

National **Safeguarding** Committee

Promoting the rights of adults who may be vulnerable



Briefing Note

Disability (Miscellaneous Provisions) Bill

to include proposed amendments to:

Assisted Decision-Making (Capacity) Act 2015

**To: Caoimhghin Ó Caoláin,
Chair of the Oireachtas Select Committee on Justice and Equality**

**From: Patricia T Rickard-Clarke,
Chair of Safeguarding Ireland (formerly National Safeguarding Committee)**

Date: 28 January 2018

Introduction:

Safeguarding Ireland was established in December 2015. It is a multi-agency and intersectoral body whose remit is to lead on encouraging an organisational and societal culture which promotes the rights of adults who may be vulnerable. Its terms of reference include the promotion of zero tolerance for abuse of adults who may be vulnerable and to provide strategic guidance to the Government, HSE and other National Stakeholders, in relation to the promotion of the rights and independence of all vulnerable adults.

Safeguarding Ireland notes that the **Disability (Miscellaneous Provisions) Bill 2016** is due for consideration by the Oireachtas Select Committee on Justice and Equality (Oireachtas Committee) on Wednesday 30th January 2019 and understands that a number of amendments to the **Assisted Decision-Making (Capacity) Act 2015** will also be considered. It wishes to bring to the attention of the Oireachtas Committee some important issues for its consideration. Safeguarding Ireland has not seen a draft of the updated Bill so some matters being raised in this briefing may already be included in the updated draft. Other matters that require clarification, amendment or updating have not been included but will be considered further by Safeguarding Ireland when it sees the detail of the proposed legislative provisions.

1 Protection of Liberty Safeguards and proposed addition to Advance Healthcare Directive contained in Part 8 of the Assisted Decision-Making (Capacity) Act 2015:

(i) The Oireachtas Committee will be aware of the need for urgency in the enactment of legislation on the issue of Protection of Liberty Safeguards which relates to right of a person to decide where they wish to receive care and not to be 'put into' a residential centre or designated centre (nursing home) against their wishes. Currently, because of the lack of a legislative framework (which must include relevant safeguards), Ireland is in breach of Article 40.4 of the Constitution, Article 5 of the European Convention of Human Rights and Article 14 of the UN Convention on the Rights of Persons with

Disabilities (UNCPRD). All of these instruments stipulate that it is necessary to have procedures prescribed by law. Currently, there are no such procedures as confirmed by the Court of Appeal in *AC v Cork University Hospital & Others* [2018] IECA.

(ii) Safeguarding Ireland is aware that Draft Heads on Deprivation of Liberty Safeguards (preferred terminology is Protection of Liberty Safeguards), of what is to become Part 13 of the Assisted Decision-Making (Capacity) Act 2015, were published in December 2017 with a Consultation Paper. Submissions on the draft were received and are being considered by the Department of Health. (Safeguarding Ireland made a detailed submission to the Department of Health in March 2018). Safeguarding Ireland understands that this issue will not be before the Oireachtas Committee for consideration on 30th January and that a separate piece of legislation will be tabled at a future date. Therefore, it will defer comments on this matter for the present. However, Safeguarding Ireland wishes to emphasise to the Oireachtas Committee **the urgency of this matter** and the need to ensure that the legislation on the Protection of Liberty Safeguards (when drafted) fully take account of the Guiding Principles set out in Part 2 of the Assisted Decision-Making (Capacity) Act 2015 (which was absent in draft Heads published in December 2017). The urgency of the need for this legislation arises, not only for each individual who is impacted by its absence which gives rise to a breach of their individual rights but there is also a cost to the State because of delayed discharges, applications to wardship, inappropriate placements and the waste of scarce healthcare resources.

(iii) Even though detailed legislation is awaited on Protection of Liberty Safeguards, this should not delay the making of provision in the Assisted Decision-Making (Capacity) Act 2015 to facilitate individuals to make a 'place of care' decision in an Advance Healthcare Directive. (This has already been referred to in our letter of 19th December 2018 with a detailed attachment). As previously stated:

- *From a personal wellbeing/self-determination/human rights perspective it is necessary to ensure that there is a formal legal framework that can accommodate the ascertainment of a person's will and preferences with regard to 'place of care' decisions with minimum barriers.*
- *It is already very evident that there are compelling societal and economic reasons of the need for the State to encourage people to put in place arrangements for care and the place where they wish to receive that care. The State has an obligation to ensure that legislation is in place to facilitate this.*
- *Given the demographic trends over the next 30 years with a requirement for increased expenditure on health and social care, it is important that public funds are used to provide an acceptable and appropriate level of such care rather than waste it on bureaucratic processes and unnecessary applications to court.*

