***Via* email only to:**
Minister Stephen Donnelly
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**CC**

- Minister Roderic O'Gorman, Department of Children, Equality, Disability, Integration and Youth, minister@equality.gov.ie
- Minister Michael McGrath, Minister for Finance, michael.mcgrath@oireachtas.ie
- Minister Paschal Donoghue, Department of Public Expenditure, National Development Plan Delivery and Reform, paschal.donohoe@oireachtas.ie.

- Mr Bernard Gloster, CEO, Health Service Executive Ceo.office@hse.ie
- Ms Laura Casey, Principal Officer, Social Care Projects, Department of Health laura_casey@health.gov.ie
- Ms Áine Flynn, Director, Decision Support Service aine.flynn@decisionsupportservice.ie

Date: 14th May, 2024

**Re: Register for Advance Healthcare Directives**

Dear Minister,

The theme of Safeguarding Ireland[1]'s public awareness campaign scheduled for June will be on planning ahead. The focus in June will be on encouraging adults to make an Advance Healthcare Directive (AHD). As you are aware an AHD is one of the decision support arrangements contained in Part 8 of the Assisted Decision-Making (Capacity) Act 2015 (Act), (which was enacted in December 2015 and commenced in April 2023) and as you are the Minister responsible for Part 8 of the Act, I am writing to you in relation to this matter.

Safeguarding Ireland is particularly concerned at the general lack of awareness of the Act and, in particular, of the various support arrangements which, if entered into, will help to reduce abuse of adults at risk and who need protection but will also be of economic benefit to the State if arrangements are in place. The Act is a significant piece of social legislation, which Ireland has been obliged to adopt to comply with the individual rights under the constitution, international human rights obligations, and is designed to uphold people's rights particularly those adults who are at risk and may be unable to make decisions for themselves at some time in their lives. For information, I attach RedC surveys commissioned by Safeguarding Ireland in May and October 2023. You will see the very low awareness of the making of an AHD and you will understand the deficits that need to be addressed.



[1] https://safeguardingireland.org/

National Safeguarding Ireland (trading as Safeguarding Ireland) (a company limited by guarantee) CRO #612163. RCN #20204851 Contact: annmarie@safeguardingireland.org
Directors: David Byrne, Carol Grogan, Bernice Evoy, Colm Nolan, Nora Owen, Amanda Phelan, Phelim Quinn, Patricia T Rickard-Clarke (Chair), Mervyn Taylor.

By Statutory Instrument (No.193/202) you, as Minister for Health, commenced Part 8 of the Act which deals with Advance Healthcare Directives on 26 April 2023. The purpose of Part 8 of the Act is clearly set out in Section 83 which provides:

*Section 83(1) The purpose of this Part is to –*

*(a) Enable persons to be treated according to their will and preferences, and*

*(b) Provide healthcare professionals with information about persons in relation to their treatment choices.*

Sections 84 -90 set out the details for the making of an AHD to include function, scope and validity. Section 91 provides for Codes of Practice and a number of codes specific to AHDs have been published by the Decision Support Service who have also published Guidance Documents on AHDs.

Section 84(12) provides:

*Section 84(12) The Minister may make regulations as respects advance healthcare directives, including regulations relating to –*

*(a) Requiring the directive-maker to give notice of the making of an advance healthcare directive, or any revocation or alteration thereof, -*

*(i) to the Director, and*

*(ii) to other specified persons, and whether or not by reference to persons who, under this Act, are required to be notified of an application made under this Act, and*

*(b) subject to subsection (12A), requiring the Director to establish and maintain a register…..of advance healthcare directives and any revocations or alterations thereof, that are so notified to him or her and that are made in accordance with this section.*

We understand from the Decision Support Service that it has made provision for such notification and has a Register prepared for AHDs but is awaiting the Regulation from you as Minister to commence its operation.

Safeguarding Ireland is concerned that currently there is no facilitation by the State to enable a person to formally record, either by way of notification to the Director or to record the making of an AHD on a register in accordance with the provisions of the Act. The lack of such a formal record continues to leave healthcare professionals in a continuing challenging position.

It is useful to bring to your attention Article 184 of **RECOMMENDATION CM/REC (2009)11 OF THE COMMITTEE OF MINISTERS TO MEMBER STATES ON PRINCIPLES CONCERNING CONTINUING POWERS OF ATTORNEY AND ADVANCE DIRECTIVES FOR INCAPACITY** – *An advance directive is of no value if it is not known by or accessible to persons who need to make decisions on behalf of or in relation to the incapacitated adult.*

Principle 1 of the 2009 Recommendation also sets out the promotion of self-determination and the making of an advance healthcare directive should take precedence.

