



**Submission to the Oireachtas Special Committee on
Covid-19 Response:
Congregated Settings – Nursing Homes**

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Rialtas na hÉireann
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1. Context

1.1 Demographic Changes

With an increasing number of people living into older age, Government policy on the provision of long-term care is central to ensuring care is accessible, high-quality, efficient and secure - even in crisis situations.

Each year in Ireland, the over 65 age group increases by 20,000 people. The number of people aged over 65 is projected to increase very significantly to close to 1.4 million by 2041, from one-fifth to over one-third of the working population over the next two decades. The number of people over 80 is set to rise even more dramatically, increasing by over 250% to between 470,000 and 484,000 in 2046.¹

The increase in the ageing population will result in higher numbers of people with dementia which will have implications for care provision and expenditure.

1.2 Long-term Care in Ireland

Long-term care includes social, healthcare and support services provided to older persons in all public and private settings, including at home, community-based services, day-care centres, residential institutions, hospitals, hospices, prisons or other settings. It is provided by both formal and informal caregivers or support providers including volunteers.²

The aim of long-term care in older age is to support us in our choice to age in place either at home in the community (e.g. home care supports) or within a residential care setting (e.g. nursing homes). It involves the right to autonomy and independence by providing the support needed to carry out daily life in accordance with an individual's will and preferences.³

In Ireland, there are three main options for people requiring assistance with care, each bringing different levels of supports, costs and regulatory requirements:

- **Nursing home care** for those needing intensive support. There are 581 nursing homes in Ireland, housing 31,250 people.⁴
- **Formal home care** for those needing support to live at home. HSE plans for 53,000 people to receive home support from the Health Service Executive (HSE) totalling 17.9 million hours in 2019.⁵

¹ Based on 2011 base figures.

<http://www.cso.ie/en/csolatestnews/pressreleases/2013pressreleases/pressreleasepopulationandlabourforceprojections2016-2046>

² UN General Assembly (2019) *Substantive Inputs in the form of Normative Content for the Development of a Possible International Standard on the Focus Areas "Autonomy and Independence" and "Long-term and Palliative Care"* Working document submitted by the Department of Economic and Social Affairs (DESA) in collaboration with the Office of the High Commissioner for Human Rights (OHCHR). Available at www.social.un.org.

³ Ibid.

⁴ Health Information and Quality Authority (2019) *Overview report on the regulation of designated centres for older persons – 2018*. Available at: <https://www.hiqa.ie/sites/default/files/2019-08/HIQA-OlderPersons-Overview-Report-2018.pdf>

⁵ Joint Committee on Health (2019) *Report on the Provision of Homecare Services*. Available at: https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/joint_committee_on_health/reports/2019/2019-11-21_report-on-the-provision-of-homecare-services_en.pdf

- **Informal home care** from a family member or other support person. 195,263 carers also provide 6.6 million hours per year of unpaid assistance to others.⁶

The Nursing Home Support Scheme (Fair Deal) came on stream over a decade ago and introduced a statutory right to nursing home care. The comparable statutory Homecare Scheme was expected in 2021, however no statutory right to home care currently exists. As a result, the interdependence of home care and nursing home care remains absent in national policy, funding and budget allocations, and delivery across providers.

Individuals can pay privately for any of these services, however in terms of Government support and funding, there is currently a legal entitlement to the provision of nursing home care but no similar entitlement to home care. Home care and nursing home care can be partly or fully State-funded, depending on financial circumstances. Informal care by a family member or another person is supported by a carer's payment for full-time care.

Much work has taken place to explore and made recommendations on the issue of long-term residential care.

The 2011 HSE report 'Time to Move on from Congregated Settings – A strategy for Community Inclusion' recommended a new model of support in the community where people with disabilities living in congregated settings would be supported to move to community dispersed housing provided mainly by housing authorities and surrounded by wraparound community, social and administrative supports to enable them to live independently. Crucially, access to specialist and hospital services are provided for after an individualised assessment. A core aim of the model is to enable people to make their own life choices. According to HIQA, there are 2,900 people with a disability still living in congregated settings the many of whom are older. The HSE reported that there were 732 people over the age of 60 living in a congregated setting in 2018, of those 262 were over the age of 70.

