Safeguarding IRELAND

Special Committee on Covid-19 Response,
Leinster House,
Dublin 2
D02 XR20
Email: covid19@oireachtas.ie

24th June, 2020.

Dear Chair and Members of the Committee,

On behalf of Safeguarding Ireland, I would like to thank you for affording us the opportunity to make this submission to the ***Oireachtas Special Committee on Covid-19 Response.***

Safeguarding Ireland is an independent organization, is a registered charity with the Charities Regulatory Authority and is also registered with the Companies Registration Office. Safeguarding Ireland was established to promote safeguarding of adults who may be vulnerable, support and promote their human rights, protect them from all forms of abuse by persons, organisations and institutions and develop a national plan for promoting their welfare. Further information is available on our website – www.*safeguardingireland.org*

I would like to wish the Committee well in its deliberations and will be pleased to answer any queries that you may have.

Yours Sincerely,

Patricia Rickard-Clarke.
Chair.

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Safeguarding Ireland Submission to Oireachtas Special Committee on Covid-19 Response.

24th June, 2020.

1) Safeguarding Ireland (S.I.) is an independent organization registered with both the Companies Registration Office and the Charities Regulatory Authority. Its objectives, broadly, are to promote safeguarding of adults who may be vulnerable, support and promote their human rights, protect them from all forms of abuse by persons, organisations and institutions and develop a national plan for promoting their welfare.

2) S.I. considers people in long term residential care settings, i.e., people in nursing homes, to be among the most vulnerable group in society. In terms of Covid-19, this group certainly bore the brunt of the suffering, with very many deaths. In addition, they suffered anxiety as a result of their vulnerabilities, sometimes lack of communication with them and their families, bereavement due to death of friends and acquaintances in large numbers and enforced extreme cocooning due to visiting restrictions. The term long-term residential care may, in itself, be misleading, as more than half of residents admitted to nursing homes die within two years (53%) with over a quarter passing away within six months (27%)[1].

3) Up to midnight on 30th May 2020, the number of clusters/outbreaks of Covid-19 in nursing homes stood at 258[2]. The National Public Health Emergency Team (NPHET) has outlined that the number of care home resident deaths, as a percentage of all Covid-19 deaths in Ireland, stands at 62%. Only Canada, at 82%, has a higher percentage. Notwithstanding the fact that it is difficult to accurately compare Covid-19 data at this time, the percentage of care home resident deaths is relatively high in Ireland. The figures do provoke questions and an impetus to review the model of provision of long-term residential care for older people. Such a review is needed, not necessarily as a result of Covid-19, but it adds to the already compelling need for such a review which has been advocated by a number of agencies, such as Sage Advocacy and others, over the last number of years[3].

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[1] *https://www.irishtimes.com/news/health/study-reveals-nursing-home-death-rate-1.747254*

[2] *Epidemiology of COVID-19 in Ireland. Report prepared by HPSC on 01/06/2020 for National Public Health Emergency Team.*

[3] *Responding to the Support and Care Needs of our Older Population. Sage (July 2016)*

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4) Our submission is primarily one that looks to the future in terms of affording older people their basic human rights through proposals for future care arrangements, not just in nursing homes, but across all care services. This submission makes a number of recommendations at the end of the document which S.I. considers to be fundamental in approaching a better future for older people in need of health and social care services.

5) Adult safeguarding involves working with adults with health and social care and support needs to keep them safe from abuse, exploitation and/or neglect. Older people with health and social care needs may be at greater risk of abuse, exploitation and/or neglect due to a number of possible factors, including age; gender; lack of capacity to make decisions, due for example, to dementia; communication difficulties resulting from a stroke; physical dependency because of a health condition or disability; isolation and social exclusion which may be due to loss of mobility or institutionalisation; and lack of access to information and support.

6) In 2019, Safeguarding Ireland and the Health Information and Quality Authority produced guidance on a human-rights based approach to care[4] which outlined a number of basic human rights principles that should be respected when people are in receipt of health and social care. These principles are ***Fairness; Respect; Equality; Dignity;*** and ***Autonomy***. Safeguarding Ireland believes that the current model of social care and support for older people inherently mitigates against the application of these principles.

7) This submission focusses on the current system in Ireland of social care for older people through the human rights lens as set out above and against the backdrop of the Covid-19 crisis. It makes recommendations for a future care model that upholds the human rights principles.

