectedness

The Covid-19 experience highlighted the absence of community connectedness in nursing homes. Restrictions on visiting clearly compounded the already weak connections between nursing homes and local communities. Even, in ‘normal’ times, it is likely that in many instances, GPs are the only community-based professionals that have a regular presence in nursing homes.

Pending a radical change to the long-term support and care architecture, more direct involvement of local communities in nursing homes could provide better quality of life for residents. The best way to maintain community standards in nursing homes is to open them to the community.⁷¹ This means having nursing home doors open and people streaming in and out; having the community present in the institution, and nursing home residents held and protected within the community.

The prioritisation of nursing homes for the delivery of long-term support and care is fundamentally at odds with a person-centred and community-oriented approach. There is abundant international

⁶⁹ COVID in Care Homes – Challenges and Dilemmas in Healthcare Delivery' <https://academic.oup.com/ageing/article/doi/10.1093/ageing/afaa113/5836695>

⁷⁰ *Ibid.* p.704

⁷¹ <https://ajph.aphapublications.org/doi/10.2105/AJPH.64.3.265>

evidence that we can reject the divide between citizens of our communities and people who are in need of support services. We do not have to choose between long-term support and care services exactly as they are or an unrealistic reliance on small-scale community volunteering efforts. We can develop a much stronger social enterprise response based on locally-tailored responses to local needs and supported and incentivised by Government. Small scale innovative approaches taken together can form the building blocks of a totally new long-term support and care system in terms of ethos, practices, use of resources and outcomes. The risks of persisting with our current long-term support and care system far outweigh the risks of radical change.

5.5 The ‘nursing home’ model

The various bodies responsible for health and social care – HSE, Department of Health and HIQA – can be regarded as having responded well to the pandemic at one level given that it was an entirely new challenge. However, the shortcomings of the current model of long-term support and care with its emphasis on nursing home provision were brutally exposed, particularly, in respect of lack of adequate clinical governance, resource shortfalls, lack of a central planning or strategy for long-term support and care, and buildings which house too many people in close contact. These shortcomings need to be addressed in a radical and fundamental manner.

Relatively little has occurred during the course of nursing home development over many years to move nursing homes, either in image or mode of operation, from the closed institution sphere to the public sphere of community responsibility. Regardless of the fact that that Government introduced regulation and quality standards for both public and private nursing homes and provided significant funding to the sector, it in no sense took over the planning or running of the nursing home sector. On the contrary, the trend towards de-investiture by the State in Ireland which has been expedited in recent years has resulted in a major gap emerging between the public health sector and the private nursing home sector. This was clearly reflected in a HSE statement during the peak of the Covid-19 crisis in nursing homes that the HSE does not normally have a direct relationship with private nursing homes. Efforts to integrate nursing homes into area wide systems of health and social care or to link them closely to hospitals, has been largely thwarted as the nursing home sector became privatised and operated independently from government and largely outside of public health and social care policy and outside the acute hospital system.

The Irish Human Rights and Equality Commission has stated that the vulnerability of people in congregated institutional settings to the impact of the Covid-19 pandemic points to the need to address the role of institutionalisation in public policy. This includes how care for older people, or people without the capacity to live independently, is treated in public policy.⁷² By pushing people into nursing homes, we are denying their liberty and their right to choose where they want to live. Alternative models of support and care may or may not result in higher costs but these costs are minimal compared to the psychological and social costs associated with our present system as evidenced in the Covid-19 experience.

5.5.1 Is there a role for nursing homes?

A central question that arises from this discussion document is whether or not nursing homes have a future in our long-term support and care infrastructure. The real silent elephant in the room is the model of long-term support and care for older people that is in place and which is culturally and socially ingrained and promoted as the only economically viable option. While one of the main arguments for residential nursing homes has to do with cost and effectiveness, given the massive amounts of money invested directly and indirectly (tax breaks, capital grants, subsidies), it is not at all clear that such an approach is cost-effective, particularly when choice and quality of life

⁷² <https://www.ihrec.ie/app/uploads/2020/07/IHREC-Annual-Report-2019-English-version.pdf>

considerations are taken into account. We need an honest acknowledgement of the fact that there are some people in nursing homes not because they need to be there but because the supports that they need to live in their home are not available. By adopting the current system, we have, perhaps unwittingly, placed people in an environment that proved to be essentially unsafe.

As a core principle, nursing care units for people who require a high level of 24/7 care must be part of a community-based care support hub which includes a wide range of social care services and supported housing.

5.5.2 Improving the quality of care in nursing homes

Notwithstanding the urgent need to move quickly to an alternative community-based model of long-term support and care for older people as referenced throughout this document, 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 role. The following questions, therefore, need to be addressed in the short-term:

- How can clinical governance be strengthened through more active engagement of community-based medical professionals – GPs, Geriatricians and Advanced Practice Nurses?
- How can the range of therapies typically required by nursing home residents be made more readily available than is currently the case?
- 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 broader participation in the affairs of the nursing home by residents' relatives and friends be accommodated?
- What is the optimum size and design of a nursing home to ensure that care can be delivered in a home-like and safe environment?
- Do nursing care units need to have a different staffing structure and, if so, what should this be?
- What professions other than nursing and care assistants should be included in staffing?
- How can nursing home staff be better trained and better paid for their work?
- How can nursing care units be configured at local level as part of an inclusive community support and care hub?
- How can a flexible system of moving in and out of residential nursing care units as needs determine be implemented?

