

**A Submission to the Department of Health on the Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013**

**7th March 2014**

**1. Introduction**

This submission is divided into three parts. The first part provides general guiding principles for formulating advance directives in the era of the UN Convention on the Rights of Persons with Disabilities. The second part responds to the Scheme of heads and identifies areas that may be problematic from a human rights perspective. The third part responds to the specific questions that were raised in the call for submissions. The final part comprises logos of all the organisations that have signed on to the submission.

This submission was developed in consultation with the organisations who have signed up to this submission and whose logos appear on Pages 13 and 14. In developing this submission, we also consulted individuals with lived experience of disability as well as those who have used mental health services, in particular, the Recovery Experts by Experience Group.[[1]](#footnote-1) Fiona Morrissey (PhD Candidate, National University of Ireland, Galway) also contributed significantly to the development of this submission.

**2. Guiding Principles for formulating advance directives in the era of the UN Convention on the Rights of Persons with Disabilities**

1. Everyone (regardless of decision-making ability) has the right to make a (written) advance directive and should be given the opprotunity to do so. A choice of instructional, proxy and a combination of both forms of advance directives should be legislated to accommodate various preferences. Support should be provided to complete the advance directive and makers should be encouraged to review advance directives regularly.
2. The point at which an advance directive enters into force (and ceases to have effect) should be decided by the person in the text of the directive and should not be based on a medical assessment that the person lacks mental capacity.
3. Once an advance directive has entered into force, third parties should be under a legal obligation to respect them. Advance directives should continue to have effect in situations of involuntary detention.
4. There may be an exception to the obligation to respect an advance directive where there is an imminent threat to the life of the person. ‘Imminent threat to the life of the person’ should be strictly construed and should apply equally in physical and mental healthcare. The refusal of life-sustaining treatment should also be addressed in the legislation. Authorisation to breach an advance directive must be provided by the court and priority should be given to delivering these decisions as quickly as possible, given the urgent nature of the circumstances.
5. The individual can specify what will constitute revocation of an advance directive in the text of the directive (whether revocation must be oral/ or in writing/other).
6. All advance directives can be revoked at any time by the person to whom it pertains – there will be no distinction between advance directives for mental health treatment and advance directives for physical health treatment in this respect. There should be the possibility for all advance healthcare decisions to be integrated.
7. An individual can choose to insert a ‘Ulysses clause’ into their advance directive, stating that their written will and preference as contained in the directive takes precedence over the individual’s own verbally expressed will and preference once the advance directive has entered into force. The Ulysses clause should only be used by individuals who clearly want their advance directive wishes to stand during specifiied periods and should be subject to independent execution safeguards to ensure it reflects the will and preference of the person.
8. The same registration criteria would apply to advance directives as to other support agreements (e.g. assistance agreements) under the Bill.
9. Where a person is nominated in the text to ensure that an advance directive is carried out, their duties must be clearly stated in the text of the Bill, and must include a requirement not to exert undue influence on the author of the advance directive. The conflict of interest in relation to healthcare providers acting should be stipulated in the legislation. The legislation should allow one or more nominated persons to be appointed for different decisions.
10. Where a person makes specific positive request(s) in an advance directive (e.g. for a specific type of medication only to be administered or to only be treated in a specific hospital or by a specific doctor) the same standard should be used to decide whether this can be honoured in both physical and mental health care.
11. Clear accountability and monitoring mechanisms should be provided to ensure that advance directives are adhered to. The Mental Health Commission and/or the Office of Public Guardian should have an oversight role in the monitoring of advance directives in the specific context of mental health. There is need for an independant adjudicator, for example an Ombusman, so that people who believe their advance directive was not adhered to, have a point of redress and independent adjudication. This needs to be a body independent of mental health services, or HIQA who do not have a role in considering an individual’s experiences of care.
12. An obligation should be placed on health care providers to find out whether someone has an advance directive before treating them. There should be serious penalties where a health practitioner or any other third party acts against the person’s wishes as stated in an advance directive.
13. There should an online registry of advance directives, accessible to health service providers when needed. However, data protection obligations to respect individuals’ privacy must be met.
14. Court decisions determining whether advance directives are overidden must be published in order to have a body of knowledge, for example to help in defining what constituted a ‘life threatening situation’ or ‘imminent danger’, etc. However, it may be necessary to anonymise the details of the individuals in these cases given the sensitive nature of the issues under discussion.

