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Irish Centre for Human Rights

Sinead Gibney, Chief Commissioner
Michael O'Neill, Head of Legal
Irish Human Rights and Equality Commission
16-22 Green Street
Dublin 7
D07 CR20

22 February 2023

By email to info@ihrec.ie

Dear Ms Gibney and Mr O'Neill,

RE: IHREC's Inquiry power under section 35 of the Irish Human Rights and Equality Act 2014

We write to you as Care Champions; and as graduates and faculty members of the Human Rights Law Clinic at the Irish Centre for Human Rights (ICHR), School of Law, University of Galway; and as other concerned individuals and organisations to request that the Irish Human Rights and Equality Commission (IHREC) use its prerogative to decide under section 35 of the Irish Human Rights and Equality Commission Act 2014 (IHREC Act 2014) to conduct a human rights-based public Inquiry into the experiences of people in residential care during the Covid-19 pandemic and their relatives and staff carers.

It is important to acknowledge at the outset of this letter that we are not seeking to dictate the exact scope of a potential Inquiry: this task falls squarely within the remit of the Commission. There are many people who would wish to make their views known on what a human rights-based Inquiry into residential care settings during the Covid-19 pandemic should cover, and how it should proceed. The very reason why the signatories to this letter are calling for a human rights-based Inquiry is that a human rights approach places the people affected by alleged mistreatment or structural failings at the centre: it focuses on their views about what is important to investigate, and it includes them centrally in the investigation process by providing them with rights to see and comment on the evidence being gathered and to suggest further lines of inquiry. In adopting a human rights approach, IHREC would of course need to consult with people affected to determine the appropriate Terms of Reference and investigative procedures of an Inquiry.

We understand that other individuals, families and groups are also in contact with IHREC regarding apparent systematic human rights violations during the Covid-19 pandemic and the need for human rights-based investigations. We hope this submission adds weight to others' requests that IHREC use its statutory powers to assist truth-telling, accountability and institutional reform regarding individuals' and families' experiences of nursing home and other residential care (including lack of access to community- and home-based care) during the Covid-19 pandemic in Ireland.

We acknowledge that the Government intends to establish some form of public inquiry into Covid-19 responses at a future date. However, as discussed further at Section C below, we are convinced (as was the Oireachtas Special Committee on Covid-19 Response in its Final Report) that the serious human rights issues raised by the treatment of people living in nursing homes and other residential settings and their relatives and staff carers require a dedicated public inquiry given those issues' breadth and complexity and the extreme situational vulnerabilities involved. Moreover, a human rights-based *method* of inquiring into the treatment of people in residential settings and their relatives and staff carers is necessary to guarantee the participation of the individuals and families affected—in keeping with Ireland's obligations under European and international human rights law. Ireland's human rights law obligations also require a prompt and adequate human rights-based investigation; yet, it is unknown when the broad-based inquiry envisaged by the Government might commence and at what point and in what ways it would address nursing homes and other residential care settings. If the Government intends to emulate public inquiries planned in the United Kingdom, it may even decide to create new primary legislation. A human rights-based public inquiry by IHREC would not supplant the Government's planned mechanism: rather, it could begin sooner, illuminate the key human rights issues at stake, involve the individuals and families affected in ways designed to safeguard their legitimate interests, and ultimately inform the methods of and feed information and findings into a generalised public inquiry effort.

Background to and structure of this letter

Care Champions is a voluntary advocacy group of people whose family members live or have lived in residential care settings in Ireland. Since the onset of the Covid-19 pandemic we have repeatedly called public attention to the evidence of grave and widespread infringements of the human rights of people living in residential care settings. In particular, we have highlighted arbitrary interferences with their family life, their access to community and health care services including palliative care and primary care services, their rights to choice and autonomy, and their access to social work safeguarding teams. We have advocated for a care partner scheme to be initiated in Ireland which would enable residents in care to have at least one continuous family or friend available to support them through Covid-19-related restrictions. (This is in line with developments in other jurisdictions: for example, in Northern Ireland the Department of Health has introduced Care Partner arrangements in addition to the normal visiting arrangements as defined in the Department's visiting guidance documents for Hospitals, Hospices and Care Homes. A Care Partner is a defined practical role to provide additional support to Care Home residents and is complementary to the care delivered by the staff in the care setting.) We continue to advocate for the protection of residents' human rights in care settings in Ireland through each level of the COVID-19 pandemic. We have submitted evidence to the Oireachtas Health Committee, lobbied Senators and TDs to reform the care system in Ireland, and continually requested the State to establish a human rights-based inquiry into human rights violations

during the COVID-19 pandemic in residential care settings. We also offer ongoing peer support for families that are experiencing complex grief and loss.

During the past year, postgraduate students at the ICHR's Human Rights Law Clinic have worked with Care Champions pursuant to ICHR ethical approval to gather sample personal statements through semi-structured interviews with family members of nursing home residents. These statements give valuable insights into the lives and deaths of nursing home residents and their families in Ireland during the Covid-19 pandemic. In parallel, an MA student in Applied Psychology, Graham Gillespie under the supervision of Dr Sarah Robinson, with ethics approval from UCC's School of Applied Psychology Ethics Committee, collected 9 family interviews about the experiences of end-of-life care during Wave 1 and Wave 3 of the pandemic. As part of a positive ethics approach, these interview transcripts were shared with ICHR Human Rights Law Clinic students for human rights analysis.

This letter addresses the three key requirements of section 35(1) of the IHREC Act 2014. Section 35(1) states that IHREC may choose to conduct an Inquiry:

'if it is considered by the Commission that—

(a) there is, in any body (whether public or otherwise) institution, sector of society, or geographical area, evidence of—

(i) a serious violation of human rights or equality of treatment in respect of a person or a class of persons, or

(ii) a systemic failure to comply with human rights or equality of treatment obligations,

and

(b) the matter is of grave public concern, and

(c) it is in the circumstances necessary and appropriate to do so.'