*Principle 1 – Promotion of self-determination*

*1 States should promote self-determination for capable adults in the event of their future incapacity, by means of continuing powers of attorney and advance directives.*



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*2 In accordance with the principles of self-determination and subsidiarity, states should consider giving those methods priority over other measures of protection.*

*Comment*: It is important to note the emphasis placed on the promotion of self-determination and that those methods that promote self-determination should take priority over other measures. This means that the making of an enduring power of attorney and an advance healthcare directive by a capable adult should take precedence over any court application or other process. This is also the approach taken in the UN Convention on the Rights of People with Disabilities (UNCRPD) which provides for the least interventionist approach and the right of the person to be supported to state his or her will and preferences. The need to respect the right of autonomy of a person is included in the Guiding Principles of the Assisted Decision-Making (Capacity) Act 2015 (the 2015 Act).

In addition to the general promotion of self-determination, Safeguarding Ireland states that there are a number of compelling reasons as to why persons should be encouraged to make an AHD and why Regulations should be made under the provisions of Section 84 of the Act.

- Section 8 of the Act sets out the Guiding Principles that must be applied in respect of any intervention under the Act and the intervener (which includes a healthcare professional) must give effect to those principles which include having regard to the need to respect the right of the person to dignity, bodily integrity, privacy and autonomy and to give effect, in so far as practicable, to the past and present will and preferences of the person. When a person sets out their wishes (in the case of an AHD concerning issues of bodily integrity) it should be clearly evident as to where those wishes are recorded and the right of the privacy of the person respected.

- The HSE Consent Policy (updated in 2024) at 7.1.1 sets out the functions and duties of a healthcare worker to ascertain if a person has made an advance healthcare directive and, if so, what steps should be taken to read and follow same. The Act also provides that an AHD must be in writing. It is important therefore that there is a reliable record that can be readily accessed by healthcare workers to ascertain the existence of an AHD.

- For persons who are resident in long term care, it is particularly important that there is a formal accessible record as to their wishes, particularly for end-of-life care/palliative care. The right to palliative care is one of the rights that will be provided for in the forthcoming UN Convention on the Rights of Older Persons.

- While the DSS and HSE websites currently encourage the maker of a directive to give copies to families, a Designated Healthcare Representative and GPs, this is not optimal or sufficient and is limited. Many older people, and a growing number of them, do not have close family members or a trusted person that is readily available if they are unable to make healthcare decisions at a particular time, but they do wish to provide for such eventualities and to record their health wises. The Act also provides that it is not necessary to appoint a Designated Healthcare Representative – a person can write down their wishes with regard to treatment choices. The State has a public duty obligation to support and facilitate a



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person to appropriately record their advance healthcare directive so that it is readily accessible no matter the circumstances.

- Since the commencement of the Act in April 2023, there is evidence of more awareness that the adhockery and the inappropriateness of asking 'next of kin' (without legal authority) to make healthcare decisions does not meet the requirements of the Act and does not respect individual rights – the right to self-determination and autonomy. It is therefore necessary to put in place a system to appropriately record the making of an AHD.

- There is significant cost to the State in not encouraging the making an advance healthcare directive. In addition to the negative impacts on the person, the lack of planning for healthcare can be financially resource-intensive for the State. For example, in a hospital/care setting when it is necessary for a healthcare professional to have consent to treatment, and it is not available, critical time and effort may be necessary before consent becomes available. Alternatively, it may be necessary to make an application to the court, for the court to make a decision, or to appoint a third party to do so, and it is usually the HSE that has to bear the cost of such applications. The Department will be very aware of the increase in the number of applications to the Circuit Court in relation to the Act and many of the applications relate to healthcare issues. These are critical policy issues that require efficient and cost-effective administration of both healthcare and justice.

- Making an Advance Healthcare Directive is a safeguarding tool to prevent abuse. Safeguarding Ireland refers also to Article 12(4) of the UNCRPD which provides that *State Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law.* Ireland, as a party to the Convention, should ensure that an appropriate safeguard in relation to the making of an AHD is that there is a formal record of an individual wishes with regard to their healthcare decisions which is readily accessible to those who need to know.

Safeguarding Ireland requests you to publish the Regulations provided for under Section 84(12) of the Assisted Decision-Making (Capacity) Act 2015 and would greatly appreciate if this could be done to coincide with the public awareness campaign in June.

You may be aware that Safeguarding Ireland has submitted to your Department on a number of occasions, in relation to the need for a Place of Care Decision to be part of an Advance Healthcare Directive. We await the publication of the Deprivation of Liberty Safeguards to further ensure that this provision is made.
We look forward to confirmation from you of the publication of the Regulation as requested.

Yours sincerely,



Patricia T Rickard-Clarke
**Chair**



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