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27 May 2020

**RE: NURSING HOMES AND OTHER INSTITUTIONAL CARE SETTINGS: A FRAMEWORK FOR EXAMINING THE STATE'S RESPONSE TO THE COVID-19 PANDEMIC**

Dear Committee members,

We write to propose a human rights-based framework for your examination of the State's response to the COVID-19 pandemic as it has concerned and continues to concern people in nursing homes and other institutional (or, 'congregated') care settings. Please see Appendix 1 for a suggested List of Questions to guide your inquiries.

We believe that a human rights-based approach, adequately informed by the knowledge base of gerontology and disability studies,<sup>1</sup> to your inquiries is necessary and appropriate because:

- 1) It focuses intently on the lived experiences of those in need of state protection in order to understand the quality and impact of the State's actions or inaction. In so doing, this approach gives dignity and voice to people who have experienced harm – most importantly people living in institutional settings themselves, and also their family members and carers;
- 2) It requires wide-ranging consideration and appraisal of the structures (and structural gaps) that have contributed to these lived experiences. Most importantly, it focuses on the measures that the State could and/or should have in place to ensure that individuals' rights are protected and realised. It allows for recognition of best practice in addition to failings;
- 3) Through its situation of lived experience within its structural context, it encourages the identification of structural changes that would guarantee non-repetition of rights violations in the future; and

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<sup>1</sup> Doron I, Cox C, Spanier B. Comparing Older Persons' Human Rights: Exploratory Study of the International Older Persons' Human Rights Index (IOPHRI). *Gerontologist*. 2019;59(4):625-634. doi:10.1093/geront/gny080

- 4) at a time when people's vulnerabilities (both embodied and situational) are exacerbated, it is all the more important that the State's constitutional and human rights law obligations are acknowledged and implemented.

We propose a **6-pillared framework for questioning** based on what we observe to be the most relevant State obligations under Irish Constitutional, European human rights and international human rights law in light of existing research on Ireland's institutional care system and recent coverage of the State's Covid-19 response. These State obligations are:

- to ensure dignity by preventing discrimination;<sup>2</sup>
- to protect and vindicate the right to life, including taking practical steps to prevent loss of life in specific situations where the State knows or ought to know that there is a real risk of death, and conducting effective investigations into deaths that occur in institutional settings;<sup>3</sup>
- to protect the right to exercise legal capacity;<sup>4</sup>
- to prevent and protect against inhuman or degrading treatment, including specific positive obligations to ensure respect for human dignity in places of *de facto* detention and in contexts of heightened vulnerability;<sup>5</sup>
- to protect the right to bodily integrity;<sup>6</sup>
- to protect the right to respect for private and family life;<sup>7</sup>
- to protect the right to liberty and freedom from arbitrary detention;<sup>8</sup>
- under international human rights law, to protect the right of persons with disabilities to live independently and to be included in the community,<sup>9</sup> and to protect the right to the enjoyment of the highest attainable standard of health without discrimination.<sup>10</sup>

You will see at Appendix 1 that we suggest lines of inquiry that consider both (1) the lived experience of the State's response, and (2) the structural factors that have impacted the State's response under the following six headings:

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<sup>2</sup> Article 40.1 Constitution of Ireland (See *Quinn's Supermarket v. Attorney General* [1972] IR 1 p13); Article 14 ECHR; Article 5 CEDAW; Article 2 ICESCR; Articles 3, 5 CRPD. See also Article 11 CRPD: 'States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.'

<sup>3</sup> Article 40.3.2 Constitution of Ireland (See for example *Devoy v Governor of Portlaoise Prison* [2009] IEHC 288); Article 2 ECHR (See for example *Oneryildiz v Turkey* 2004-XII, 41 EHRR 325; *Osman v United Kingdom* 1998-VIII, 29 EHRR 245; *Opuz v Turkey* Hudoc (2009), 50 EHRR 695; *Calvelli and Ciglio v Italy* App No 32967/96); Article 10 CRPD.

<sup>4</sup> Article 12 CRPD.

