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Chief Commissioner
Irish Human Rights and Equality Commission
16-22 Green Street
Dublin 7

Via Email and Post

2 September 2020

Dear Chief Commissioner,

Congratulations on your recent appointment and please extend my congratulations to the new Commissioners.

I am writing to you regarding the position of, and action by, the Irish Human Rights and Equality Commission in relation to the impact of COVID-19 on older people, noting your submission to the Oireachtas Special Committee on COVID-19 Response in June 2020 on *The Impact of COVID-19 on People with Disabilities*.

COVID-19 has highlighted the longstanding inequalities we face as a society and the vital role which Government supports and planning plays for people in the most vulnerable situations. There are a number of known issues that the IHREC could bring attention to and seek to mitigate.

To support IHREC to give priority consideration to issues of equality and human rights of older people in the context of COVID-19, Age Action has gathered together examples of the lived experience and impact of recent response measures on older people.

1. Disproportionate burden on older people

The impact of the COVID-19 pandemic, the manner in which this has been managed, and the response measures involved have placed a disproportionate burden on older people. In particular, we believe, this is evident in the 'cocooning' measures; access to mainstream health services; economic impacts; and for those living in residential care settings. In addition, official Government response measures, addressing COVID-19, failed to reflect the diversity of experience and resilience of those considered as older aged.

Cocooning measures recommending that older people remain at home were presented without consultation by Government and immediately left older people bearing a disproportionate burden in the national response measures. The Government narrative on cocooning presented the advice as standard for all older people, rather than empowering older people's autonomy. The risk of COVID-19 to older people was not presented to people in an accessible and detailed way to allow them to manage their decision making regarding self-isolation. Blanket Government advice for Ireland based on age (e.g. for all over 70s) exacerbated negative stereotypes about older people as frail and vulnerable, rather than linking cocooning advice to physical health alone. The linking of cocooning to age, in turn, led to broader media narrative focusing on older people as dependent and a sense in the community that older people seen in public locations should not be there. Age

Action heard from older people who felt that they were judged by other members of the community when they were out of their homes during this time.

Age Action heard from many older people who found the sudden – and lengthy – curtailment of their activities to have had an impact on their physical and mental health, including those recovering from ill-health being left unsure how best to follow their medical advice for recovery. It is reasonable to assume that cocooning had an unequal impact on those already experiencing existing inequalities, such as older people at the intersection of age and disability, socio-economic status and sexual orientation.

Changes to **mainstream health services** during COVID-19 have had a disproportionate impact on older people and impacted on their ability to achieve equal outcomes in relation to their health. Chronic health conditions are often more prevalent in old age; increasing risks for older adults.[1] As we age, we are more likely to have ongoing health needs that require medication and assistance, and to require routine home-based visits and community care.[2] In the face of the demands of COVID-19 on the healthcare system, we saw that older people faced challenges in accessing medical treatments and health care.[3]

Since March 2020, Age Action has heard reports of those cocooning experiencing difficulties in accessing non-COVID-19 related healthcare for on-going conditions e.g. post-operative rehabilitation, long term conditions. We heard of difficulties in contacting GPs for non-COVID-19 supports as they were prioritising COVID matters. Guidance on this by the HSE was unclear.

Looking at **income adequacy and supports**, many older workers have faced a delayed return to the workplace – or unemployment – due to continued advice to cocoon or restrict their movements based on age. The measures taken by the Government to protect public health has affected individuals' right to work. Older workers were not eligible for Pandemic Unemployment Payment (PUP) by virtue of their age alone (aged over 66). This would seem to constitute age discrimination. This negative situation for those aged over 66 has continued, the announcement in recent weeks of recovery grants - the Enterprise Support Grant - for self-employed recipients is restricted to those previously in receipt of the PUP and thus effectively excludes self-employed business owners aged over 66 from accessing the support.[4]

Age Action has received almost daily calls and contacts from those in receipt of the pension who had lost their jobs and were worried about how they would meet their cost of living: both new and existing costs.