8) The current system of social care for older people accommodates, by and large, only two options, namely homecare or residential care in a nursing home. There are few other options available, despite some voluntary or community provision of sheltered housing-type arrangements. Home care and residential care, i.e., nursing home care, is provided directly by the HSE, or by private or voluntary providers with funding from the HSE. Private provision of both home care and nursing home care currently makes up a very high proportion of total care provision. The HSE website lists, by CHO, over 100 approved home care provider agencies for older people that are funded to provide care by the HSE. Though some of these

[4] *Guidance on a Human Rights-based Approach in Health and Social Care Services. HIQA. Safeguarding Ireland. (2019).*

providers are voluntary organisations, the vast majority are for-profit agencies. The HSE's target for 2020 is to deliver 19 million hours of home care, including that provided through intensive home care packages. A large proportion of these hours will be delivered by private agencies.

9) There are approximately 31,969 nursing home beds for older people in the state provided through 585 HIQA-registered centres. Of these, 122 are HSE facilities, 443 are private facilities with the remaining 20 funded by the HSE under Section 38 or 39 arrangements. The budget for residential care provision, i.e., the Nursing Homes Support Scheme (Fair Deal), for 2020 is just over €1bn.

10) Currently, the administration of social care for older people is fragmented. There is little integration between home care and residential nursing home care and there is a separate funding stream for each. The process of, and tools used for, assessment for home care differs across the country. In some areas, assessment is carried out by Home Help staff, some of which have no clinical qualification, while in other areas the assessment is completed by the public health nursing service. The public health nursing service is aligned with the Primary Care Division within the HSE structures while the budget for home care rests within the Older Persons' Division. The care needs assessment for residential care is carried out by the public health nursing service, with different assessment tools used across the country. The budget for residential care is separate to the rest of the budget for Older Persons' Services.

11) Looking at these arrangements through the lens of the human rights principles outlined above highlights some very obvious shortcomings. It may be useful, at this juncture, to look at the meaning of each of the five principles outlined in the ***Guidance on a Human Rights-based Approach in Health and Social Care Services.***

a. ***Fairness*** "*means ensuring that when a decision is made with a person using a service about their care and support, that the person is at the centre of the decision-making process. The person's views are sought, listened to and weighed alongside other factors relevant to the decision. It is important that decisions are made in a way that is clear and fair, to allow others to know how they might be treated in similar circumstances. If a decision interferes with a person's human rights, this must be legally justified, proportionate and only taken when all other alternatives have been considered".*

b. ***Respect*** *"is the objective, unbiased consideration and regard for the rights, values, beliefs and property of other people. Respect applies to the person as well as their value systems".*

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c. ***Equality*** *"means people having equal opportunities and being treated no less favourably than other people on the grounds set out in legislation. In an Irish context, these grounds are: age; civil status; disability; family status; gender; membership of the Traveller community; race, colour or nationality; religion or sexual orientation"*
d. ***Dignity*** *"means treating people with compassion and in a way that values them as human beings and supports their self-respect, even if their wishes are not known at the time".*
e. **Autonomy** *"is the ability of a person to direct how they live on a day-to-day basis according to personal values, beliefs and preferences. In a health and social care setting, autonomy involves the person using a service making informed decisions about their care, support or treatment".*

12) If we examine the current system of social care in Ireland and the various stages in the application for, and provision of, social care, it can be seen that the human rights principles are not adequately embraced. Once a person applies for care, be it home care, e.g., a home help service, or nursing home care, the assessment of the need for the services is inconsistent, as described above, without a single standardized assessment tool. This inconsistency does not conform to the principles of ***fairness, respect or equality.***

13) The HSE has been planning, for a number of years, to introduce the interRAI assessment tool, so there is a tool that has been tested and is readily available. [I]nterRAI comprises a "*suite of seamless and comprehensive clinical assessment instruments, developed by an international collaborative to improve the quality of life of vulnerable people".*[5] It is used in up to 50 countries to determine healthcare needs of people.