In 2016, Sage, Third Age, Family Carers Ireland and Alone convened looked at the future of long-term care for older people via a public request for submissions, a forum and a national survey on long-term care for older people. A resulting report with recommendations – 'Responding to the Support & Care Needs of our Older Population Shaping an Agenda for Future Action Report of Forum on Long-term Care for Older People'⁷ was subsequently published and includes preferences for a community-based model of care delivery, clarity on funding, the need for appropriate community housing stock and need for funding for retrofitting, and the need for an integrated and holistic individual assessment to gauge care needs.

2. Congregated settings: long-term strategy for these settings in Covid-19 environment

2.1 Adopting a Human Rights-Based Approach to Care

Recommendation 1: A rights-based approach to care in Ireland requires action to fund and legislate for the right to care as the means to the highest attainable standard of physical and mental health for older people.

⁶ Central Statistics Officer (2016) *Census of Population 2016 – Profile 9 Health, Disability and Carers*. Available at: <https://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9cr/>

⁷ See www.sageadvocacy.ie.

Age Action supports a rights-based approach which empowers people to know and claim their rights. Central to the realisation of rights in this context is the adoption of a human rights framework to an integrated care model – one that supports the participation of older people in decision making and with effective and accessible remedies for disputes.

Significant gaps remain in applying a rights-based approach in practice in relation to longer term care in Ireland, notably by a lack of adequate Exchequer funding to allow for the standardisation of a rights-based approach to care delivery across services.

There are two levels to considering a human rights-based approach to the delivery of care: *systemic* and *operational*. Put more simply: whether care is available and accessible, and how it is delivered.

At the *operational* level, this relates to the individual's experience of their rights and dignity in delivery of health and care services and their involvement in decision making. This influences service's decisions such as staffing levels, provision of treatment, physical restraint, personal care, end-of-life decisions, privacy of personal information, and decisions which affect the day-to-day lives of people who use the service. HIQA uses the internationally recognised 'FREDA' framework to simplify the principles underpinning a human rights-based approach to care services. FREDA stands for: Fairness, Respect, Equality, Dignity and Autonomy.⁸

At the *systemic*, level, this relates to the individual's ability to access care based on planning for and ensuring appropriate care services are available. This influences state decisions such as financial planning to meet demand, the types of care available to the general public, and responding to systemic issues raised that are outside the remit of service providers. The previous 'FREDA' principles apply to the systemic level, in addition to the foundational right to health care⁹ as part of the right to enjoyment of the highest attainable standard of physical and mental health.¹⁰

There has been much discussion during recent weeks regarding the protection of rights and decision making involving older people during COVID-19, most notably in their transfers from acute hospitals to nursing homes and vice versa for care. Age Action notes the commitment by the HSE at the Committee to analyse the data, decision-making criteria and procedures employed to make these decisions and urges the publishing of all data to increase transparency and to aid in the integration of a rights-based approach in preparation for future waves.¹¹

Of concern and discussed at this Committee previously, we know from HIQA's most recent report into designated centres for older persons pre-COVID-19 showed that 27% were not compliant with regulations on resident's rights.¹²

⁸ Health Information and Quality Authority (2019) *Guidance on a Human Rights-based Approach in Health and Social Care Services*. Available at: <https://www.hiqa.ie/reports-and-publications/guide/guidance-human-rights-based-approach-health-and-social-care-services>

⁹ United Nations (2020) *Policy Brief: The Impact of COVID-19 on older persons*. Available at: <https://unsdg.un.org/resources/policy-brief-impact-covid-19-older-persons>

¹⁰ United Nations *Universal Declaration of Human Rights* Article 25 Available at: <https://www.un.org/en/universal-declaration-human-rights/>

¹¹ Health Service Executive (18 June 2020) *Oireachtas Special Committee on COVID-19 Response*.