Section A of this letter summarises the evidence provided by 13 families, as appended to the letter either in statement/transcript form in **Appendix 1** or as excerpts in **Appendix 2**, which indicates gross and systematic human rights violations of people living in residential care settings and their relatives during the Covid-19 pandemic, resulting from deficient State regulatory structures, resource provision, strategic planning and intervention. Section A also highlights key human rights laws by reference to which this evidence must be analysed, while noting the non-exhaustive nature of such a list of human rights laws. This section should be read alongside **Appendix 4** which is a background research paper on relevant human rights and Constitutional law norms, **Appendix 5** which is an LLM thesis by Erin Nic an Bhaird arguing that the visitor restrictions imposed in Ireland's residential care settings during the pandemic breached the European Convention on Human Rights (ECHR), and **Appendix 6** which is an MA thesis by Graham Gillespie exploring family members' experiences of their relative's experiences, and death, in nursing homes during the pandemic.

Section B refers to the ever-mounting expressions of grave public concern regarding the experiences of people living in residential care settings and their families, and staff, during the Covid-19 pandemic in Ireland and the need for a dedicated public inquiry into these matters. The evidence of deprivation,

neglect and mistreatment provided by the 13 family members referenced above, and the concerns expressed by Care Champions and the other signatories to this letter, are supported by the evidence received by and recommendations of the Oireachtas Special Committee on Covid-19 Response; the information received by and findings of the Covid-19 Nursing Homes Expert Panel; the concerns raised consistently in the Oireachtas by TDs and Senators of all political hues; the representations received by and public calls for an inquiry by coroners in Ireland; and the the fact of the thousands of communications to the Health Information and Quality Authority (HIQA) from residents, relatives, nursing home staff and others.¹ **Appendix 7** supports this section: it is a list of 63 incidences in the Oireachtas, since mid-2020, of TDs and Senators calling for a dedicated Inquiry into the experiences and treatment of people in nursing homes and their relatives during the Covid-19 pandemic.

Section C discusses why it is now necessary and appropriate for IHREC to undertake the human rights-based Inquiry that is so clearly required by Ireland's human rights law obligations and desired by affected individuals and families and wider civil society. In particular, we refer to the Government's plan to establish a general (i.e. non-dedicated) review of the State's actions in response to the Covid-19 pandemic and the persistent absence at governmental level of a human rights focus on the experiences of people in residential care settings and their relatives. We also discuss IHREC's capacity to interpret and use the legal powers and procedures set out at Schedule 2 of the IHREC Act 2014 in a human rights-compliant way.

In support of this letter's contents, as noted already, we attach the following documents:

- Appendix 1** four detailed statements/interview records gathered by ICHR postgraduate students;
- Appendix 2** a compilation of excerpts from the above four interviews and the further nine interviews conducted by Graham Gillespie MA, with notation of the serious human rights concerns raised by the excerpts;
- Appendix 3** a description of the methodology and ethical protocols by which the interview transcripts, statements and excerpts were created;
- Appendix 4** a basic background research report highlighting key Constitutional and European human rights norms that must be considered in relation to the experiences of people living in residential care during the Covid-19 pandemic;
- Appendix 5** an LLM thesis by Erin Nic an Bhaird, graduate of the ICHR, School of Law, University of Galway, analysing the visitor restrictions imposed in Irish residential care settings and arguing that Article 8 ECHR was breached on numerous grounds;

¹ HIQA, *Overview Report: Monitoring and Regulation of Older Persons Services in 2020 and 2021* (December 2022), pp39-41, <https://www.hiqa.ie/sites/default/files/2022-12/Overview-Report-on-the-Monitoring-and-Regulation-of-Older-Persons-Services-in-2020-and-2021.pdf>; Maeve Sheehan, 'More than 3,000 concerns raised about nursing homes during Covid-19 pandemic' *Irish Independent* (21 January 2023), <https://www.independent.ie/world-news/coronavirus/more-than-3000-concerns-raised-about-nursing-homes-during-covid-19-pandemic-42304616.html>.

- Appendix 6** an MA thesis by Graham Gillespie, graduate of the School of Applied Psychology at University College Cork, analysing the experiences of nine families in Ireland whose relative died in a nursing home during the Covid-19 pandemic: we particularly refer you to the experiences of a relative being ‘locked in’ and the family ‘locked out’ of the nursing home, family concerns about care practices, communication issues relating to family members’ experiences of nursing home resident’s life and death, relatives’ deaths as ‘bad deaths’ for family members, and difficulties grieving related to experiences of loss; and
- Appendix 7** a non-exhaustive list of calls in the Oireachtas to date by TDs and Senators—of all political parties and Independent—for a dedicated public or statutory inquiry into the treatment and experiences of people in nursing homes (among other residential care settings) and their relatives during the Covid-19 pandemic.

A: Evidence of serious human rights violations and systemic State failures

Under section 35 of the IHREC Act 2014, IHREC may choose to conduct an Inquiry where there is ‘evidence of a serious violation of human rights or equality of treatment obligations in respect of a person or a class of persons, or a systemic failure to comply with human rights or equality of treatment obligations’.

Facts highlighted by the statements

The statements and interview excerpts attached to this letter (**Appendices 1 and 2**) attest to inadequacies in State regulatory structures, resource provision and strategic planning and intervention (not only arising specifically in the course of the pandemic but also long-standing) which have caused certain people living in nursing homes during the Covid-19 pandemic and their relatives to experience:

Failures in care and poor treatment, for example:

- Neglect of urgent medical care needs, in some cases leading to irrevocable long-term damage;
- Neglect and negligence on the part of nursing home staff contributing to suicide attempts by affected residents;
- Failure to respond to requests from residents for assistance and care;
- Failure to properly manage pain;
- Forcing residents to drink against their will;
- Failure to change residents’ incontinence pads in timely manner;
- Failure to seek medical assistance e.g. to call a doctor or ambulance when such assistance was clearly necessary;
- Administration of antibiotics without a doctor’s supervision or approval;
- Dehydrated residents;
- Failure to provide requisite assistance to enable residents to have proper nutrition;