5.6 Rebuilding our long-term support and care system

There has never been a better opportunity to reconfigure our long-term support and care system and to develop structures and services that protect people's rights by moving them out of nursing homes into safe, supportive communities. We need to champion the right to community living for older people with care needs. Fundamentally, we need a health and social care system that supports citizens to live at home, or a place that feels like home, with care organisations that are part of and controlled by the local community. At its very core, 'home' means small, personal and living with people a person has chosen to live with. It is almost certain that the absence of strong community connections for nursing home residents with its concomitant isolation and loneliness compounded their experience of Covid-19.

While we rebuild our long-term support and care systems, we can hardly want to reconstruct the fractured nursing home system which has, heretofore, been hidden in plain sight. The fault lines exposed by the pandemic are not solely related to poor clinical governance and sectoral distancing between the HSE and the private nursing home sector. They are also related in a fundamental way to the fact that as a society we have tended to privilege residential nursing home care over care in the community for older people with complex support needs. The State currently spends over 1 billion euros a year on the Nursing Home Support Scheme, a figure that will undoubtedly increase as the population ages and if the current system remains intact. We need to find a better way to spend this money.

We need to find sustainable, creative and more humane ways to care for people with long-term support and care needs. We need a more comprehensive and holistic approach rather than the one currently pursued which is underpinned by a profit agenda, sectional interests and a dangerous architecture of intertwined but unintegrated state agencies. Responsibilities, resources, and risks need to be more evenly and transparently shared. All of society – citizens, front line services, and government – need to take radical action to achieve this vision.

Formal support and care services, whether in the community or in a residential care facility cannot be run remotely, nor owned offshore. Obscure corporate entities are the antithesis to a socially inclusive and integrated support and care system. If we want communities to continue to step up, connect and be generous, they must be offered a greater sense of ownership and real relationships in return. Indeed, social care interventions prioritised by health and social care services should be those which are informed by local communities. Community action at scale can only be delivered by locally-rooted care services. Neighbourhood level care organisations can reach tens of thousands, e.g., the Dutch Buurtzorg dementia support service with its self-managing community teams, or Shared Lives (in the UK) which reaches 14,000 vulnerable people through a family-based support model which behaves like a franchise in every way except for the fact that no one owns it, nor profits from it.⁷³ As was evidenced in the Covid-19 community responses, new technology has the power to identify who needs or can offer support, and to connect people with each other.

5.7 Legislative and strategic underpinning

As proposed in Section 4 above, there is a need for a Sláintecare Social Care Act to bring together all the elements of an integrated system in order to ensure that a seamless health and social care service is available to all who need it. The Assisted Decision-Making Capacity Act 2015 is a crucially important piece of legislation which has the potential to improve quality of life for many people whose capacity is compromised and needs to be fully implemented. Legislation is required to give older people right of access to supports to enable them to live at home. The National Dementia Strategy⁷⁴ needs to be renewed and ring-fenced funding allocated to progress the important initiatives that have been put in place. Legislation regarding Safeguarding Adults⁷⁵ and Protection of Liberty in Places of Care is pending and the establishment of a National Support and Safeguarding Agency is under active consideration. The Oireachtas Special Committee on Covid-19 recommended that there should be no unnecessary delay in implementing legislation on adult safeguarding (Recommendation 17).

⁷³ Alex Fox (2018), *A new health and care system: Escaping the invisible asylum*, <https://www.researchgate.net/publication/323527338>

⁷⁴ <https://assets.gov.ie/10870/3276adf5273f4a9aa67e7f3a970d9cb1.pdf>

⁷⁵ In March 2017, the Adult Safeguarding Bill was introduced in the Seanad. The Bill received cross party support and was passed to Committee stage.

5.8 Time for Action

The Covid-19 crisis has demonstrated that, more than ever before, there is an urgent need for good political leadership in older people's services in Ireland and for a shift in the balance of care away from nursing home models towards alternative potentially cost-effective approaches. Greater emphasis must also be placed on home adaptation, universal design, and technological solutions to enable older people to live well in their own homes.

While it may be tempting to leave long-term reform until 'after the crisis' and until further research and analysis is carried out, there is a clear imperative to start building a new long-term support and care system now. The Forum on Long-term Care 2016 report⁷⁶ referred to the need to fundamentally question the social and cultural norms that have become embedded in society that result in the model of long-term support and care that currently exists and which is not what people want and does not adequately enshrine a rights-based approach. This requires us to critically look at past and current practices and to explore alternatives that could and should be developed. As a society, we should not be victims of 'the system' as if it were impervious to change: There is no abstract system – the long-term support and care system that exists is the one that we as a society have allowed to be created and which we allow to continue operating on a daily basis. We make small changes at the margins but leave the system itself entirely intact. "Currently we choose constantly to ignore, patch up and even rebuild the invisible asylum".⁷⁷ The post Covid-19 climate provides a good opportunity to bring into full visibility both what communities did in response to the crisis and what is basically unsafe within our long-term residential care support services – "the asylum that they offer us when we need them and the asylums they can become if their grip is too unyielding".⁷⁸ While it difficult to predict what will constitute the point of no return, what is certain is that the nursing home model that has been promoted and resourced to date is no longer tenable from either a rights or a safeguarding perspective.

⁷⁶ https://www.sageadvocacy.ie/media/1124/report_of_forum_on_ltc_for_older_people.pdf

⁷⁷ Alex Fox (2018), A new health and care system: Escaping the invisible asylum, <https://www.researchgate.net/publication/323527338>

⁷⁸ *Ibid.*

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