¹² Health Information and Quality Authority (2019) *Overview report on the regulation of designated centres for older persons – 2018*. Available at www.hiqa.ie.

2.2 Congregated Settings: Capacity/Accommodation

Recommendation 2: A statutory model of care is needed to provide adequate, quality affordable care supports across the continuum of care, implemented fairly to support people's choice to age in place as they wish.

Ireland does not have an integrated system of long-term care either in legislation or in practice. We have seen from recent experience that older people are not systematically involved in the planning or review of their care services.

The system of long-term care in Ireland remains disjointed. The lack of policy integration between home care and residential care continues to put people directly at risk.

Person-centred care requires better integration of the transitions between care options to ensure the most appropriate type of care, at a set quality standard, is available to those who require it. A national integrated care pathway between home care and longer-term residential care is needed with standardised oversight of all types of care across all types of suppliers.

Currently, approximately 20% of older people need some form of support and care.¹³ There has been a clear bias in practice to date towards providing care in residential settings where approximately 4.5% of the over 65 population reside. While over 95% of the over 65 population are not residing in residential care and remain living in their communities, just 8% are in receipt of home care services.

Age Action hears from our daily work with older people and their families that adequate, quality affordable care supports is a critical issue which – when not available or implemented fairly - undermines people's choice to age in place as they wish.

The current statutory right to nursing home care only can drive users to enter nursing homes earlier than needed due to inability to access adequate home care supports or in recent months due to the lack of community home supports. For many more, nursing home care has been unavailable due to the spread or risk of COVID-19 and people have been left in limbo between services.

We know from international practice that long term care tends to be complicated by the involvement of different government ministries or departments, budget sources, and complicated guidelines and regulations for older persons to access entitlements. In the Irish context, all of these difficulties ring true.

Provisions for a clear continuum of care do not exist and as discussed above there are known issues with the availability of care (within the community and in nursing homes), access to adequate care, oversight and redress.

The spread of COVID-19 has further highlighted the fact that the challenges across nursing home, home care and family care sectors cannot be separated and gaps in the system have been exacerbated.

Age Action was concerned to hear of reports that people had their home care hours suddenly reduced without consultation during the recent pandemic. Many more told us they felt they were left with no choice but to voluntarily suspend their care hours due to fear about the spread of COVID-19 and lack of PPE for their care providers coming into their homes.

¹³ Sage presentation (26 May 2020) *Oireachtas Special Committee on Covid-19 Response*.

Given that there are approximately 7,000 people alone on the initial home care waiting list, losing home care hours and being returned to the waitlist is a significant issue that will – and has - resulted in some people being pushed towards nursing home care due to lack of home supports.

The impacts of lack of connection in the planning, funding and regulation of each sector cannot be ignored. In recent months, people in receipt of home care hours have had their time reduced or temporarily removed to allow for the temporary redeployment of staff to the nursing home sector during the crisis phase of the pandemic. This in turn put pressure on informal carers to provide support and we know that the care dependency need of many was increased as a result.

Any future pandemic planning must cover the whole care system.

We must learn these lessons to ensure a secure, integrated system of high quality care is available for all who need it going forwards, enabling people to access the most appropriate level of care for their needs.

Changes to admissions and discharge procedures in nursing homes in recent months saw transition between care types restricted and people left unable to access the care option most appropriate to them. Age Action remains concerned to hear of cases where people were left in limbo in nursing homes, unable to return home due to cuts to home care packages.

In one case, a person was forced to enter a private nursing home just before the pandemic to take up respite care due to home care hours not being available. Their initial two weeks of medically-recommended respite care resulted in them spending 3 months in the private nursing home when COVID-19 restrictions hit the sector. They could not return home as they wished as no home care hours were available. They were unable to move to a public nursing home which was not accepting new admissions in light of COVID-19. They have now been left with a bill of thousands for private nursing home care that they are expected to pay for from their own pocket.