- Visible, rapid decline in health as evidenced by weight loss, dry skin, distress;
- Blanket refusal to transfer Covid-positive residents to hospital;
- Avoidance by staff of Covid-positive residents;
- Failure to check on or attend to ill residents on a sufficiently regular basis;
- Reliance by residents on their family members, rather than on nursing home staff, to meet basic care needs;
- Perceived lack of expertise, knowledge and experience on the part of nursing home staff;
- Lack of necessary medical equipment in nursing homes to properly meet residents' care needs;
- Failures to ensure proper staff numbers;
- Failure to treat skin conditions such as bedsores in a timely manner, leading to severe infection;
- Leaving residents confined to their beds, chairs and rooms for lengthy periods of time;
- Improper use of incontinence pads;
- Lack of respect shown to residents, residents' property, and their family members;
- Failure to ensure residents were taking their medication;
- Failure to refer residents to specialists for medical assessments;
- Failure to assist residents to wash regularly;
- Failure to clean residents' dentures;
- Using other residents' razors to shave residents;

Failures in communication between nursing homes and family members, for example:

- Failure to update family members regarding serious medical issues experienced by residents in a timely manner / at all;
- Failure to update families in relation to outbreaks of Covid-19 in nursing homes in a timely manner / at all;
- Lack of basic sensitivity in communication with family members about residents' deaths;
- Misleading, conflicting, and false information conveyed by nursing home staff to residents' family members regarding their wellbeing;
- Misleading, conflicting, and false information conveyed by nursing home staff to residents' family members regarding the quality and nature of care being provided;
- Failure to respond to and return family members' calls, texts and emails in a timely manner / at all;
- Misleading, conflicting, and false information conveyed by nursing home staff to residents' family members regarding the circumstances surrounding the time of their deaths;
- Inaccurate recording of information regarding residents' wellbeing;

Failures to facilitate communication between nursing home residents and family members, for example:

- Failure to facilitate visits in critical and compassionate circumstances;
- Failure to facilitate window visits;
- Restrictions on the facilitation of window visits in terms of the number of window visitors permitted, the frequency of visits, and the length of visits;
- Failure to facilitate residents to have phone calls or virtual visits with their loved ones;
- Misleading and false information provided by nursing home staff to residents regarding the reasons why their loved ones had stopped visiting during the Covid-19 pandemic;

- Perceived failure to adhere to the public guidance in relation to visiting restrictions;
- Failure to facilitate private communication between residents and their family members;
- Total separation of family members who had been active contributors to their resident relative's family life and care plans—who walked and talked with them, kept sight of their clothes, medication, well-being, mood, what gave them joy, and what caused them pain—and found themselves disregarded while their loved ones did not understand, suffered loneliness and fear, and were deprived of friends and family ties;

Failures in oversight, for example HIQA's absence of authority to investigate or decide on individual cases and complaints;

Failures to ensure dignity in death, for example:

- Residents being 'left' to die alone;
- Isolation and deprivation of family and social engagement exacerbating existing conditions such as dementia or confusion as a result of infection, and impacting catastrophically on the experience of dying, often alone;
- A deceased resident being 'left in soiled clothes' when transferred to funeral directors;
- Failure to provide palliative care to residents at the end-of-life stage;
- Requiring family members officially pronounce their parent dead;

Failures to protect residents from Covid-19, for example:

- Reports of nursing home staff members being 'forced' into contact with Covid-positive residents without adequate PPE;
- Reports of Covid-positive and Covid-negative residents being permitted to come into contact with one another;
- Lack of adequate PPE provided to staff and visitors;
- Improper use of PPE by staff and visitors;
- Failure to test residents for Covid-19; and
- Perceived failure to vaccinate residents in a timely manner.

For some family members, as Graham Gillespie's MA thesis at **Appendix 6** observes, their relative's suffering in a nursing home while family contact was prohibited caused, for example: fear, constant rumination on their relative's suffering, a feeling of being 'locked out and locked away' from their relative, stress, anxiety about the level of care their relative was (not) receiving, uncertainty as to whether their relative was receiving food and drink or palliative medication, 'a sense of being in the dark' as their relative was at the end of life, a feeling of being a nuisance due to their treatment upon inquiring after their relative, anger at their powerlessness, and 'feelings of being gaslit, when the information they were provided with differed from reality'.

Gillespie observes that '[t]he restrictions were especially difficult for [family members] whose relatives had dementia' and that: 'Participants also felt more could have been done to cater for visits as they believed that some visiting restrictions were arbitrary. They also described how window visits were often impractical due to unsuitable architecture and difficulties for residents with hearing or sight impairment.' Gillespie contends that: 'for relatives of participants, [nursing homes] failed to balance the "moral dilemma" of protecting them from the risk of COVID-19, whilst also ensuring their physical,

mental and emotional well-being. Families were positioned as risk, rather than valued as [an] essential part of the care ecology...'. Gillespie notes: 'All participants described how the unique nature of their relative's death inhibited their ability to grieve.' He concludes, among other things, that for families, 'the residents' deaths may fit the description of "traumatic" deaths...'. He argues that his research supports others' calls 'for family caregivers to be recognised as essential partners in residents' care' and 'also points to the need for greater oversight and safeguarding within [nursing homes] as well as the need for a public inquiry into [nursing homes'] practices during COVID in Ireland.'

Key rights affected

Along with the experiences described in the appended statements and interview excerpts, the fact that 62% of identified Covid-19 deaths in Ireland between March 2020 and the end of November 2021 occurred in nursing homes, with 4.1% linked to other residential care settings,² raises questions of the State's compliance with its positive obligation under Article 2 ECHR to implement practical measures to guard against reasonably anticipated risks to life including in social care settings. A Constitutional law obligation exists, also, for the State to vindicate the personal right to life by taking practical steps to prevent loss of life in specific instances where the State knows or ought to know there to be a real risk of death. IHREC itself raised the State's Article 2 ECHR obligations specifically in relation to nursing homes and other care providers (both public and private) when making a submission to the Oireachtas Special Committee on Covid-19 Response in June 2020. Notably, Article 11 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) requires the State to take 'all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including...humanitarian emergencies and the occurrence of natural disasters.'