There are a number of advantages to having a 'place of care' decision in an Advance Health Directive. These include - a less formal procedure, less costly for those who cannot afford to pay for professional advice and an Advance Healthcare Directive (rightly) does not require to be registered to come into effect but should require notification to the Director of the Decision Support Service. The Director, should however, have an obligation to establish and maintain a Register. Safeguarding Ireland therefore submits that **Section 82 in Part 8 of the Assisted Decision-Making (Capacity) Act 2015 be amended** to include, in addition to a treatment decision, a 'place of care' decision. This also means that a person may also give power to a Designated Healthcare Representative to make a 'place of care' decision on their behalf to come into effect when they lack the capacity to make such a decision personally. In addition, and in line with a treatment request, the legislation should also provide that a 'place of care' decision is not legally binding as it may not always be possible for practicable, medical or legal reasons to accommodate such a request. It would be important however, that the legislation provides that

although not legally binding, a 'place of care' decisions shall be respected unless there are very specific reasons why the person's will and preferences cannot be acceded to.

(iv) Safeguarding Ireland also urges **the immediate commencement of Part 8 of the Assisted Decision-Making (Capacity) Act 2015** to implement the legal framework for Advance Healthcare Directives. This would greatly facilitate people to plan ahead and to put arrangements in place in the event of future incapacity. The lack of planning ahead currently leads to huge delays and the waste of resources. One of the reasons for the delay in the discharge, particularly of older persons, from an acute hospital is that the older person had not nominated any person with authority with regard to treatment decisions nor have they given authority to anyone to consent to a 'place of care' decision on their behalf when the lack the capacity to consent personally. This often leads to great distress within families who have no legal authority to make such decisions, difficulties for healthcare professionals and also may result in the receiving of inappropriate care by some older people.

2 Review of Wards of Court – Part 6 of the Assisted Decision-Making (Capacity) Act 2015:

(i) Safeguarding Ireland wish to highlight to the Oireachtas Committee the glaring gap in Part 6 of the Assisted Decision-Making (Capacity) Act 2015 in relation to the lack of representation in relation of a Review of the capacity of Wards of Court. Part 5 of the Assisted Decision-Making (Capacity) Act 2015 provides that where an application is being made to the court in relation to a 'relevant person' with regard to determinations of his or her decision-making capacity, the person has a right to representation and assistance (both legal and non-legal) and sets out in detail how this may be facilitated. Section 52 contained in Part 5 also provides for legal aid and legal advice be available to a 'relevant person'. However, unfortunately Part 6 of the Act does not make any provision for representation, assistance, legal aid or legal advice when applications are being to the court for a Review under Part 6. This must be rectified.

(ii) Safeguarding Ireland understands that in previous discussions before the Oireachtas Committee, an official from the Department of Justice and Equality acknowledged awareness of these gaps in the Act. It is important that the Oireachtas Committee ensures that amendments to the Assisted Decision-Making (Capacity) Act 2015 are made to include the provisions as provided for relevant persons in Section 36 and 52 are also provided for Wards of Court in relation to a review of their decision-making capacity in accordance with the provisions of Part 6 of the Assisted Decision-Making (Capacity) Act 2015.

(iii) Another point for clarification that is contained in Part 6 of the Assisted Decision-Making (Capacity) Act 2015 is to ensure respect for the rights of each individual ward of court, for example Section 57(b) should be deleted as it refers to a 'class of wards' which would not align with UNCRPD requirement of the need to respect the dignity of each person. There are other provisions that may also need scrutiny. Safeguarding Ireland hopes that these issues have already been addressed and look forward to seeing the updated Disability (Miscellaneous Provisions) Bill 2016. These amendments are necessary to comply with the principle in Article 5 of the UNCRPD – *...all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.*

3 Guiding Principles – Part 2 of the Assisted Decision-Making (Capacity) Act 2015:

(i) Members of the Oireachtas Committee will be aware that the main purposes of the Disability (Miscellaneous Provisions) Bill 2016 is to, as set out in the title, give further effect to the UNCRPD. Ireland ratified the Convention in March 2018 and has undertaken to comply with it. The Bill therefore is providing for the amendment of a number of pieces of legislation to enable Ireland to comply with its

internationals human rights obligations. There are a number of core principles contained in the UNCRPD which are incorporated into the Assisted Decision-Making (Capacity) Act 2015 and are set out as part of the Guiding Principles contained in Part 2 Section 8 – to identify but one – Article 12.3 *State Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.* For persons whose decision-making capacity is at issue, this is an extremely important provision as the ability to make a decision personally goes to the core of personhood.

- (ii) Section 2 of the Assisted Decision-Making (Capacity) Act 2015 currently provides:
The principles ...shall apply for the purposes of an intervention in respect of a relevant person, and the intervener shall give effect to those principles accordingly.