**3. General Response to the Scheme of Heads**

The following aspects of the Scheme of Heads raise concerns:

1. *Non recognition of universal legal capacity for all*

The Scheme does not recognize universal legal capacity for all. The possibility of making a binding directive depends on the individual passing the functional test of mental capacity. This approach is in conflict with Article 12 of the UN Convention on the Rights of Persons with Disabilities. Since the publication of the UN Committee on the Rights of Persons with Disabilities’ [Draft General Comment on Article 12](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx) in September 2013, it is now clearer than ever before that the Convention prohibits the use of mental capacity as a justification for denying or restricting a person’s legal capacity. As suggested by a coalition of civil society groups in a [response to the Bill](http://www.nuigalway.ie/cdlp/documents/amendments_to_bill.pdf), everyone should have the right to benefit from the positive, support-oriented provisions of the Assisted Decision-Making (Capacity) Bill 2013. This principle extends to the ability to make a binding advance directive and would suggest that the person’s clear expression of her will and preferences and adherence to the registration and notice provisions of the Scheme should be sufficient to create a binding directive. Otherwise, the dichotomy between capacity and incapacity will continue to prevail, and many of those who wish to make advance directives may not be found ‘capable’ of doing so.[[2]](#footnote-2)

Head 3 (2)a provides that the presumption of capacity shall exist ‘unless there is evidence to the contrary’. It is not clear what such ‘evidence to the contrary’ might be or who would make this determination. The Scheme does not provide further detail on who is responsible for determining whether an individual has sufficient ‘capacity’ to make an advance directive. Ideally, a valid advance directive should not be made on the basis of a person ‘having mental capacity’. An advance healthcare directive should be valid as long as it is made by a person over the age of 18, witnessed by a person who is over 18 years of age, and the witness can demonstrate that they know the person making the directive.

1. *Provisions relating to overriding an advance healthcare directive*

The law should provide that only the court can authorize the overriding of an advance healthcare directive. When an advance healthcare directive is sought to be over-ridden in a mental health context, a member of the Mental Health Tribunal should be required to meet the person whose directive is sought to be overridden and give evidence to the court. Alternatively, the Office of Public Guardian could develop a panel of experts who have experience in advance planning to give advice to the court as to whether an advance directive, for either physical or mental healthcare decisions, should be upheld. The person whose advance healthcare directive is being sought to be over-ridden should have an automatic right to legal representation including, where relevant, as should the patient designated healthcare representative. Finally, the party challenging the advance healthcare directive should bear the legal costs of the case.

1. *Applicability of advance directives to the administration of basic care*

The Scheme of Heads provides that advance healthcare directives are not applicable to the administration of basic care. Basic care is described as including warmth, shelter, oral nutrition, oral hydration and hygiene measures. Under current Irish law, an adult with the relevant legal capacity can make a valid contemporaneous refusal of medical treatment.[[3]](#footnote-3) The Supreme Court has acknowledged that artificial hydration and nutrition constitute medical treatment.[[4]](#footnote-4) Therefore, the legislation on advance directives must clarify that oral hydration and oral nutrition does not include artificial hydration and nutrition – and must ensure that individuals can make valid advance refusals of medical treatment on an equal basis with a valid contemporaneous refusal of treatment.

It is particularly important to ensure that palliative care, where necessary, can be provided, but the definition of basic care should explicitly exclude artificial hydration and nutrition.

Similarly, the general scheme should distinguish between ‘life saving’ treatment and ‘life prolonging’ treatment, and clarify that a valid refusal of ‘life prolonging’ treatment can be made, where the proposed course of treatment meets the definition of ‘medical treatment’.