2. Situation of older people in residential settings

Overall, 56% of all deaths during COVID-19 took place in nursing homes (as of July 2020) where 0.65% of the population live. Questions have arisen over whether the approach taken to COVID-19 in care homes has been sufficient and appropriate including whether residents of care homes

[1] UN Secretary General (May 2020) *Policy Brief: The Impact of COVID-19 on older persons.* Available at https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2020/05/COVID-Older-persons.pdf.
[2] *Ibid*.
[3] *Ibid*.
[4] Department of Employment Affairs and Social Protection (14 August 2020) *Enterprise Support Grant for businesses impacted by COVID-19*. Available at https://www.gov.ie/en/service/739f3-enterprise-support-grant-for-buisnesses-impacted-by-covid-19

were afforded equal access to hospital treatment, the delay in access to personal protective equipment for the protection of both staff and residents in non-HSE homes, and the availability of COVID-19 testing of care home residents and staff.[5]

Age Action has spoken to several families of nursing home residents who have died during the pandemic. They have a number of concerns. These include:

- The absence of an independent review or enquiry – or commitment to such - into a number of deaths which remain unexplained
- The apparent absence of a body in a position to provide independent oversight, enquiry or review mechanisms, regarding nursing home practices during COVID-19, as distinct from HIQA's role in the management of COVID-19 in nursing homes and as members of the NPHET
- The standards of clinical care provided to those who died and the basis of certain clinical decisions taken as part of their care
- The standards of overall care provided in nursing homes - including infection control measures, staffing resources in place, procedures and protocols followed - in the context of a regulatory regime that is tasked with ensuring adequate and enforceable standards
- The links and communication channels in place between private nursing homes and HSE infrastructure on a local and national basis
- The reason for the unexpected passing of relatively young and well relatives, who died during the height of the pandemic
- The apparent variance in the care experience among families with relatives in the same home, including communication with family members
- The reason(s) for why certain nursing homes experienced a far higher number of deaths than others, or the national average
- The basis for - and reason why - the management of certain homes was taken over by hospital groups/HSE
- The system and robustness of the attestation of death warrants in light of recent commentary by HIQA on variances between their analysis on excess mortality due to COVID-19 and official COVID-19 deaths[6] and updated guidance from the Irish Coroner which provides for acceptance of a clinical diagnosis without the requirement for post-

[5] Similar issues were raised in the submission of the Scottish Human Rights Commission (22 July 2020*) Submission to the Equalities and Human Rights Committee, Inquiry COVID-19.* Available at https://www.scottishhumanrights.com/media/2063/covid-19-ehric-submission.pdf.

[6] On the launch of HIQA (July 2020) *Analysis of excess all-cause mortality in Ireland during the COVID-19 epidemic. Available at www.higa.ie*, Chief HIQA Scientist stated that 'Based on an analysis of the death notices reported on RIP.ie since 2010, there is clear evidence of excess deaths occurring since the first reported death due to COVID-19 in Ireland. There were about 1,100 to 1,200 more deaths than we would expect based on historical patterns; a 13% increase between 11 March to 16 June. However, the number of excess deaths is substantially less than the reported 1,709 COVID-19-related deaths over the same period.' See https://www.higa.ie/higa-news-updates/covid-19-causes-13-increase-deaths-ireland-between-march-and-june-2020-higa.

mortem viral swabbing.[7]

Early in the COVID-19 pandemic, international evidence showed that older people in nursing homes were particularly vulnerable to the disease. International rights bodies have highlighted that residential care institutions were not prioritised in terms of intervention in the beginning of the crisis in many countries, which left residents and staff unprotected.[8]

In Ireland, the known disproportionate risks to older people in long term residential care were not considered on an equal basis to other demographics in relation to Government COVID-19 planning. While public health advice focussed on the risk for 'older people' in general in early stages, similar planning for those in an even more vulnerable setting – in longer term residential care – did not take place at this time.