The system of care in Ireland is biased towards congregated settings due to the absence of a statutory right to home care similar on a similar footing as long-term residential care (the Nursing Homes Support Scheme).

The physical infrastructure of many nursing homes as congregated, institutional settings creates situations where residents' rights to dignity and privacy are not upheld. HIQA's most recent report notes that 43% of centres for older persons failed to conform to premises regulations, which means that the people who live in these centres experience a poor quality of life.

In their day-to-day lives, these residents live in an institutional environment where they have very limited privacy during the delivery of intimate and personal care, no protection from noises or unpleasant odours, cannot choose the time they want to get up or what they watch on television, and have very limited ability to meet and converse with family and visitors in private.

HIQA notes that centres that struggle to comply with premises regulations, also struggle to achieve compliance with infection control regulations. The difficulty in meeting the premises requirements of the 2013 regulations experienced by some providers, led to an extension in 2016 to allow providers until 2021 to achieve compliance with physical infrastructure requirements. The generosity of this timeframe is clear in the context of the average length of stay of nursing home residents, which is 2.9 years.¹⁴

¹⁴ Nursing Homes Ireland (2018). *Advocating Equality in Fair Deal*. Available at: <https://nhi.ie>.

A recent study into deaths in Irish nursing homes notes that, in relation to spread of COVID-19, 'early epidemiological studies have suggested that long-term care facilities with a supportive living "own-door" model have fared much better compared to traditional multi-occupancy buildings.'¹⁵

Ireland needs to implement a move away from congregated care settings as committed to in the 2011 'Time to Move on from Congregated Settings – A strategy for Community Inclusion' report. COVID-19 highlights that alternative models of care for high-dependency older people must be considered, to promote older people's safety, rights, independence and quality of life in line with a rights-based approach to care, and the UN Convention on the Rights of Persons with Disabilities.

2.3 Scrutiny of response to initial Covid-19 clusters in nursing homes and impact of updated supports for the sector

Recommendation 3: In order to learn lessons, build trust and confidence in the sector, the circumstances of each and every death in residential care settings during COVID-19 should be independently reviewed.

There are pockets of good practice in evidence in recent months, and Age Action notes that 56% of nursing homes remained COVID-19 free during the pandemic.¹⁶

However, in order to learn lessons and build trust, it is crucial that an independent review into the response of the nursing home sector is urgently conducted. Specifically, Age Action urges a review into each death in residential care settings during COVID-19 as well as to look at nursing home responses to the pandemic. These learnings are vital to inform future policy development in this area including labour market issues, access to staff and equipment and infection control, with a Government commitment to implement any recommendations.

This investigation's recommendations should include the development of a whole-of-care-system contingency plan for future crises affecting formal and informal care.

2.4 Scrutiny of nursing home deaths and clusters during the Covid-19 crisis; Monitoring of nursing home standards during/post Covid-19; Supplies of PPE and protective equipment; Testing and tracing in nursing; Infection control in nursing homes

Recommendation 4: To strengthen the sector and provide an equitable standard of care, an independent review of the governance, oversight and enforcement mechanisms within the nursing homes sector (public, private and non-profit) should take place

Recommendation 5: A Commissioner for Ageing to be appointed to provide an independent voice to investigate and report to parliament on issues related to long-term care, where the sector has highlighted issues to the best of their ability and yet significant risk of harm has resulted from Government delays in responding.

The model of longer-term care in Ireland remains separated between home care and nursing homes, with a prioritisation on exit from hospital for allocation of care and evidenced difficulties in transitioning between both models. Within each mode of care, care is provided by statutory,

¹⁵ Romero-Ortuno, R. and Kennelly, S. (2020). *COVID-19 deaths in Irish Nursing Homes: exploring variation and association with the adherence to national regulatory quality standards.* <https://ltccovid.org/wp-content/uploads/2020/06/Ireland-care-home-variations-in-numbers-of-deaths-and-quality-indicators.pdf>

¹⁶ Department of Health (18 June 2020) *Oireachtas Special Committee on COVID-19 Response.*

voluntary and private entities with no national Government agency taking the lead to manage care provision.