1. *Implied revocation of advance healthcare directives*

Head 5(1) d provides for implied revocation of an advance directive where the person, ‘while he or she had capacity to do so, has done anything clearly inconsistent with the advance healthcare directive remaining his or her fixed decision’. The implied revocation of advance directives is problematic because it creates the possibility of an advance directive being questioned from a subjective reading of a person’s will and preferences. We recommend that this form part of best practice, i.e that people be encouraged to act consistently with their advance directive or to formally change the directive when it no longer represents their will and preferences.

1. *Advance health care directives and Part 4 of the Mental Health Act*

Advance healthcare directives should be legally binding where an individual’s treatment is regulated under Part 4 of the *Mental Health Act/*where an individual is under involuntary detention and treatment, or for individuals subject to the Criminal Law (Insanity) Act 2006. If an advance directive can only be made when a person ‘has mental capacity’ (as the Scheme of Heads provides), a person’s advance directive should apply even when they are involuntarily detained. This proposal conflicts with the Scheme’s principles of valuing autonomy and respecting will and preferences – as many of those who wish to make advance directives may have very specific concerns about what should happen if they are involuntarily detained. This creates a discriminatory standard for mental health as compared to physical health.

Instead of a blanket statement denying the use of advance healthcare directives in the case of involuntary detention, the law should limit the recognition of advance healthcare directives in the case of involuntary detention only when the situation is life threatening. For example, in the US State of New Mexico, a person’s preferences regarding medication and other aspects of treatment while hospitalized are required to be followed even when a person is involuntarily committed.

Since this submission strongly recommends that a validly made advance directive be legally binding even where a person is under involuntary detention, this entails further amendment of the Mental Health Act. Unless the Mental Health Act is reformed to reflect the positive provisions of the Capacity Bill, there is a grave risk that respecting advance directives could be used to continue to keep people in involuntary detention under the Mental Health Act (where an individual has validly refused all treatment but still meets the criteria for involuntary detention). Article 14 CRPD states that no person can be deprived of their liberty on the basis of a disability, and the UN Committee has made strong statements to the 10 countries it has examined to date to the effect that this requires the abolition of discriminatory laws which authorise detention and involuntary treatment of people with psychosocial disabilities in psychiatric hospitals  (see for example the Committee’s Concluding Observations on Australia).

In light of the prohibition of the UN CRPD on forced treatment, and our proposal in this submission that advance directives must be respected unless there is an imminent and grave risk to the person’s life, this will also necessitate reform of the Mental Health Act 2001, since the current position under section 57 of the Act allows a consultant psychiatrist to adminster treatment without consent where it is deemed necessary to “to safeguard the life of the patient, to restore his or her health, to alleviate his or her condition, or to relieve his or her suffering.”

Steps must be taken to accomplish the goal of abolition of involuntary detention in psychiatric hospitals, and these could include for example, greater scrutiny by the Mental Health Commission and increased safeguarding by the Mental Health Tribunals where involuntary detention is being authorised and the individual has made a valid advance refusal of treatment. Similarly, respect for an advance directive should not be used as a justification for greater use of restrictive practices, such as restraint and seclusion, where a person has made a valid advance refusal of treatment. In addition, where a person is detained under the Criminal Law (Insanity) Act, similar concerns may arise where their advance directive is respected, leading to a situation of indefinite detention. In our view, respect for an advance directive should not be used as a justification for continuing involuntary detention, since such detention could continue indefinitely if the person continues to meet the criteria. We strongly urge that the criteria for involuntary detention under both the Mental Health Act and the Criminal Law (Insanity) Act be reviewed and reformed in light of international human rights norms.

1. *Ensuring that 3rd parties are aware of the existence of an advance healthcare directive*

Currently, the Scheme of Heads provides that ‘A healthcare professional shall not incur civil or criminal liability if acting in good faith he /she was unaware of the existence and content of an advance healthcare directive’. We recommend that the law should place an onus on third parties to find out if an individual has an advance directive. Health care providers should be required to ask a person at the point of admission whether they have an advance healthcare directive.

Secondly, as part of good practice, every person who has an advance healthcare directive should be encouraged to carry a card that states that they have an advance healthcare directive. However, we do not believe that this should be a legally binding obligation on the individual.