In Ireland's initial National Action Plan in response to COVID-19, nursing homes were mentioned specifically in relation to providing step-down facilities to free up hospital beds, and the risks to existing residents were not addressed.[9] While additional plans were put in place for the nursing home sector and their residents 2.5 weeks later, the formal Government of Ireland *National Action Plan in Response to COVID-19 (coronavirus)* has not been updated to include additional nursing home commitments. There was delayed action by Government in responding to concerns of private nursing homes regarding PPE supplies, testing and staffing shortages, potentially putting older people at greater risk.

Many nursing homes restricted access to visitors in line with advice received from Nursing Homes Ireland and subsequently in line with public health advice as an infection prevention and control practice. The removal of the potential for visiting in residential care centres caused upset both for those living there and their family members. In addition, the lack of visitors in nursing homes as a result of HSE guidance on visiting in residential care eroded the opportunity for family oversight and raised the risk of abuse or neglect going unnoticed. The restriction of visiting and physical distancing can negatively affect the physical and mental health and well-being of older persons, particularly those with cognitive decline, and who are highly care-dependent.[10] The autonomy of older people to be involved in their own decision making regarding visitors was also removed.

There are long-known issues in Ireland in relation to standards and quality monitoring for nursing homes and home care. Pre-existing care issues have been exacerbated during COVID-19, relating to the regulation of the nursing home sector and the lack of Government support for other types of care which results in additional pressure on nursing homes. As long ago as 2017, HIQA

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[7] Coroner Service (2020) *Guidance in relation to the Coroners Service and Deaths due to Covid-19 infection.* Available at www.coroners.ie.

[8] Age Platform EU (May 2020) *COVID-19 and human rights concerns for older persons.* Available at www.age-platform.eu.

[9] Government of Ireland (16 March 2020) *Ireland's National Action Plan in Response to COVID-19 (coronavirus).* Available at https://www.gov.ie/en/publication/47b727-government-publishes-national-action-plan-on-covid-19/#:~:text=Government%20Publishes%20National%20Action%20Plan%20on%20COVID%2D19,-From%20Department%20of&text=The%20plan%20has%20been%20prepared,risk%20of%20people%20becoming%20unwell&text=reduce%20the%20economic%20and%20social%20disruption%20associated%20with%20the%20COVID%2D19%20outbreak.

[10] UN Secretary General (May 2020) *Policy Brief: The Impact of COVID-19 on older persons.* Available at https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2020/05/COVID-Older-persons.pdf.

has advocated for the development of regulations and standards for the home care sector.[11] Reports from the Department of Health (2018)[12] and from the Oireachtas Joint Committee on Health (2019)[13] have also consistently raised the need to regulate the formal home care sector.

As seen in the most recent 2019 HIQA overview report on the regulation of designated centres for older persons, only 23% of centres were fully compliant, and basic rights were not always respected in relation to dignity and privacy (such as privacy in the provision of intimate care), and safety.[14] Some 27% of centres were not compliant with regulations on resident rights, and 18% not compliant on infection control. HIQA's report *The Impact of COVID-19 on nursing homes in Ireland* notes that of 44 high-risk homes inspected since late May 2020, none were fully compliant with regulations, and 50% were not compliant with infection prevention and control measures.

Beyond questions on the quality of provision, COVID-19 has highlighted issues that relate to the model of provision. Since 2011 the Irish Government has committed to end the use of congregated settings and has noted that these institutional settings mean that many residents lack basic privacy and dignity. This change has not yet been fully implemented and many residents remain without single room occupancy and concerned about privacy.[15] This has been brought to IHREC's attention on previous occasions. These centres are known to not only constitute rights restrictions but to also lead to significant rights abuses. The August 2020 HIQA report on care during COVID noted that it is mainly older facilities operated by the HSE that rely on multi-occupancy rooms where there is limited communal day space.[16]

3. Critical Care

Concerns have been raised globally about the allocation of critical care resources to older people during COVID-19, with the inclusion of age-related criteria for the allocation of critical care.