The right to freedom from inhuman or degrading treatment under Article 3 ECHR is absolute; no form of emergency justifies the State's failure to ensure the provision of basic care, resources or legal protections to people who are dependent on others to meet their subsistence needs—particularly when detained, either by law or *de facto*. The threshold of severity of suffering which must be met in order for a finding of 'degrading treatment' to be made has a particular connection with the concept of human dignity and with feelings of humiliation, powerlessness, worthlessness and debasement. The European Court of Human Rights (ECtHR) has established without question that degrading treatment may arise from deficient regulatory structures or from the absence of state funding for basic care in a setting for which the state is responsible. In other words, deliberate or individual malpractice is not necessary for degrading treatment to arise. Intent to cause suffering, similarly, is not required in order for 'inhuman treatment' to be experienced; inhuman treatment is generally found to have occurred in situations of serious suffering, either physical or mental. The ECtHR has found it possible for relatives to suffer inhuman or degrading treatment on account of the grave mistreatment of their family members. European and international human rights bodies have also clearly established that the State must put in place protective measures to safeguard against ill-treatment that the State knows or ought to know about. Whether people are in a situation of 'vulnerability' is relevant to their experience, or not, of inhuman or degrading treatment and to the State's positive obligations to protect from such mistreatment. Notably, in *Heinisch v Germany App*

² Walsh B, Connolly S, Wren MA and Hill L. Supporting sustainable long-term residential care in Ireland: a study protocol for the Sustainable Residential Care (SRC) project, HRB Open Research 2022, 5 :30
<https://doi.org/10.12688/hrbopenres.13543.1>.

No 28274/08 (ECtHR, 21 July 2011) the ECtHR found older people living in institutional care to experience ‘particular vulnerability’ due partly to the fact that they ‘often may not be in a position to draw attention to shortcomings in the provision of care’.

Arbitrary deprivation of liberty, in contravention of Article 5 ECHR, has long been recognised by international and European human rights bodies as being likely to occur in residential care settings where there are insufficient or absent legal rules and procedures to govern the circumstances in which a person may be lawfully detained, restrained or otherwise denied access with the outside world. Well before the Covid-19 pandemic began, Ireland was known to lack a clear (or any) legislative and procedural framework to guard against arbitrary deprivations of liberty in social care settings including nursing homes.³ In 2022 the Oireachtas Sub-Committee on Mental Health recommended State measures aimed at ‘ensuring less restrictive forms of treatment in the community be available’ and the ‘ultimate eradication of coercion’ in respect of people with a psychosocial disability.⁴ The United Nations Human Rights Committee has repeatedly found arbitrary detention capable of amounting also to inhuman or degrading treatment on account of the suffering which can be caused by a lengthy or indefinite, unsupervised period of detention in relation to which a person cannot access procedural safeguards or legal review.

The right to respect for one’s private and family life, home and correspondence under Article 8 ECHR is of clear relevance to how people in Irish residential settings have been treated during the Covid-19 pandemic. Among other issues arising under this human rights norm we urge you to consider carefully the arguments of Erin Nic an Bhaird in the attached LLM thesis, which focus on the restrictions imposed on visits to nursing homes and question the legal quality and proportionality of those restrictions and, therefore, their compliance with the requirements of Article 8 ECHR.

A range of additional human rights protected by the Irish Constitution, the ECHR and additional international human rights treaties have great relevance to the experiences described in the appended statements and interview excerpts. These include and are not limited to the rights to equal treatment and freedom from discrimination, dignity, bodily integrity, exercise of legal capacity, and independent living and inclusion in the community (Article 19 UNCRPD). IHREC has the capacity to apply all relevant Constitutional, European and international human rights norms through the substance and methods of an Inquiry under section 35 of the IHREC Act 2014. IHREC’s position as the designated independent monitor of Ireland’s implementation of the UNCRPD is notable in this regard.

B: Grave public concern

³ See for example Sage Support & Advocacy Service, *Submission to the United Nations Committee Against Torture on the Second Periodic Report of Ireland* (August 2017), 5, <https://www.sageadvocacy.ie/media/1158/sage-submission-to-cat-review-of-ireland-june-2017.pdf>; Maeve O’Rourke, *Irish Council for Civil Liberties Submission to the Department of Health for its Consultation on the Deprivation of Liberty Safeguard Proposals* (16 March 2018), <https://www.iccl.ie/wp-content/uploads/2018/05/ICCL-submission-on-deprivation-of-liberty-safeguards-web-version.pdf>. The absence of such a regulatory framework, including hospital settings, was the subject of IHREC interventions in the case of *AC v Cork University Hospital* [2019] IESC 73; [2018] IECA 217.

⁴ Houses of the Oireachtas Sub-Committee on Mental Health Report on Pre-Legislative Scrutiny of the Draft Heads of Bill to Amend the Mental Health Act 2001 [October 2022]

Section 35 of the IHREC Act 2014 further requires that, in order to be the subject of an Inquiry, ‘the matter is of grave public concern’.

Since May 2020 there have been at least 63 instances in the Oireachtas of TDs and Senators of all political hues raising the need for a dedicated public or statutory inquiry into the experiences and treatment of people in nursing homes and their relatives during the Covid-19 pandemic. These Oireachtas debates, statements, and questions and answers are listed non-exhaustively in **Appendix 7** to this letter.

The Final Report of the Oireachtas Special Committee on Covid-19 Response, published in October 2020, stated as its very first recommendation: ‘That a public inquiry be established to investigate and report on all circumstances relating to each individual death from Covid-19 in nursing homes. Draft terms of reference should be presented for consideration by the Joint Committee on Health by the end of 2020.’ This was an all-party Oireachtas Special Committee of TDs, demonstrating the wide-ranging nature of the public concern represented by the Oireachtas Special Committee members.