<sup>5</sup> Article 40.3 Constitution of Ireland (See *Ryan v Attorney General* [1965] I.R. 345; *The State (C) v Frawley* [1976] IR 365; Hogan & White, *JM Kelly: The Irish Constitution* (4<sup>th</sup> ed., Tottel Publishing, 2003), para 7.3.76); Article 3 ECHR; Articles 15, 16 CRPD.

<sup>6</sup> Article 40.3 Constitution of Ireland. Article 17 CRPD.

<sup>7</sup> *McGee v Attorney General* [1974] IR 284; *Kennedy v Ireland* [1987] IR 587; Article 8 ECHR; Articles 19, 22, 23 CRPD

<sup>8</sup> Article 40.4.1 Constitution of Ireland; Article 5 ECHR; Article 14 CRPD.

<sup>9</sup> Article 19 CRPD.

<sup>10</sup> Article 25 CRPD; Article 12 ICESCR.

1. **Social inclusion** (linked to the rights and equality and non-discrimination, respect for human dignity, and societal participation)
2. **Accountability mechanisms** (linked to all rights)
3. **Autonomy and choice** (linked to the rights to liberty, recognition of legal capacity, independence and inclusion in the community, non-discrimination, dignity, respect for private and family life)
4. **Standard of care** (linked to the rights to respect for private and family life, freedom from inhuman and degrading treatment, bodily integrity, life, health)
5. **Family and community life** (linked to the rights to equality and non-discrimination, dignity, respect for private and family life, societal participation)
6. **End of life** (linked to the rights to life, dignity, bodily integrity, respect for private and family life, respect for legal capacity)

We have suggested some issues at Appendix 1 that we can already see falling under the areas suggested for questioning (partly on the basis of the Bibliography at Appendix 3). We hope that others will emerge through taking this approach.

These questions should be asked of people in all categories of experience (including those with best practice to share), with a view to ensuring that the Committee's work itself engages in a human rights-based approach of inclusion, non-discrimination and respect for dignity (equal worth). Evidence should be taken directly from people living in institutions, as well as from family members, staff, policy-makers and representative bodies. We include as Appendix 2 a list of categories of witness and some suggestions as to who might be called in particular.

We wish you the best with your work and are available to you at any time.

Yours sincerely,

Colette Kelleher, Former Senator and Former CEO, Alzheimer Society of Ireland

Prof Kieran Walsh, Professor of Ageing & Public Policy; Director, Irish Centre for Social Gerontology, National University of Ireland Galway

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Prof Eilíonóir Flynn, Established Professor, School of Law and Centre for Disability Law and Policy, National University of Ireland Galway

Dr Sarah Donnelly, Assistant Professor of Social Work, School of Social Policy, Social Work & Social Justice, University College Dublin

Dr Maeve O'Rourke, Lecturer in Human Rights, Irish Centre for Human Rights, National University of Ireland Galway

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Stroke and Dementia Care; Co-Chair, Special Interest Group on Long-Term Care, European Geriatric Medicine Society; **Previously:** Chair, Government Working Group on Elder Abuse; President, Irish Gerontological Society and European Union Geriatric Medicine Society; Chair, Policy Group on Ageing, RCPI; Investigator, Leas Cross Report.

## **APPENDIX 1: QUESTIONS FOR COMMITTEE TO ASK & LINES OF INQUIRY**

### **I. SOCIAL INCLUSION**

*What has been the lived experience during the Covid-19 pandemic?*

- What has been the tone and content of public discussion, including media coverage?
- (How) have people affected been involved in discussion?
- What methods of communication have been employed to involve those affected?
- (How) have the lives of people in institutional care settings been recognised, both relating to and beyond the impact of COVID-19 been considered?
- (In what ways) have older people, people with disabilities and people with experience of mental health services experienced stigmatising / homogenising / paternalistic / de-valuing / discriminatory discourse and decision-making?