14) Following an assessment of care needs, if a person is in need of home care, there is no automatic entitlement to such care. In addition, the wait for home care is dependent, to a large extent, on what part of the country one lives in. If the assessment determines that there is a need for residential nursing home care, there is an automatic entitlement to such care and, by and large, there is no waiting list. This incentivises decisions being made with a bias towards residential care. Moreover, because of the lack of integration between the arrangements for home care and residential care, the service is fragmented and does not afford an older person either choice or the most optimum available service for them. These arrangements impact negatively on older people's rights to

[5] *www.interrai.co.nz*

autonomy, dignity, fairness and equality. Ideally, the provision of social care for older people should embrace a continuum of care, from living at home with supports at one extreme to some form of residential care at the other extreme, with a variety of options along the continuum, including, for example,

- Home Share – Older people having someone else living with them for low rent and some support in return.
- Split Housing – Older people living independently or adjacent to relatives.
- Boarding Out – People who require support moving into another person's home on a paid basis.
- Supportive Housing – Dedicated Housing for people which provides supports for independent living.
- Retirement Villages – Clustered age-friendly housing with provision for social interaction.
- Older Persons' Co-Housing Communities - Group living which groups of houses around shared space and amenities.
- Housing with Supports – round-the-clock support and care.
- Long Term Residential Care such as Teaghlach Model or Bruff Carebright Community.

15) The provision of these care options requires a number of government departments to be involved, including, for example, the Department of Health; the Department of Transport; the Department of Housing; the Department of Agriculture, Environment and Rural Affairs; etc.

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16) The vast majority of older people wish to remain in their own homes and communities for as long as possible. Most families of older people do not want their loved ones to have to enter nursing home care, though some people might prioritise perceived safety in a nursing home over an older person's freedom to choose to live with risk. Entering residential care is a life-changing event. While nursing home care may be necessary for some, it should be considered only when all other care/accommodation options have been deemed unsuitable. For other care groups, namely people with mental health challenges and people with physical and/or intellectual disabilities, there has been a policy shift away from the provision of institutional care. However, for older people, residential care is incentivised through financial support and minimum waiting times. The current arrangements do not support peoples' equality, dignity and autonomy.

17) It is a fact that, as people age, they tend to become more dependent. They tend to be at greater risk of developing chronic and enduring conditions such as Cardio-Vascular Disease, Arthritis, Chronic Obstructive Pulmonary Disease, Type 2 Diabetes, Parkinsons Disease and Dementia. As they age, older people are likely to be less resistant to stressors (such as Covid-19); they tend to have comorbidities; they may have very different disease presentations[6]; and assessment can be difficult due to cognitive impairment. All of these challenges require specialist expertise. However, most nursing homes have limited and/or inequitable access to the expertise of Consultant Geriatricians, Old Age Psychiatrists, gerontological nursing and allied health professional expertise (Physiotherapy, Speech and Language Therapy, etc.). In addition, there needs to be explicit staffing to dependency ratios in nursing homes or other care centres. Moreover, end of life care and palliative care and expertise is not universally available in all care settings. The foregoing impacts on nursing homes residents' rights to ***Fairness, Equality, Dignity and Autonomy.***

18) If an older person is in receipt of care, regardless of the setting, there should be written standards in place, underpinned by regulations, which ensures the care is delivered safely and to a high quality and the rights of older people are respected and upheld. Currently only "designated centres" are required to be registered with the Health Information and Quality Authority (HIQA). A designated centre is a place where a dependent person receives care and accommodation. HIQA *"is committed to protecting and safeguarding those who are vulnerable. In doing so, we look to take a human rights-based approach to our work. The evidence outlined in this paper shows that there are large numbers of people being*

[6] *Geriatric Medicine and why we need Geriatricians! by Juergen H. A. Bludau, MD*

cared for in a range of different care settings. There are currently a significant number of these settings that do not fall under the definition of a designated centre and are therefore unregulated. Service users in these unregulated sectors may be just as vulnerable as those being cared for in designated centres. They also have the same right to high-quality care as those people living in designated centres. As such, there is a need to review and expand regulation to have oversight and provide public assurance on the different models of care and service delivery[7]".

19) Older people in receipt of care, regardless of where this care is delivered, can be vulnerable to abuse, exploitation and/or neglect. In fact, older people in receipt of care in their own homes may be more susceptible to abuse because there tends to be less oversight of the care, there can be many organisations involved in care delivery and there are no regulations in place on the standards of care to be provided. It is important that all older people, regardless of the care setting, be it their own homes or elsewhere, are in receipt of care that protects and promotes all of the principles of their human rights.