The Oireachtas Special Committee’s October 2020 Final Report states by way of justification and explanation (at pages 12 and 13):

‘The Committee, despite devoting more meeting time to this single issue than to any other, was unable to get satisfactory answers as to why 985 residents of nursing homes died after they contracted Covid-19.⁵ This amounts to 56% of all deaths in the State from Covid-19, which is totally disproportionate for a group comprising of 0.65% of the population who were unique in terms of frailty and vulnerability. The Committee examined reports from HIQA⁶ and the Expert Panel⁷ which highlight some of the systemic weakness in our care of the elderly (these are addressed below). They also highlight a silo type approach on behalf of the State that certainly did nothing to prevent the spread of the disease. The key issues that emerge from the evidence include:

- i. The State, through the public health authorities, became overly focussed on preparing acute hospitals for the oncoming pandemic in February and March and failed to recognise the level of risk posed to those in nursing homes.
- ii. There were delays in reacting to an evolving and deteriorating situation in nursing homes, especially in the provision of supports like replacement staff and PPE.
- iii. While Trojan efforts were made by nursing home staff, there are unanswered questions as to why some nursing homes were free of Covid-19 whereas others were severely impacted through the death of residents and the sickness levels of staff.
- iv. There has been a failure to provide answers to the relatives of those who died and this has exacerbated their pain and suffering – this issue must be addressed.

In light of these issues, the Committee recommends the following:

⁵ Covid-19 Nursing Homes Expert Panel, *Examination of Measures to 2021: Report to the Minister for Health* (19 August 2020), <https://www.gov.ie/en/publication/3af5a-covid-19-nursing-homes-expert-panel-final-report/>.

⁶ HIQA, *The impact of Covid-19 on nursing homes in Ireland* (21 July 2020), <https://www.hiqa.ie/reports-and-publications/key-reports-and-investigations/impact-covid-19-nursing-homes-ireland>.

⁷ Covid-19 Nursing Homes Expert Panel, *Examination of Measures to 2021: Report to the Minister for Health* (19 August 2020), <https://www.gov.ie/en/publication/3af5a-covid-19-nursing-homes-expert-panel-final-report/>.

Recommendation 1:

That a public inquiry be established to investigate and report on all circumstances relating to each individual death from Covid-19 in nursing homes. Draft terms of reference should be presented for consideration by the Joint Committee on Health by the end of 2020.

That inquiry will have to look, inter alia, at the circumstances that lead to the spread of the virus to, and within, nursing homes, the impact, if at all, of the following:

- *The largescale discharge of patients from acute hospitals to nursing homes at the beginning of March*
- *The decision-making around those discharges in individual hospitals, and by the HSE, the Department of Health, including NPHE, and by Government*
- *The response of those said key actors to the difficulties encountered by nursing homes in preventing and managing the spread of the virus due to staffing difficulties and a shortage of PPE which were communicated to the Department of Health*
- *The recommendation by NPHE on 10 March that visitor restrictions to nursing homes were premature*
- *Decisions taken not to transfer patients with Covid-19 from nursing homes to acute care settings*
- *The medical expertise and treatment available in each nursing home in which residents died from Covid-19, and*
- *The nature of the health care plans and medical records (including individual decisions taken re patient care) maintained for each resident who subsequently died from Covid-19.*

The actions taken at that time cannot be examined in the light of what we now know about Covid- 19, its transmission and treatment, but instead must be examined in the light of what was known, or ought to have been known, at the time when such measures were taken in preparation for the pandemic.

Recommendation 2:

A review should be undertaken into the impact of privatisation of Ireland's nursing homes and to ascertain its impact on:

- *Nursing levels*
- *Expertise and qualifications of staff*
- *Medical and other facilities available in older people's care settings as a result of the policy decision by previous administrations to incentivise private care settings resulting in 80% of residential care being in the private sector, and*
- *The adequacy of funding to deliver optimal outcomes'*

In December 2022 HIQA reported that it had received unprecedented levels of communications about nursing homes from 2020 onwards, with thousands of concerns and queries raising the following: quality of care, including general welfare and development; safeguarding; residents' rights; infection prevention and control measures; governance and management; communication; staffing, training and development; and complaints handling.⁸ In her evidence to the Oireachtas Special Committee on

⁸ HIQA, *Overview Report: Monitoring and Regulation of Older Persons Services in 2020 and 2021* (December 2022), pp39-41, <https://www.hiqa.ie/sites/default/files/2022-12/Overview-Report-on-the-Monitoring-and-Regulation-of-Older-Persons-Services-in-2020-and-2021.pdf>; Maeve Sheehan, 'More than 3,000 concerns raised about nursing homes during

Covid-19 Response in May 2020 the HIQA Chief Inspector of Social Services and Director of Regulation stated that most of the concerns received by HIQA ‘centred around the fact that families were unable to see their relatives within a nursing home’.⁹

Relatedly, the Covid-19 Nursing Homes Expert Panel, in its Final Report to the Minister for Health in August 2020, noted that it had received numerous stakeholder submissions arguing that ‘the voices of residents and families themselves are absent from planning processes’.¹⁰ The Expert Panel’s Final Report noted further that:

- The ‘needs and rights of the dying and bereaved’ were raised by stakeholders, as well as ‘end of life care’;¹¹
- Many submissions to the Expert Panel ‘questioned the timing or length of time that visitor restrictions were/are in place, and the severity of those restrictions. Some reported that window visits were not allowed and virtual visits were not being facilitated’;¹²
- Stakeholders contended that ‘additional supports may now be required for those who have suffered the impact of long-term isolation and loneliness’;¹³
- The visiting restrictions were ‘thought to have been cruel, especially for residents who were close to death and also for residents with dementia whose diminished insight as to what was going on was compounded by not seeing their relatives’;¹⁴ and
- All family members and residents with whom the Expert Panel engaged ‘expressed their utter frustration bordering on anger regarding the “no visiting” policy particularly when a family member was close to death “and no family member allowed in to say goodbye”’;¹⁵

The Expert Panel found in its Final Report that ‘[t]he experience of dying in the Covid pandemic may well result in a large number of families suffering pathological grief into the future.’¹⁶ Crucially, it added:

‘We must have a keen appreciation for the impact of a death on a fellow resident. For those who witnessed many losses and may suffer varying degrees of emotional trauma, it is important to recognise that they need a formal way of expressing their grief as a community. If not facilitated, the resident may quietly fear their own death. Residents need reassurance that their own death will be acknowledged and their life celebrated and that friends and family will be cared for when their time comes.’¹⁷

Covid-19 pandemic’ *Irish Independent* (21 January 2023), <https://www.independent.ie/world-news/coronavirus/more-than-3000-concerns-raised-about-nursing-homes-during-covid-19-pandemic-42304616.html>.