The Department of Health *Ethical Framework for Decision-Making in a Pandemic* guidelines on prioritising allocation of critical care contains mixed messages about age. These can be interpreted in ways that favour younger people and discriminates against older people by virtue of their age alone. The guidelines note the need to avoid 'categorical exclusion e.g. "on the basis of age" but also note that:

> "A multi-principled approach takes into account estimates or projections of: the total

[11] Health Information and Quality Authority (September 2017). *Submission to the Department of Health's consultation on homecare services.* Available at: https://www.hiqa.ie/sites/default/files/2017-10/HIQA-submission-to-the-Dept-Health-homecare-services.pdf
[12] Institute of Public Health Ireland (2018). *Improving Home Care Services in Ireland: An Overview of the Findings of the Department of Health's Public Consultation.* Available at https://assets.gov.ie/9990/1e6ec3b04d8a4c1480c6637cce471c88.pdf
[13] Houses of the Oireachtas, Joint Committee on Health (November 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
[14] Health Information and Quality Authority (August 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
[15] Health Information and Quality Authority (2019) *Overview report on the regulation of designated centres for older persons – 2018*. Available at www.hiqa.ie.
[16] Health Information and Quality Authority (July 2019) *The impact of COVID-19 on nursing homes in Ireland*. Available at www.hiqa.ie.

number of lives saved; **the total number of life years saved**; and long-term functional status should patients survive; these estimates or projections may be made based on empirical data if they are available, or on sound clinical rationale." [17]

Reference to consideration of life years saved is an unknown quantity that inherently favours access for younger over older people (even with an age difference of one year).

4. Disruption of support services

Inadequate planning and lack of information meant that there were inequalities in how older people could access support services. Older people were left unsure where to turn to, particularly in the early weeks of the pandemic following the introduction of cocooning.

Many of those living alone were in a more vulnerable situation due to lack of household members able to facilitate cocooning by providing help accessing shopping and medication. Of those who indicated they lived alone in Census 2016, just under 40% were aged 65 and over. Over half of all people with disabilities living alone were aged 65 and over. The national rollout of the Community Call forum – launched initially on 2 April 2020 - which provided support for people in vulnerable situations came much later than cocooning advice, leaving people in limbo for assistance in the interim.

Age Action heard from older people across the country how Government failure to roll out adequate supports at the same time as removing access to businesses and promoting self-isolation resulted in difficulty in meeting their daily needs for some people who were cocooning, particularly those living alone.

Many people in receipt of home care hours saw a sudden reduction or withdrawal of hours early in the pandemic as home care workers were redeployed. Older people were disproportionally affected by this change as they constitute a high proportion of those with disabilities (20%), and of those receiving home care. For many older people's home care supports were removed without consultation, with their removal based on HSE categorisation of home care needs. The sudden removal of home care took place for many without consultation or consent and without clarity on their reinstatement. People aged 65 or over provided 15% of all the informal care noted in Census 2016 – almost 30,000 people in caring roles. This unexpectedly and significantly increased pressure on many carers – many of whom were untrained. This increased the risk of suboptimal care or abusive care practices. Adequate statutory supports to mitigate the impact of the extra caring role on carers were not provided.

Wider social care has been among the most significantly and seriously affected sectors in the course of the pandemic. This has had a severe impact on the enjoyment of rights by a whole range of groups and individuals including, people with disabilities, older people, people with learning disabilities, people with dementia, and family carers. The impact has included

[17] Government of Ireland (2020) *Ethical framework for decision-making in a pandemic*. Available at https://www.gov.ie/en/publication/dbf3fb-ethical-framework-for-decision-making-in-a-pandemic.

'underfunding, understaffing, limited participation and voice for people, their families, and to some extent, even providers'.[18]

As an unintended consequence, many older people were left without adequate supports for their care in recent months. The closure of daycare centres and supports without adequate measures in place to replace these services saw an overreliance on the voluntary sector to provide labour and support. Many public health nurses – crucial to the on-going management of health and social care for many older people in the community – were redeployed during COVID-19. The largescale disruption of daily routine saw a particular impact on those with cognitive decline such as dementia.