This lack of policy integration between firstly public and private nursing homes, and secondly between home care and residential care, continues to put people directly at risk. There are 581 registered nursing homes in Ireland, providing care to over 31,000 people.¹⁷ Approximately 80% of these nursing homes are outside the HSE structure in the format of private or voluntary entities.

Experience gained over the recent months has shown us that adequate clinical oversight, monitoring with appropriate enforcement capability and clear governance structures are absent across the nursing home sector. Adequate and standardised medical care in nursing homes is also urgently needed and measures are needed to ensure that sufficient staffing resources are planned for across the sector.

We know that public health and Government messaging clearly identified older people as medically vulnerable from the outset of the pandemic and their protection formed a key motivating message to us all to adhere to public health advice. It is thus difficult to understand how the protection of those older people living in nursing homes was not prioritised at an operational level. It appears that nobody had responsibility for residents in the nursing home sector at the COVID-19 response decision-making table and that no national agency has the responsibility for taking the lead to manage either nursing home care or wider care provision.

Despite concerns raised by the sector in March, nursing home COVID-19 cases and deaths have continued to increase as proportion of all cases and deaths in Ireland over time – from being 15.5% of cases on 27 April, to 22% of cases on 22 June; and from 49.5% of deaths on 27 April, to 56.1% of all deaths on 22 June.

Nursing homes must be treated as part of the national health infrastructure to ensure consistent care standards. Nursing homes in the private and non-profit sector must be integrated into the wider framework of health and social care to standardise care, and nursing homes should follow shared guidelines on nursing, staffing, skill levels and medical care.

It is simply not acceptable to have a sector caring for over 31,000 residents without clear governance and accountability structures. Lessons have been learned through the COVID-19 pandemic about how public and private/non-profit nursing homes saw differences in lines of communication, oversight and crucially access to staffing, PPE and clinical supports. This disconnect in the sector regarding critical safety issues was known prior to COVID-19, for example HIQA's most recent report on designated centres for older persons notes the concerns raised by private nursing homes about their inability to access the expertise of the HSE's Safeguarding Office in responding to potential cases of abuse, a service available to HSE or HSE-funded nursing homes.

We are pleased to note the progress made recently with regard to HSE supports to all nursing homes and the roll out of multidisciplinary teams. However, without adoption of a single governance structure to manage all nursing homes in this jurisdiction, there is a real risk of current – and new – gaps impacting on the adequacy and quality of care being provided.

There is an urgent need for strengthening of HIQA's mandate for effective enforcement of appropriate care standards and investigation of individual complaints. Regulation monitors, supports and enforces quality standards in service provision. Without it, recipients of care may

¹⁷ Health Information and Quality Authority (2019) *Overview report on the regulation of designated centres for older persons – 2018*. Available at www.higa.ie.

receive inconsistent standards of care and service. There are long-known issues in Ireland in relation to standards and quality monitoring for both nursing homes and home care.

It is vital that an effective, independent and trusted oversight authority with appropriate enforcement powers is in place to provide for both investigation of complaints and to provide a voice for the most vulnerable.

Many older people feel left behind in the eyes of policymakers. An independent champion and advisor to government in the form of a Commissioner for Ageing is vital to promote cohesive, efficient, best practice government policy and services for this growing cohort. A Commissioner for Ageing is urgently needed to safeguard the interests of older people and with statutory authority to investigate systemic issues affecting older people, review the adequacy of policy, legislation and services affecting older people and to champion the future proofing of policy, legislation and practice to support responsive policy planning.

2.5 Communication between the nursing home sector and State bodies during the Covid-19 crisis; Nursing home restrictions (access by relatives)

Recommendation 6: The participation of older people in shaping the policies that affect their lives must be enabled.