*What are the existing structures?*

- How do the structures of the older adult health and social care sector (particularly the provision and quality of institutional care, and the provision and quality of home care, and the balance between the two) mediate exclusion and inclusion outcomes for older people, people with disabilities and people with experience of mental health services?
- Has institutional care been separated from the norms of healthcare provision available to those living in the community?
- (How) does institutional care in Ireland relate to social exclusion?
- To what extent has the representation of older people in official government policy and government-instigated forums such as the Citizen's Assembly<sup>12</sup> contributed to the homogenisation or problematisation of ageing and older people?
- What recommendations have been made regarding the structural changes required to ensure equality, dignity, and social inclusion of people with disabilities, older people and people with experience of mental health services through approaches to care in Ireland?

### **II. ACCOUNTABILITY MECHANISMS**

#### **(1) Policy / response formulation**

*What has been the lived experience during the Covid-19 pandemic?*

- What decisions were made by NPHET & Government, and when, relating to people living in institutional care settings and what were the consequences of these decisions?
- How were people living in institutional care settings considered and heard from in the planning process? (How) is this happening now?

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<sup>12</sup> O'Neill D. Careless talk costs lives – mind your language on ageing. Irish Times, 20 June 2017.  
<https://www.irishtimes.com/life-and-style/health-family/careless-talk-costs-lives-mind-your-language-on-ageing-1.3116630>

- Is it possible that ageism, ableism or other unconscious biases were factors in decision-making?
- To what extent was there cross-sector collaboration and at what point (including with practitioners' representative organisations) regarding the required response?

*What are the existing structures?*

- What is known, and what recommendations have been made, regarding ageism / ableism / exclusion/lack of participation in policy-making and decision-making for people living in institutional care settings in Ireland?
- What progress has been made in teasing out and responding to the challenges of advocacy for those with significant degrees of cognitive impairment? <sup>13</sup>
- Are there recommendations in the Citizens' Assembly Report on ageing which those with lived experience, and in practice and research wish to see implemented?

## **(2) Regulation and monitoring of sector**

*What has been the lived experience during the Covid-19 pandemic?*

- What has been the role of HIQA regarding the Covid-19 response in institutional care settings, including from the perspective of people receiving care, family members and carers?

*What are the existing structures?*

- What relationship does the mix and balance of residential long-term care provision across private, public and voluntary sectors have with accountability and quality of care, including from the perspective of people receiving care, family members, and carers?
- What is known about the regulation and monitoring of care provision in the institutional care sector in Ireland and what, if any, recommendations have been made regarding its reform?
- What is the relevance to accountability through regulation and monitoring of legislative gaps such as (and not limited to): the non-ratification of the Optional Protocol to the Convention Against Torture and corresponding lack of a National Preventive Mechanism in Ireland; the lack of deprivation of liberty / protection of liberty safeguards; the non-commencement of the Assisted Decision-Making (Capacity) Act in full; the lack of adult safeguarding legislation; and the lack of statutory rights to advocacy?

## **(3) Adult safeguarding**

*What has been the lived experience during the Covid-19 pandemic?*

- What have been the experiences of people receiving care, family members, carers, advocates and others regarding safeguarding during the Covid-19 pandemic?

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<sup>13</sup> Dixon J, Laing J, Valentine C. A human rights approach to advocacy for people with dementia: A review of current provision in England and Wales. *Dementia (London)*. 2020;19(2):221-236. doi:10.1177/1471301218770478

- What considerations were given to the need to safeguard people living in institutional care settings beyond the immediate health protections stemming from Covid10 pandemic?

*What are the existing structures?*

- What structural gaps exist and what recommendations for reform have been made regarding adult safeguarding in Ireland?
- What is the progress of the Adult Safeguarding Bill?
- What is the ability of HSE Safeguarding and Protection Teams to carry out safeguarding inquiries if a private care home provider refuses to cooperate/refuses entry?

#### **(4) Advocacy and complaints<sup>14</sup>**

*What has been the lived experience during the Covid-19 pandemic?*

- What have been the experiences of people receiving care, family members, carers, advocates and others regarding safeguarding during the Covid-19 pandemic?
- What have been the experiences of people living in institutional care settings in accessing advocacy services during the Covid-19 pandemic?