5. Limited participation of older people and their organisations in the response

The voices, perspectives, and expertise of older people in identifying problems and solutions are often not sufficiently incorporated in policymaking, particularly on subjects where older persons are affected by the decisions under consideration.[19]

Age Action heard from many older people themselves that they felt left outside the decision-making process and their voices were not heard. They felt that Government should have consulted with them and facilitated their participation in policy decisions that affect their lives. Age Action wrote to the Department of Health during the pandemic to highlight the lack of consultation with older people or their representative organisations.

6. Lack of data

Data on older persons disaggregated by age groups, and covering all living arrangements, such as older persons in residential care facilities, are crucial to identifying the full picture of pandemic impacts and to targeting responses. Data on older persons, where they are collected, often merely portray a homogenous group.[20]

The COVID-19 crisis has highlighted the invisibility of older people in public data analysis.[21] The lack of data disaggregation discriminated against older people having equal knowledge as to their risk as other age cohorts. Initial government HPSC reporting: was only in age categories of '65+' for older people (compared to 9-year age categories for other ages); treated older people as a homogenous group; failed to respond to international data indicating that meaningful changes in COVID-19 death rate data can be expected to be in age groupings above 65; and left civil society and the media unable to track risk and impact across over 3 decades of older people in a way that was possible with younger ages.

[18] Scottish Human Rights Commission (22 July 2020) *Submission to the Equalities and Human Rights Committee, Inquiry COVID-19.* Available at https://www.scottishhumanrights.com/media/2063/covid-19-ehric-submission.pdf.
[19] UN Secretary General (May 2020) *Policy Brief: The Impact of COVID-19 on older persons.* Available at https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2020/05/COVID-Older-persons.pdf.
[20] *Ibid*.
[21] *Ibid*.

7. Digital exclusion and inequality

Looking at the situation of older people in Ireland, a third (33%) of those aged 60-74 in Ireland have never been on the internet.[22] Best available figures for over 75s show 50% have never used the internet.[23] For those who were online, 43% of 55-74 year olds have 'low' digital skills, meaning they cannot undertake basic digital tasks independently and as such are prevented from full digital participation.

Older people were excluded by the Government's reliance on online channels for dissemination of information and access to services as part of the COVID-19 pandemic response. Adequate and targeted digital supports for older people to maintain their access to information were not in evidence.

During the pandemic, Government and HSE television briefings most often referred people to the Government or HSE websites for further information. This included referring people to a website to find the number for the Community Call Forum, that aims to 'provide supports or services to any vulnerable person who needs them', which older people such as those living alone or with a disability may be more likely to need.

When the Government public health advice asked people to stay at home for all but essential journeys, and closed all but essential businesses, older people suffered greater social exclusion as a result of lesser digital access and digital skills relative to the rest of the population, most likely causing greater negative effects on quality of life.

Lack of consideration for the rate of digital exclusion in older people, combined with advice to cocoon at home, resulted in disproportionate social exclusion of older people as the bulk of the transactions of daily life moved online. This is particularly the case for those living alone, in rural areas, or living with disabilities that restrict mobility and who may not have been able to access help to get online. Social distancing had an unintended consequence of removing the potential for face-to-face supports e.g. to pass on information or to help complete forms. This left many older people unable to fully participate in society or access supports.[24]

During the pandemic many shops refused to accept cash as a preventative public health measure.[25] As a result, many people felt left with no choice but to hand their financial affairs to someone more digitally literate or to opt into digital services they did not understand.