⁹ Mary Dunnion, Chief Inspector of Social Services and Director of Regulation at HIQA, May 2020 evidence to Oireachtas Special Committee on Covid-19 Response, https://www.oireachtas.ie/en/debates/debate/special_committee_on_covid-19_response/2020-05-26/4/.

¹⁰ Covid-19 Nursing Homes Expert Panel, *Final Report to the Minister for Health* (19 August 2020) 65, <https://www.gov.ie/en/publication/3af5a-covid-19-nursing-homes-expert-panel-final-report/>.

¹¹ *Ibid*, 65.

¹² *Ibid*, 73.

¹³ *Ibid*, 73.

¹⁴ *Ibid*, 77.

¹⁵ *Ibid*, 77.

¹⁶ *Ibid*, 98.

¹⁷ *Ibid*, 98.

The Expert Panel also found:

‘There is a degree of resistance by some nursing homes to support and provide access to independent advocacy, as was mentioned in a number of responses to the Panel. The HSE safeguarding service, while it is available to all settings, does not have any legislative authority in relation to private nursing homes. There is no legal or contractual obligation on private nursing homes to cooperate or assist with the safeguarding service. Social work services for older people are essential; many older people have to negotiate difficult life altering decisions and transitions. When they do not have access to social worker support advocacy services are of increased importance.’¹⁸

In June 2021 the Coroners Society of Ireland called publicly for a comprehensive statutory inquiry into the deaths of people in nursing homes during the Covid-19 pandemic, on the basis that the inquest system at present is not equipped to respond adequately to relatives’ legitimate concerns and questions.¹⁹ Such a call from the existing designated state infrastructure for discharging Ireland’s Article 2 ECHR obligations must be taken extremely seriously.

Internationally, civil society organisations, human rights bodies and scholars have drawn attention to the grave human rights concerns arising from the treatment and abandonment of people living in residential care settings including nursing homes during the Covid-19 pandemic.²⁰ Significant academic literature raised concerns about the treatment of older people in Irish nursing homes from 2020 onwards.²¹

In its June 2022 report to the United Nations Human Rights Committee (HRC), IHREC itself questioned Ireland’s compliance with its Right to Life obligations bearing in mind the ‘disproportionate impact [of the pandemic] on people resident in institutional and detention settings such as nursing homes, residential disability facilities, mental health settings and prisons.’²² IHREC recommended ‘that the experience of residents, their families and staff of institutional settings should inform the adoption by

¹⁸ Ibid, 97.

¹⁹ Neil Michael and Niamh Griffin, ‘Coroners call for statutory inquiry into Covid-19 nursing home deaths’ *Irish Examiner* (10 June 2021); Dáil Debates, Leaders’ Questions (15 June 2021), Denis Naughten TD, <https://www.kildarestreet.com/debates/?id=2021-06-15a.5#g55>

²⁰ For example, United Nations, ‘Policy Brief: The Impact of COVID-19 on Older Persons’ (May 2020) 5, <https://unsdg.un.org/resources/policy-brief-impact-covid-19-older-persons>; Caroline Emmer De Albuquerque Green, ‘The human rights of people living in care homes: never again an afterthought’ (2022) 2 *Nature Aging* 767; Janet Carter Anand, Sarah Donnelly, Alisoun Milne and others, ‘The covid-19 pandemic and homes for older people in Europe - deaths, damage and violations of human rights’ (2022) 25:5 *European Journal of Social Work* 804.

²¹ See for example: Anand, Janet Carter, Sarah Donnelly, Alisoun Milne, Holly Nelson-Becker, Emme-Li Vingare, Blanca Deusdad, Giovanni Cellini, Riitta-Liisa Kinni, and Cristiana Pregno. "The covid-19 pandemic and care homes for older people in Europe-deaths, damage and violations of human rights." *European Journal of Social Work* 25, no. 5 (2022): 804-815; Hartigan, I., Kelleher, A., McCarthy, J., & Cornally, N. (2021). Visitor restrictions during the COVID-19 pandemic: An ethical case study. *Nursing ethics*, 28(7-8), 1111-1123; O’Caoimh, Rónán, Mark R. O’Donovan, Margaret P. Monahan, Caroline Dalton O’Connor, Catherine Buckley, Caroline Kilty, Serena Fitzgerald, Irene Hartigan, and Nicola Cornally. "Psychosocial impact of COVID-19 nursing home restrictions on visitors of residents with cognitive impairment: a cross-sectional study as part of the engaging remotely in care (ERIC) project." *Frontiers in psychiatry* 11 (2020): 585373; Sweeney, Mary Rose, Andrew Boilson, Ciara White, Mary Nevin, Briege Casey, Patrick Boylan, and Anthony Staines. "Experiences of residents, family members and staff in residential care settings for older people during COVID-19: A mixed methods study." *Journal of Nursing Management* 30, no. 4 (2022): 872-882.

²² IHREC, *Ireland and the International Covenant on Civil and Political Rights: Submission to the Human Rights Committee on Ireland’s fifth periodic report* (June 2022), 52, https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2FCCPR%2FNH%2FIRL%2F48895&Lang=en.

the State of preparatory measures to protect older and structurally vulnerable groups in future crises.²³ In its report to the HRC, IHREC highlighted the exacerbation of ‘existing issues such as inappropriate facilities and multi-occupancy rooms’ which ‘made already vulnerable people particularly susceptible to Covid-19.’²⁴ IHREC further stated that it was ‘concerned that during the pandemic there has been an increased use of digital door codes for residents to access and exist residential care institutions, with the result that people can be de facto locked in’²⁵ without legal safeguards.

C: In the circumstances necessary and appropriate

Finally, section 35 of the IHREC Act 2014 requires that ‘it is in the circumstances necessary and appropriate’ for IHREC to conduct an Inquiry.