*What are the existing structures?*

- What structural gaps exist and what recommendations for reform have been made regarding the right to independent advocacy in institutional care settings in Ireland?
- When will the Assisted Decision-Making (Capacity) Act be instrumentalised in a manner compatible with human rights and the current disability and gerontology knowledge base, and then fully commenced and how will effective access to independent advocacy services to support the Act's implementation be ensured for every person in institutional care?

#### **(5) Access to information**

*What has been the lived experience during the Covid-19 pandemic?*

- (How) have disaggregated data on the experiences of people in various institutional care settings been gathered and published?
- What have been the experiences of people receiving care, family members, carers and others regarding access to and provision of information?

*What are the existing structures?*

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<sup>14</sup> Dixon J, Laing J, Valentine C. A human rights approach to advocacy for people with dementia: A review of current provision in England and Wales. *Dementia (London)*. 2020;19(2):221-236. doi:10.1177/1471301218770478



### III. AUTONOMY & CHOICE

*What has been the lived experience during the Covid-19 pandemic?*

- How have decisions regarding Covid-19-related care been made?
- (How) have people with disabilities, people with experience of mental health services and older people been involved in decision-making regarding their own healthcare, including their place of residence and their end-of-life care?
- What role have Advance Care Planning and Advance Healthcare Directives and Do Not Attempt Resuscitation Orders played during the pandemic (including statistics and policies on their use)<sup>15</sup>?
- To what extent have wardship applications, involuntary detention under the Mental Health Act and detention under the Health (Preservation and Protection and other Emergency Measures in the Public Interest) Act 2020 been used during the Covid-19 pandemic to restrict the liberty of older people, people with disabilities, and people with experience of mental health services?

*What are the existing structures?*

- What structural problems and recommendations for reform have been identified regarding older persons' and disabled persons' control over their healthcare in Ireland?
- What structural problems and recommendations for reform have been identified regarding reliance on institutional care, clarity on entitlement and investment in community-based care, and policy coherence and legislative bases for care (including choice of care) in Ireland?

### IV. STANDARD OF CARE

#### (1) Prevention of infection

*What has been the lived experience during the Covid-19 pandemic?*

- Regarding testing, contact tracing and social distancing?
- Regarding access to personal protective equipment (PPE) and other workplace health and safety precautions?
- Regarding the provision of information to people receiving care, family members and carers?
- Regarding care management?
- Regarding staffing levels?
- Regarding integration of primary, secondary and public health care?

*What are the existing structures?*

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<sup>15</sup> O'Neill D. Towards realistic and flexible advance care planning. *Ir Med J.* 2013;106(10):293-294.

## **(2) Care of Covid-19 patients and others in institutional care settings**

*What has been the lived experience during the Covid-19 pandemic?*

- (How) has human dignity been protected, in relation to all aspects of care?
- What policies / practices were in place, including in relation to hospitalisation and the involvement of different levels of clinicians?
- (How) was equality and non-discrimination in clinical decision-making ensured?
- (How) have non-Covid-19-related health needs been met?
- What have been the conditions of work?
- How universal is training in gerontology, disability studies and dementia care?

*What are the existing structures?*

## **V. FAMILY AND COMMUNITY LIFE**

*What has been the lived experience during the Covid-19 pandemic?*

- (How) have community links been recognised and impacted for people living in institutional care settings?
- What efforts were made to maintain contact and a right to a family life for family members of people living in institutional settings during Covid19 pandemic?
- To what extent has Covid-19 hampered the Government's implementation of the transition from congregated settings to community for people with disabilities?
- What psychosocial supports were offered and provided to people living in institutional settings and their family members during the Covid-19 pandemic?
- To what degree have there been spillover effects on carers?

*What are the existing structures?*

- Are people forced to live in institutions away from their family members? What guarantees of person-centred care and personal support options exist? What is the entitlement and access to Personal Assistance across the lifespan?