When decisions were being made over the recent months, we did not hear the voices of residents, their families, staff or organisations representing older people represented during discussions. It is crucial that these voices and experience are involved in decision making to enable decisions to be made in the framework of a true understanding of sectoral needs, the impact on those involved and how best public health advice can be applied. In particular, the voices and views of people with dementia should be enabled.

From early on in the COVID-19 pandemic, our organisations heard from the family members of those in nursing homes simply unaware of why they could not visit their loved ones, confused about changes to the visiting regime and preventative practices, and concerned and in the dark about the measures individual nursing homes were taking to protect them.

Family members were left communicating with loved ones through the ground floor windows if they were lucky enough to be able to, with their calls going unanswered by low levels of overstretched staff. We know that digital communication was not possible in many cases due to low levels of digital literacy in an older population and their need to rely on the already overstretched staff. Many others simply did not have devices.

Clearer, standardised guidance from a single governance structure across the nursing home sector is needed to support nursing homes to effectively communicate with residents and representatives.

Inherent to a rights-based approach is the ability to exercise choice and control over one's own life and advocate for oneself. The experiences of older people during COVID-19 must shape our future responses. No evidence-based policy can be designed without the voices of older people being sought in a manner that allows their experience and diversity in older age (e.g. age, health, disability and location) to be included in decision making.

Traditionally, older people in Ireland are excluded from full participation in public consultation processes whether for reasons of digital literacy or supports to engage.

Age Action welcomes the commitment by the HSE at a recent Committee to broaden the National Care Experience Survey to include nursing homes, however we remain concerned as to the specific enabling measures in place to capture the varied voices and needs to be

adequately represented. It is vital that the experience of family members and carers is also adequately captured.

Of concern, older people were largely absent from public data analysis for much of the pandemic with large age cohorts such as ‘Over 65’ or ‘75+’ in evidence. This lack of disaggregated data is ageist and does not allow us to firstly, adequately capture the diversity of experience and outcome and secondly, to adequately plan for future policies.

We also need to broaden partnership with civil society and others involved across the care sector. It is crucial that those most directly involved across the sector are proactively consulted to have a true understanding of sector needs, the impact on those involved and how best public health advice can be operationalised. As we make preparations for future preparedness, it is vital that these lessons are learned and shared across the sector.

5. Conclusion

Older people want to age in place - meaning the choice to remain in their own homes and in communities as long and independently as possible.¹⁸ The vital role of adequate care supports such as home care to enable people to age in place safely has been highlighted during COVID-19, with gaps in the system exacerbated.

Policy decisions in response to COVID-19 highlighted both the lack of priority for our older people in vulnerable situations and also for those frontline workers providing essential – and often at risk – care and often poorly paid.

It is a time to re-evaluate and reassess the choice of care available for older people in Ireland as well as the governance of the sector. COVID-19 presents an obligation and an opportunity for a more inclusive, representative and age-friendly society with no one left behind. Older persons have long been subject to inadequate protection of their human rights and overlooked in national policies and programmes and this is particularly evident in terms of the provision of long term care.

About Age Action

Age Action is the leading advocacy organisation on ageing and older people in Ireland. Our mission is to achieve fundamental change in the lives of all older people by eliminating age discrimination, promoting positive ageing and securing their right to comprehensive and high-quality services.

Age Action supports and advocates for equality and human rights for all older people. Everything we do is based on a recognition of the diversity of identity and situation among older people and a concern for equality for all older people. In addressing ageing, our work includes a concern to influence perspectives on and responses to ageing. This pursuit of equality and human rights is underpinned by our work to promote ageing in place, life-long learning, and health and wellbeing for older people, empowering them to live as active citizens.

¹⁸ For example, see Browne, Michael (2016) *Responding to the Support & Care Needs of our Older Population Shaping an Agenda for Future Action Report of Forum on Long-term Care for Older People*. Available at www.sageadvocacy.ie.