On 8 February 2023 Taoiseach Leo Varadkar addressed the question of a potential public inquiry into Covid-19 responses by stating that ‘this is being scoped out’ and that:

‘It will be wider than just the health response and will take into account the economic and other responses. We hope to have it established by mid-year and we will be guided by what they are doing in other countries. They have different legal systems but they have also set up inquiries, and it is right that is done. We intend that it will also examine how nursing homes handled Covid-19. We also need to be fair to the management and staff of nursing homes. This was an unprecedented event in our lifetimes with a pandemic and a new virus. I do not think anyone had a manual or roadmap as to how it could be best managed. It is an area we will inquire into.’²⁶

On 1 February 2023 Taoiseach Leo Varadkar stated:

‘I would hope to have a public inquiry into the response to Covid up and running this year, ideally by the middle of the year, but it needs to be scoped out. It will be extensive. It could go on for quite some time. We are keen to get it right. I extend my profound sympathy to the families of people who died in nursing homes. Covid was a difficult time for all of us, but particularly hard for those who could not mourn their loved ones properly or be by their side during their last days. We need to recognise that in the vast majority of cases, if not all cases, people working in and managing nursing homes did their best in what was an unprecedented scenario. There was no handbook as to how one manages a pandemic. I believe that in almost all cases, people did the best they could.’²⁷

On 30 November 2022 Taoiseach Micheál Martin responded to the question of a ‘public inquiry in respect of nursing homes...’ as follows:

‘[A]t this stage I would not be minded towards a statutory public inquiry, but I know the Minister for Health has established a public health reform expert advisory group on the lessons that can be learned,

²³ Ibid, 53.

²⁴ Ibid, 54.

²⁵ Ibid.

²⁶ Dáil debates, Questions: Programme for Government, Taoiseach Leo Varadkar TD (8 February 2023), <https://www.kildarestreet.com/debate/?id=2023-02-08a.201>.

²⁷ Dáil debates, Questions on Policy or Legislation, Taoiseach Leo Varadkar TD (1 February 2023), <https://www.kildarestreet.com/debates/?id=2023-02-01a.122#g172>.

an evaluation of how we performed in the pandemic, incorporating the lessons learned into a continued response to Covid but also potentially future pandemics and general preparedness in terms of the public health front. We do need a wider evaluation from the country's perspective in terms of how we manage Covid-19, covering all aspects of it, because that again would enable us to gain from the experiences of the Covid period.²⁸

In January 2022 Taoiseach Micheál Martin replied to a request that a commission of inquiry be established to examine the deaths of Dealgan nursing home residents as follows:

'I am not convinced that commissions of inquiries are the optimal way to investigate these issues. They go on much longer than people anticipate or expect. This is a genuine issue; I do not want the Deputy to get me wrong. The Department is examining a variety of options as to how best to respect and meet the needs and concerns of families of those affected.'²⁹

It is wholly unclear what form the Government's envisaged inquiry might take, and how or whether individuals and families who suffered in nursing homes and other institutional care settings would be fully involved in the sense of being able to see and comment on the substance of all relevant evidence, and to suggest lines of further inquiry. In *Heinisch v Germany* the ECtHR drew attention to the particular need for open disclosure mechanisms where nursing home care is concerned:

'In societies with an ever growing part of their elderly population being subject to institutional care, and taking into account the particular vulnerability of the patients concerned, who often may not be in a position to draw attention to shortcomings in the provision of care on their own initiative, the dissemination of information about the quality or deficiencies of such care is of vital importance with a view to preventing abuse.'³⁰

Aside from the methods of a future public inquiry, the Government has made no promise that Constitutional or human rights law will be used as an analytical framework. Nowhere in the Government's statements regarding a future investigation has there been a focus on Constitutional or European or international human rights standards or guarantees. Whilst a general public evaluation of system-wide responses to the Covid-19 pandemic in Ireland is also appropriate, people who survived mistreatment in nursing homes and other residential care settings, and relatives of people who died, have specific rights to remedies for Constitutional and human rights violations that require among other measures a human rights-based prompt, thorough, independent public inquiry given the apparent systemic failings of State protection.

International and European human rights law establishes that an 'effective' investigation:³¹

- is prompt,
- is capable of leading to the establishment of all the facts of a serious human rights violation,

²⁸ Dáil Debates, Priority Questions, Taoiseach Micheál Martin TD (30 November 2022), <https://www.kildarestreet.com/debates/?id=2022-11-30a.282&s=covid+nursing+homes+inquiry#g323>

²⁹ Dáil Éireann, Official Report, 25 January 2022, Taoiseach Micheál Martin TD to Fergus O'Dowd TD, <https://data.oireachtas.ie/ie/oireachtas/debateRecord/dail/2022-01-25/debate/mul@/main.pdf>.

³⁰ *Heinisch v Germany* App no 28274/08 (ECtHR, 21 July 2011) para 71.

³¹ See Maeve O'Rourke, *A human rights framework: Background Research for the Truth Recovery Design Process* (Belfast: Truth Recovery Design Panel, September 2021), <https://aran.library.nuigalway.ie/bitstream/handle/10379/17277/ORourke-Background-Research-Report-27.9.21.pdf?sequence=1&isAllowed=y>

- includes investigation of individualised circumstances,
- involves archival preservation,
- through information disclosure contributes to the functioning of other justice mechanisms,
- results in recommendations for reforms to prevent future human rights violations,
- is carried out by an independent, competent and impartial body,
- is gender-sensitive and accessible,
- has all necessary powers to secure and compel the production of evidence,
- involves those affected to the extent necessary to safeguard their legitimate interests, including by providing access to hearings and all other relevant information and by allowing them to submit evidence and suggest lines of further inquiry,
- has flexibility to amend its scope,
- provides access to personal information and information about deceased family members,
- adopts evidence-gathering methods that protect witnesses' due process rights and safety,
- provides support to those affected by human rights violations who testify, and
- is transparent, allowing a sufficient element of public scrutiny to secure accountability in practice as well as in theory.

IHREC is uniquely placed to implement an 'effective' human rights-based statutory public inquiry due to its expertise regarding dignity and equality, and its focus on structural state obligations and reforms. Crucially, IHREC has the knowledge necessary to interpret the powers and procedures set out in Schedule 2 of the IHREC Act 2014 in a way that permits the maximum possible freedom of expression and information to those affected and the general public, and that allows for a comprehensive exploration of the State's obligations under Constitutional, European and other human rights law.