20) In any decision relating to care for older people, the older person must be at the centre of the decision-making process. This is not always the case and there is evidence that some older people are placed in residential care against their preferred wishes, which is a clear breach of their human rights. Article 40.4.1 provides that *"No person shall be deprived of his personal liberty save in accordance with law".* The current gap in procedural safeguards to protect a person's liberty in relation to care placements must be immediately addressed to comply with fundamental rights under the Constitution. This breach of human rights is exacerbated in many cases by the imperative to "free up" acute hospital beds. There are many older people who are discharged from acute hospitals to nursing homes as a quick and expeditious means of freeing up acute beds. This is actively supported through the provision of transitional care funding which provides financial support to private nursing homes to take such clients. This practice creates a powerful incentive for acute services, families and nursing homes to promote residential nursing home care, sometimes against the wishes of older people and, in many cases, may provide for unnecessary residential care arrangements. It is a fact that older people tend to become increasingly dependent in acute hospital settings and, sometimes, these dependencies can be reversed if given the opportunity. The need to free up acute beds and ensure that older people are accommodated in the most appropriate setting might be achieved by converting a number of beds in public community hospitals/community

[7] *Exploring the regulation of health and social care services – Older People's Services Health Information and Quality Authority (March 2017).*

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nursing units into intermediate/transitional care beds. These beds could be used to rehabilitate some older people following an acute illness, allowing them to gain some independence and return home, with or without supports, depending on the need. These intermediate care facilities must be part of an overall single integrated system of care for older people. Consideration might also be given to increasing the resources of Community Intervention Teams (C.I.T.) in order to provide robust, responsive and accessible inter-disciplinary teams in the community which can be mobilised if health deteriorates to prevent hospital admission and promote rehabilitation, as well as accepting hospital discharges. Unfortunately, many older people, particularly those in residential care, may not be able to express their wishes and preferences. This should not be a barrier to eliciting their wills, preferences and choices.

21) As a society, we have an obligation to protect our most vulnerable and, in line with our obligations under the UN Convention on the Rights of People with Disabilities, which Ireland signed in 2007 and finally ratified in 2018, we have undertaken to provide appropriate and effective safeguards to prevent abuse in accordance with human rights law. Legislation needs to be enacted to specifically protect all vulnerable people and enshrine their rights in law.

22) Safeguarding Ireland strongly believes that if we are really serious about providing the best quality care for older people, the recommendations outlined below provide a sound initial starting-point.

23) Safeguarding Ireland's final two recommendations lie at the core of everything that has preceded them. S.I considers the enactment of safeguarding legislation to support and protect all vulnerable people fundamental to any future consideration of care needs.

RECOMMENDATIONS.

Recommendation No. 1.

The HSE should immediately introduce a standardised assessment tool for all social care needs assessments for older people.

Recommendation No.2

There should be a single statutory, centrally managed and integrated system for the assessment, delivery and funding of all social care across the whole care continuum, from home care to residential care.

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Recommendation No. 3
A range of social care options should be available for all older people as they become dependent.

Recommendation No.4
An expert group should be established to determine the future model of social care for older people with meaningful consultation with older people. This group should publish its findings by the end of 2020.

Recommendation No.5
Every older person, regardless of where they live, should have equity of access to specialist care services, including palliative and end-of-life care, as their needs dictate.

Recommendation No. 6
There should be clear oversight, responsibility and accountability arrangements for clinical care in all residential care settings.

Recommendation No.7
There should be mandatory minimum staffing requirements relative to dependency levels of residents in all residential care settings.

Recommendation No.8
Delivery of care for older people in all care settings should be subject to regulation which is underpinned by care standards and subject to monitoring and inspection.

Recommendation No. 9
Immediately enact Protection of Liberty Safeguards to ensure a person's right to autonomy is respected in relation to Place of Care.

Recommendation No.10
Review the practice of discharging older adults directly from acute hospital care to residential care settings. Consider the provision of more intermediate/transitional care beds in public long-stay units with the purpose of rehabilitating and assessing older people for future care needs. Review and strengthen the role of Community Intervention Teams in hospital and residential care avoidance.

Recommendation No. 11
Immediately fully implement the provisions of the Assisted Decision-Making (Capacity) Act, 2015.

Recommendation No. 12
Enact Adult Safeguarding Legislation.