



## 1. Introduction

The Alliance of Age Sector NGOs,<sup>1</sup> appreciates the opportunity to make a submission to the COVID-19 Nursing Homes Expert Panel.

The Alliance has consistently called for a coherent whole-of-government approach to influence policy for better delivery of services and supports for all as we age. 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.

The vital role of adequate care supports to enable people to age in place safely has been highlighted during COVID-19, with gaps in the system exacerbated.

When people are provided with the level of care and support they need, they can continue to live dignified lives whether in their own homes or in residential care, which is their preference and right.

### 1.1 Rights-Based Approach to Care

**Recommendation: 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.**

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.

Across the system of longer-term care in Ireland, it is clear that access to quality and accessible care is a critical enabler for older people to realise their rights.

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<sup>1</sup> The Alliance of Age Sector NGOs is a collaboration of eight leading Non-Government Organisations working together to address the key issues facing older people. The members of the Alliance are Active Retirement Ireland, Age Action, Age & Opportunity, ALONE, The Alzheimer Society of Ireland, The Irish Senior Citizens Parliament, Third Age and the Irish Hospice Foundation.

The Alliance of Age Sector NGOs 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 – crucially one that supports the participation of older people in decision making and with effective and accessible remedies for disputes. 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.

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.

## 1.2 Value of Care in Ireland

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

The COVID-19 crisis has shown that care is not valued in Irish society. The pandemic has laid bare the weaknesses in the provision of home care and nursing home integration and within the nursing home sector itself between public and non-public nursing homes.

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. Urgent action is needed to introduce decent pay, conditions and supports for those working in the care sector to promote stable and ongoing staff in each location and reduce staff movement between homes.

An independent review into each and every death in residential care settings during COVID-19 is needed in order to inform future policy development in this area including labour market issues, access to staff and equipment and infection control. This review should consider the development of a whole-of-system emergency plan for future crises affecting formal and informal care.

## 2. Recommendations

### 2.1 Effective Oversight

**Recommendation: 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.**

There are 581 registered nursing homes in Ireland, providing care to over 31,000 people.<sup>2</sup> As of 8 June, there were 5,232 cases of COVID-19 in nursing homes, and 933 deaths. Despite concerns raised by the sector in March, nursing home cases and deaths have continued to increase as proportion of all cases and deaths in Ireland over time.<sup>3</sup>

The model of longer-term care in Ireland remains separated between home care and nursing homes, with arguably a focus on hospital exit for both sectors and evidenced difficulties in transitioning between both models. Within each mode of care, care is provided by statutory, voluntary and private entities with no national Government agency taking the lead to manage care provision.

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.<sup>4</sup>

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. Access, adequacy, regulation and access to resources is not standardised and varies as a result of the setting in which they receive it.

We know that pre-existing care issues have been exacerbated during COVID-19. Shared guidelines are urgently needed on staffing, skill levels and medical care. Nursing homes in the private and non-profit sector must be integrated into the wider framework of health and social care and all nursing homes should follow shared guidelines on nursing staffing, skill levels and medical care.

Nursing homes must be treated as part of the national health infrastructure.

It is simply not acceptable to have a sector caring for over 30,000 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.

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<sup>2</sup> HIQA (2019) *Overview report on the regulation of designated centres for older persons – 2018*. Available at [www.hiqa.ie](http://www.hiqa.ie).

<sup>3</sup> This saw an increase of nursing home residents are being 15.5% of cases on 27 April to 20.7% of cases on 8 June 2020 and from 49.5% of deaths on 27 April to 55.4% of all deaths on 8 June 2020. Source, Department of Health COVID-19 briefing 8 June 2020.

<sup>4</sup> As discussed in Sage (2020) *Delivering Quality Medical Care in Irish Nursing Homes Current Practice, Issues and Challenges A Discussion Document* which outlined a 'lottery effect' for medical care with regard to location, size of nursing home, local GP availability and whether a nursing home is public or private. It also discusses the greater role for multidisciplinary training between 'nursing home staff, GPs, Allied Health Professionals and geriatricians in respect of delivering quality medical care in the nursing home setting'.

To date over 55% of all COVID-19 deaths have taken place in nursing homes. The HSE has been clear that they have acquired a new and unexpected role in bringing all nursing homes in Ireland under their governance remit during COVID-19 and there has been a focus in the media on the apparent failure to plan for and support nursing homes as sites of significant infection risk in COVID-19 pandemic planning.

We are pleased to note the progress made in recent weeks with regard to HSE supports to all nursing homes. 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 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.<sup>5</sup>

Regulation monitors, supports and enforces quality standards in service provision. Without it, recipients of care may 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.

## 2.2 Effective Engagement with those Directly Affected

**Recommendation: To enable the participation of older people to harness their knowledge and ensure their full inclusion in shaping the policies that affect their lives and also broaden partnership with civil society and others.**

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.

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 about the measures individual nursing homes were taking to protect them.

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

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

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<sup>5</sup> HIQA’s most recent report found 23% of nursing homes were fully compliant with all regulations, down from 27% in 2017. 18% were not compliant with infection control regulations. HIQA (2019) *Overview report on the regulation of designated centres for older persons – 2018*. Available at [www.hiqa.ie](http://www.hiqa.ie).

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.

### 2.3 Choice of Care in Ireland

**Recommendation: To re-evaluate and reassess the choice of care available for older people in Ireland, one which provides for a continuum of care and does not leave people without the ability to age in place at home if that is their wish.**

We know from the Alliance's 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.

Ireland does not have an integrated system of long-term care either in legislation or in practice. 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. This ongoing absence of a statutory model to provide a continuum of care between home supports and nursing homes has resulted in people left without adequate care.

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.

The development of a statutory home care scheme – reflecting a rights-based approach to the design and implementation of the scheme – will provide a legislative basis for equitable access to home supports across the country. The numbers of people aged over 85 is projected to double in the next 20 years. It is estimated that 72.3% of the population aged 85 and over will have a disability. By 2030 the over 65 cohort will increase by 59% and the over 85 group by over 95%. The increase in the ageing population will result in higher numbers of people with dementia which will have implications for care provision and expenditure.<sup>6</sup>

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.

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<sup>6</sup> Cahill S. et al (2012) *Creating excellence in Dementia care: A research review for Ireland's National Dementia Strategy*. DSID's Living with Dementia Research Programme, School of Social Work and Social Trinity College Dublin & the Irish Centre for Social Gerontology, NUI Galway, Dublin.

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.<sup>7</sup> In the Irish context, all of these difficulties ring true. Provisions for a clear continuum of care do not exist and there are known issues with the availability of care (within the community and in nursing homes), access to adequate care, oversight and redress.

In many cases, people have been forced to consider nursing home care due to the lack of community home supports. In many of these cases, nursing home care has been unavailable due to the spread or risk of COVID-19 and people have been left in limbo between services.

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. Gaps in the system have been exacerbated. The impacts of lack of connection in their planning, funding and regulation cannot be ignored.

We must learn these lessons to ensure a secure, integrated system of high quality care is available for all who need it going forwards.

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<sup>7</sup> 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](http://www.social.un.org). and Sage Advocacy (2019) *Financing Long-term Care in an Ageing Society The Challenge Facing Ireland Summary*. Available at [www.sageadvocacy.ie](http://www.sageadvocacy.ie).