## **VI. END OF LIFE**

*What has been the lived experience during the Covid-19 pandemic?*

- What policies / practices were in place in relation to end of life and palliative care?
- What efforts were made to facilitate end of life care conversations between people living in institutional settings and their family members/loved ones?
- What psychosocial, end of life, and bereavement support were offered and provided?
- Were bereaved families offered the opportunity to have a review of care meeting with the clinicians and relevant care staff who cared for their loved one at the end of life?
- How were funeral arrangements arranged and negotiated?

*What are the existing structures?*

- Regarding palliative care?
- Regarding the Coroner's involvement and procedures?
- Regarding case reviews?

## **APPENDIX 2: INDICATIVE LIST OF WITNESSES**

### People with direct experience of institutionalisation

National Platform of Self Advocates  
Recovery Experts by Experience  
Irish Dementia Working Group  
Ár Guth Ár gCearta  
Disability Federation of Ireland Group of young people living in Nursing Homes  
Aslam  
Independent Living Movement in Ireland (Shelley Gaynor, James Cawley)

### Families and other advocacy organisations

Inclusion Ireland  
National Advocacy Service  
SAGE  
Irish Advocacy Network  
Alzheimer Society of Ireland  
Age Action  
Mental Health Reform  
LEAP  
Inclusion Ireland  
Third Age, Áine Brady  
Family Carers Ireland  
Dementia Carers Network  
Nora Owen

### Clinical practice

Prof Des O'Neill, TCD  
Prof Rose Anne Kenny, TCD  
Deirdre Lang, Director of Nursing / National Lead, Older Persons' Services, HSE  
Georgina Bassett, Access Officer, South East Primary, Community & Continuing Care, HSE  
Rachel Simmons, Acting Director HSE CHO 9; Director of Nursing, Lusk Community Unit for Older Persons  
Irish Association of Directors of Nurses and Midwifery  
Irish College of General Practitioners  
Dr Cathal Morgan, HSE (disability)  
Prof Diarmuid O'Shea, Consultant in Geriatric Medicine, St Vincent's University Hospital; former Clinical Lead, National Clinical Programme for Older People (until May 2019)  
Dr Brendan O'Shea, Family Doctor and Adjunct Professor, Trinity College Dublin (end of life planning, health system design)  
Prof Kate Irving, DCU (clinical nursing, person-centred dementia care)

### Care practice cont'd

SIPTU / Care workers

Irish Association of Social Workers  
Nursing Homes Ireland  
Irish Hospice Foundation  
All-Ireland Institute of Hospice and Palliative Care

#### Regulatory

Pheilm Quinn, HIQA  
John Farrelly, Mental Health Commission  
Peter Tyndall, Ombudsman  
Irish Human Rights and Equality Commission

#### Policy-making

NPHET  
Michael Fitzgerald, HSE (older people) (Fair Deal and National Dementia Strategy)  
Dr Kathleen McLellan, Department of Health (social care infrastructure)  
National Disability Authority  
Dr Michael Kendrick (consultant on community living)  
Irish Human Rights and Equality Commission  
Judge Mary Laffoy  
Safeguarding Ireland  
Aine Fynn, Decision Support Service

#### Research / academia

Prof Suzanne Cahill, Trinity College Dublin (social work and social policy)  
Prof Eilionóir Flynn, NUI Galway (disability law and policy)  
Prof Gerard Quinn, University of Leeds / University of Lund (disability law and policy)  
Prof Kieran Walsh, NUI Galway (social gerontology)  
Dr Joan McCarthy, UCC (healthcare ethics)  
Prof Eamon O'Shea, NUIG (economics of ageing, dementia and rural ageing)  
Dr Sarah Donnelly, UCD (social work)  
Dr Marita O'Brien, Independent Health Policy Analyst  
Prof Mary Donnelly, UCC (medical / capacity law)  
Prof Amanda Phelan, TCD (ageing and community nursing)

## **APPENDIX 3: BIBLIOGRAPHY**

### ***Journal articles***

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