Third, the Office of Public Guardian should establish an electronic database to record advance healthcare directives. As discussed above, this database must respect privacy and data protection laws, but should be easily accessible to healthcare providers who may need to access it. For example, the ‘Health Identifiers Bill’ should be expanded to include data on advance directives, and to provide requisite privacy protection on the same. This proposal also requires further consideration of an electronic health services and information database for the health system as a whole.

1. *Emergency situations*

The Scheme of Heads provides that ‘in general, apart from emergency situations, treatment cannot be provided to an individual without his/her consent’. We recommend that in general, the authority to override an advance healthcare directive should only be granted by the court where there is an 'imminent and serious threat' to the person's life. However, the legislation should clarify that 'imminent and serious threat to life' does not provide sufficient justification to override a valid refusal of care which has been made as part of an advance directive on end of life decisions.’

1. *Ulysses Clause*

The Scheme of Heads states that ‘enabling a person who lacks capacity to revoke or alter his or her directive would defeat the purpose of preparing the directive’ without allowing the possibility that this limitation should be allowed only when the advance healthcare directive has a Ulysses clause.

The Ulysses Clause should only be used by individuals who clearly want their advance healthcare directive wishes to stand during specified periods and be subject to independent execution safeguards to ensure it reflects the 'will and preferences' of the person. This option addresses situations where a person with self-experience knows they will object when unwell, but wishes his/her expressed preferences to take precedence to avoid deterioration. The person can change the advance directive at any time unless he/she chooses to execute this clause. Where an advance directive does not have a Ulysses Clause, a person should be able to verbally revoke their directive in real time/contemporaneously.

1. *The requirement of anticipating future circumstance*

The Scheme of Heads places too much emphasis on anticipating future circumstances that could arise. Head 4(2)b states that ‘a treatment outlined in an advance healthcare directive must be followed provided the circumstances in which the treatment refusal is intended to apply is clearly outlined’. This provision allows for the invalidation of an advance directive on account of the fact that a person did not anticipate some of the surprises that happen in the course of life.

1. *Safeguards*

There is need for additional safeguards to prevent abuse. For example, the Scheme should expressly state that an advance directive should be completed ‘free from coercion’. ‘Coercion’ is defined elsewhere in Irish law in Section 9(1) of the Non-Fatal Offences Against the Person Act, 1997. This includes when a person ‘with a view to compel another to abstain from doing or to do any act which that other has a lawful right to do or to abstain from doing, wrongfully and without lawful authority, (a) uses violence to or intimidates that other person or a member of the family, (b) injures or damages the property of that other.’

The advance healthcare directive sample form/draft form should have a statement to the effect that an advance directive should be made without duress, undue influence or coercion. The law should make coercing a person to make, revoke or alter an advance directive a criminal offence for which section 113 of the Bill on offences should apply.

There is a concern that elder abuse may arise with respect to AHDs. A response that prioritises autonomy and the will and preference of the individual must be developed with adequate safeguards.

1. *Liability protection for third parties who act in good faith*

The law should make it clear that where an adult refuses treatment with the result of deterioration is his/her health or where the refusal results in his or her death, the third party (hospital or individual doctor) is free from liability/protection for healthcare workers who abide by the advance healthcare directive in good faith.

1. *Positive requests*

Positive requests for specified treatment options should be honored where the request is budget neutral or would not impose a disproportionate burden. Where positive requests are declined, a written account of the reasons for declining should be entered into the person’s medical records.

1. *Support to families*

There should be a strong piece on support to families in terms of information, etc. One way to allow for the input of families is to incorporate advance directives into individual planning, which is usually completed with the input of family. The code of practice could have a statement which requires people to consider that their decision has an effect on other people.

Major life decisions for most people, including healthcare decisions, are rarely made in isolation. Family and other supporters are often present and may be affected significantly by such decisions. The safeguard provisions against undue influence and duress must be balanced against efforts to include family and supporters during important decision-making moments. Health professionals should promote family involvement as much as possible. Guidance can be sought from the 2013 National Carers Strategy, which provides a best practice guide for involving family and supporters in healthcare decision-making.