Section 1 of Schedule 2 of the IHREC Act 2014 gives broad discretion to IHREC to hold aspects of an Inquiry in public where such an approach is requested by a witness or is in the interests of the Inquiry and fair procedures (and, likewise, IHREC may undertake private proceedings where warranted). To the extent that proceedings are held in public, documents produced by witnesses may also be made public. Section 2 of Schedule 2 requires IHREC, generally speaking, to disclose to any witness before it 'the substance of any evidence in its possession that, in its opinion, the person should be aware of for the purposes of the evidence that person may give or has given to the Commission', and to allow the witness to comment on such evidence. This provision allows for the protection of the participation rights of those affected by alleged human rights violations. Section 5 of Schedule 2 gives IHREC a broad power to establish appropriate rules and procedures, having regard to the necessity for fair procedures (which pursuant to the European Convention on Human Rights Act 2003 also entails acting in accordance with ECHR requirements). Section 6 of Schedule 2 gives IHREC extensive powers to compel the production of evidence. According to section 12 of Schedule 2, legal costs are payable to all witnesses whose 'personal or property rights...are at risk of being jeopardised as a result of any evidence received by the Commission'; this provision seems capable of being interpreted to protect the personal rights of family members whose relatives died in nursing homes following, and individuals who survived, alleged Constitutional rights violations. There is flexibility in section 12 of Schedule 2 for the creation of a legal costs regime that may emulate the manner in which 'core participants' are treated in analogous public inquiries in the United Kingdom.

Crucially, the conducting of an Inquiry by IHREC, as the State's permanent national human rights and equality institution, would ensure that implementation of the Inquiry's findings and recommendations were monitored into the future. An alternative dedicated inquiry format, on the other hand, could be decommissioned and its findings left to languish without oversight or implementation. As emphasised by the ECtHR in *Heinisch* (mentioned above) among numerous other cases, people living in residential care settings are in a situation of extreme vulnerability and truth-telling about their experiences of human rights violations is not easy but essential. There is a need for a dedicated Inquiry that places the people directly affected at its centre, and seeks accountability for failings to-date as well as the discernment of future protective structures (including best practice in the sector at present) that will guarantee non-recurrence. This proposal aligns with Ireland's ongoing statutory reforms, and with the approaches of other professional bodies and health care providers.³²

In January 2023 IHREC launched a national campaign focusing on care and related State and societal responsibilities and structures (including the gender discrimination inherent in the devaluing of care). Questions of the human rights entitlements and State obligations arising as people age and require assistance with the tasks of everyday living are at the forefront of national and international policy and law-related debates, and an Inquiry by IHREC into Ireland's treatment of people in residential care settings including nursing homes during the Covid-19 pandemic would contribute to the development of best practice and clearer enunciation of human rights law's requirements in this field, including at an international level. Moreover, IHREC is the designated independent monitor of Ireland's implementation of its UNCRPD obligations, offering it particular expertise (notably through the input of its Disability Advisory Committee) and opportunity regarding the need for truth-telling, accountability and guarantees of non-recurrence in respect of the treatment of people living in residential care settings during the Covid-19 pandemic. IHREC has established a track record of litigation, advocacy and contribution to policy and law reform in the arenas of older people's rights and disability rights, including for example IHREC's detailed report to the Oireachtas Special Committee on Covid-19 Response and its intervention in the case of *AC v Cork University Hospital & ors* and *AC v Fitzpatrick & ors* [2019] IESC 73.

A human rights-based public inquiry by IHREC would not supplant the Government's planned mechanism: rather, it could begin sooner, illuminate the key human rights issues at stake, involve the individuals and families affected in ways designed to safeguard their legitimate interests, and ultimately inform the methods of and feed information and findings into a more general inquiry effort.

Conclusion

In requesting IHREC to choose to conduct a human rights-focused Inquiry pursuant to section 35 of the IHREC Act 2014, Care Champions is joined by numerous other concerned organisations and individuals in a context where public representatives, families of nursing home residents, civil society

³² See for example the Preamble to the Assisted Decision-Making (Capacity) Act 2015 (No. 64 of 2015), which has regard 'to the protections afforded by the Convention for the Protection of Human Rights and Fundamental Freedoms done at Rome on the 4th of November 1950, as it applies to the State'; the Health Information and Quality Authority (HIQA) and Safeguarding Ireland's Guidance on a Human Rights-based Approach in Health and Social Care Services, the 'FREDA principle' [2019]; and the Psychological Society of Ireland (PSI) Pronouncement, International Union of Psychological Science (IUPsyS) Responses in Crises and Emergencies [October 2022], regarding the invitation to contribute ideas on the IUPsyS responses to crises and emergencies, which proposes a set of human rights-based recommendations.

and professional bodies across Ireland have called repeatedly since mid-2020 for a public, statutory, dedicated Inquiry into such matters. IHREC itself has stated in numerous reports following the Covid-19 pandemic's onset that human rights and equality considerations were (1) crucial to place at the centre of State planning and operations, and (2) insufficiently central to State planning and operations.³³ People who survived neglect or mistreatment and their relatives, and the relatives of those who died, in nursing homes and other residential care settings during Covid-19 pandemic have rights to remedies including accountability, access to justice and reparation (involving truth-telling, acknowledgement, rehabilitation, memorialisation and guarantees of non-repetition). The Government has made clear that while it is minded to initiate a general national public review of how the State has handled the Covid-19 pandemic, a dedicated Inquiry into nursing homes and other residential care settings is not planned nor anticipated. IHREC is uniquely placed, with its statutory powers and its mandated focus on individuals' and families' lived experiences of human rights violations and the State's structural responsibilities for human rights violations, to conduct the Inquiry that Care Champions and the other signatories to this letter, and innumerable other members of Irish society, wish to see.

We hope that IHREC will act upon the matters discussed above and look forward to being of further assistance in any way that you may require,

Yours sincerely,

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³³ See Conor Casey, Oran Doyle, David Kenny and Donna Lyons, *Ireland's Emergency Powers During the Covid-19 Pandemic* (Irish Human Rights and Equality Commission, 2021); IHREC, *The Impact of Covid-19 on People with Disabilities* (June 2020).

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