Age Action heard of many older people in nursing homes who – in the face of restricted visiting – did not have the device and skills to maintain connection with family members and therefore

[22] Eurostat (2019). *ICT usage in households and by individuals: Individuals: Internet use*. Available at: https://ec.europa.eu/eurostat/web/digital-economy-and-society/data/database
[23] Central Statistics Office (2020). *Impact of COVID-19 on ICT usage by Households*. Available at: https://www.cso.ie/en/releasesandpublications/ep/p-ict
[24] For example, in 2019, of those age 60-74 who did not submit forms online to public authorities in Ireland, almost 40% said another person did it on their behalf. See Central Statistics Office (2018*) Information Society Statistics - Households 2018*. Available at https://www.cso.ie/en/releasesandpublications/er/isshh/informationsocietystatistics-households2018
[25] See https://www.ecb.europa.eu/press/blog/date/2020/html/ecb.blog200428~328d7ca065.en.html.

lacked support of family members in making decisions as to their care.

The intersection of low digital literacy and high medical needs for an older population means that any change to face-to-face services will have a disproportionate impact on those needing health supports. It is clear that those not in the possession of digital skills – a disproportionate number aged over 65 – are prevented from accessing health supports on an equal basis as the rest of the population. The HSE has not allocated sufficient resources to combat digital exclusion when rolling out critical public health services such as telehealth services and COVID tracking app. Neither 'Attend Anywhere' nor the 'Covid Tracker App' allocated any resources, at the time of launching, to supporting access for those that lack basic digital skills.

8. Intersectional disadvantage and discrimination

Internationally, concerns about the equality and human rights of older people during COVID-19, have emphasised the exacerbation of conditions for older persons with underlying health conditions and those who are already socially excluded, living in poverty, having limited access to health services, or living in confined spaces such residential care homes.[26]

There is a cumulative impact of COVID-19 policy measures on older people who were already experiencing multiple and intersecting forms of inequalities prior to COVID-19, e.g. older women who provided the bulk of care in their households, and their ability to continue doing so without endangering their own health is contingent on their access to adequate healthcare and adequate income.[27]

Conclusion

As current chair of the ENNHRI Board and Board member of Equinet, Age Action urges you to use your leadership positions to secure an EU drive for an explicit consideration of human rights and equality in responding to COVID-19, including specific attention to the impact on older people.

We are mindful, from the websites of both these networks, that NHRIs and equality bodies across Europe have taken action on this issue. At this level, Age Action believes that IHREC should:

- Seek a report from the European Parliament with associated resolutions on the situation and experience of older people in relation to responses to the COVID-19 pandemic
- Seek a recommendation from the European Commission on the mainstreaming of equality and human rights considerations in the development and implementation of responses to the COVID-19 pandemic and subsequent recovery strategies

Age Action requests that IHREC give priority attention to the lack of an explicit consideration of human rights and equality in responding to COVID-19 and the resulting impact on older people in Ireland. In particular, Age Action believes that IHREC should:

- Enquire into the deaths of older people in a number of settings where there has been a

[26] *Ibid*.
[27] UN DESA (2020) '*COVID-19 and Older Persons: A Defining Moment for an Informed, Inclusive and Targeted Response'*. Available at https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2020/05/PB_68.pdf.

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disproportionate or higher than the national average number of deaths – this could be done on a site specific or localised basis

- IHREC should seek to ensure such an enquiry takes place
- Implement a programme of work to support, monitor, and enforce implementation of the public sector equality and human rights duty in service, contingency and other planning processes for living with COVID-19 and for the transition from COVID-19
- Prepare a report with recommendations, on the lessons to be drawn regarding institutional models of care from the experience of COVID-19 and the implications of these for future policy and provision that would rest on human rights and equality principles
- Prepare a code of practice on ethical guidelines and frameworks in regard to access to life-saving interventions
- Ensure that the process of attesting to deaths during the height of the pandemic, and current practice, comply with human rights and equality standards.

Age Action believes that priority attention from IHREC to the equality and human rights concerns raised by COVID-19 response measures is merited and necessary in order to establish the policy measures which can prevent and mitigate the disproportionate impact of an event like the COVID-19 pandemic on older people, particularly those in more vulnerable situations in institutional care.

Age Action is available to provide further information or other inputs, should you require them.

Yours Sincerely,

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