**4. Responding to the Specific Questions for Consultation**

**1. What are your views on requiring an individual to obtain professional advice (e.g. clinical and/or legal) before preparing an advance healthcare directive?**

The requirement that an individual obtain professional advise before preparing an advance healthcare directive should form part of best practice rather than a legislative requirement. It should be adequate to register ones’ advance directive with the Office of Public Guardian.

The sample advance healthcare directive form/draft form could have a statement to the effect that ‘you are advised to seek advise from professionals but failure to do so will not be construed as invalidating the advance healthcare directive’.

**2. Is it necessary for the provisions to designate a specific, mandatory time period within which an advance healthcare directive must be reviewed (e.g. every 2 years, every 5 years, every 10 years)?**

Regular review of advance directives is important; however, review should form part of best practice rather than a stipulation in the legislation. If the review period is included in the legislation, the failure to review may render the advance directive invalid, even when the person would wish for the advance directive to apply.

**3. Should a standard format be developed for advance health care directives?**

A standard format may be developed, but this should act as a guide only – advance directives should not be invalidated merely because they are not aligned to the standard format.

Further, the standard format could have sections, to ensure adequate details for the different scenarios. For instance, advance directives in the mental health context are quite different from those in the end of life context and while it would not be ideal to have different forms, it would be advisable to have sections that address the specific issues that arise under different situations.

**4. If a standard format for advance healthcare directives was developed what information should it contain?**

Advance directives should contain:

1. Name and date of birth of the person
2. Name and date of birth of the person proposed to be appointed as representative under the advance directive
3. Date of making advance directive
4. Statement to the effect that the advance directive is made free of coercion and/or undue influence
5. Specific description of the point at which the advance directive enters into force and ceases to have effect
6. Express provision regarding means of revocation
7. An option for a Ulysses clause, which should explain in simple language what the effect of a Ulysses clause would be
8. Name of preferred healthcare professional if any

**5. Where should advance healthcare directives be kept to ensure that their existence is known about and they can be readily accessed when required?**

The Office of Public Guardian should establish an electronic database that keeps a record of advance healthcare directives.Further, the ‘Health Identifiers Bill’ should be expanded to include data on advance directives, and to provide requisite privacy protection on the same.

**6. What additional measures could be included in the provisions to ensure that healthcare professionals are made aware that an individual has prepared an advance healthcare directive?**

The law should place an onus on third parties to find out if an individual has an advance directive. Health care providers should be required to ask a person at the point of admission whether they have an advance healthcare directive.As part of good practice (not legally binding), every person who has an advance healthcare directive should be encouraged to carry a card that states that they have an advance healthcare directive.

**7. The provisions enable an individual to make a legally-binding refusal of treatment in an advance healthcare directive, however, requests for treatment in such directives will not be legally-binding. What should be done to ensure that such treatment requests, while not legally-binding, are adequately considered during the decision-making process?**

Positive requests for specified treatment options should be honored where the request is budget neutral or would not impose a disproportionate burden. Where positive requests are declined, a written account of the reasons for declining should be entered into the person’s medical records.

**8. Given that advance healthcare directives relating to mental healthcare and treatment are intended to be used on a recurring basis, as opposed to advance healthcare directives for general healthcare which are predominantly used once, should a different format be used for both types of directive?**

See answer to Question 3 above

**Logos of All the Organisations**

**Recovery Experts by Experience Group**

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1. Recovery Experts by Experience group were formally known as Experts by Experience Advisory Group under the Amnesty International Mental Health Campaign, see http://www.amnesty.ie/mentalhealth [↑](#footnote-ref-1)
2. Human Rights in Ireland <http://humanrights.ie/mental-health-law-and-disability-law/advance-directives-and-irelands-new-capacity-legislation/> [↑](#footnote-ref-2)
3. Fitzpatrick V F.K. and another (2009) 2 IR 7. [↑](#footnote-ref-3)
4. In Re A Ward of Court (withholding medical treatment (No. 2) (1996) 2 IR 79. [↑](#footnote-ref-4)