An 'Intervention' is defined *in relation to a relevant person, means an action taken under this Act, orders made under this Act or directions given under this Act in respect of the relevant person by –*

- (a) *the court or High Court,*
- (b) *a decision-making assistant, co-decision-maker, decision-making representative, attorney or designated healthcare representative,*
- (c) *the Director,*
- (d) *a special visitor or general visitor, or*
- (e) *a healthcare professional,*

and the above referred to in (a) to (e) above are defined as 'interveners'.

(iii) Safeguarding Ireland is concerned (as indeed are many others) that the scope of the Guiding Principles as currently provided for in Section 2 of the Assisted Decision-Making (Capacity) Act 2015 is limited by the use of the words '*for the purposes of an intervention*' and is further restricted by providing that the Guiding Principles only apply to the class of specified interveners rather than to any person interacting with a relevant person. These are major limitations with clearly unintended consequences and certainly not intended by the Oireachtas as indicated in many debates prior to its enactment. It is necessary to amend Section 2 to ensure that the general principles set out in the UNCRPD are given practical and meaningful effect to and not interpreted so narrowly as to make the Guiding Principles largely redundant with regard to interactions with a relevant person. The legislation must provide that there is general applicability of the Guiding Principles in relation to any interaction with a relevant person and everyone interacting with a relevant person must give effect to them. The General Principles are key guidelines as to how to respect the autonomy and dignity of the relevant person.

4 Social Welfare Consolidation Act 2005:

(i) The Explanatory Memorandum to the Disability (Miscellaneous Provisions) Bill 2016 states that a new provision (which was not included in the General Scheme of the Bill as published) will amend the Social Welfare Consolidation Act 2005. The Explanatory Memorandum goes on to state that: *The Assisted Decision-Making (Capacity) Act 2015 sets out guiding principles that are intended to safeguard the autonomy and dignity of the person with impaired capacity. In order that the social protection arena takes full account of those principles, it is necessary to explicitly reference the Assisted Decision-Making (Capacity) Act in Section 244 (Payment to persons other than claimant or beneficiary) of the Social Welfare Consolidation Act 2005.* (This further emphasises point being made above that the Guiding Principles must have general applicability).

(ii) An agent appointed under Section 244 of the Social Welfare Consolidation Act 2005 has an obligation under the legislation to use the benefit or pension obtained for the benefit of the claimant or beneficiary but there is in fact little or no oversight of such agents. Safeguarding Ireland is very concerned about the level of financial abuse particularly in relation to State benefits to which the many vulnerable in society are entitled. (In particular, the level of financial abuse of the older old is at an unacceptable level). Safeguarding Ireland therefore believes that the proposed amendment, as suggested in the Explanatory Memorandum, does not address some fundamental requirements of the UNCRPD – the requirement to have appropriate safeguarding provisions and the need to respect the autonomy of each claimant or beneficiary.

(iii) A number of points need to be made.

- The Social Welfare Consolidation Act 2005 predates both the UNCRPD and the *Assisted Decision-Making (Capacity) Act 2015*. In addition to the 2015 Act providing that the Guiding Principles should be given effect to, it provides that capacity must be construed on a functional basis and that a person may choose to enter into different support arrangements to take account of different levels of decision-making ability thereby ensuring the least restrictive approach of the person's rights. Where decision supporters are involved with a relevant person, they have reporting obligations to the Director of the Decision Support Service who has a statutory oversight function to ensure that they are acting within the scope of their functions.
- Article 12(4) of the UNCRPD provides:
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. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
- Article 12(5) of the UNCRPD provides:
Subject to the provisions of the article, State parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own and inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

(iv) Safeguarding Ireland states that amending Section 244 of the Social Welfare Consolidation Act 2005 as indicated in the Explanatory Memorandum to the Disability (Miscellaneous Provisions) Bill 2016 is insufficient. It therefore suggests that the Social Welfare Consolidation Act 2005 be amended to provide that where a person, who is in receipt of any benefit or pension, is or becomes a relevant person as defined in the Assisted Decision-Making (Capacity) Act 2015 and who needs support in managing any payment received under the Social Welfare Consolidation Act 2005 then the provisions of the Assisted Decision-Making (Capacity) Act 2015 shall apply. In other words the person who will be appointed 'agent' for the purposes of receiving social welfare payments will be any of a Decision-Making

Assistant, Co-Decision-Maker, Decision-Making Representative or an Attorney all appointed under the provisions of the Assisted Decision-Making (Capacity) Act 2015 or as the case may be an Attorney appointed under the Powers of Attorney Act 1996. This also ensures that the right of autonomy of the individual person is respected.

5 Nursing Home Support Scheme Act 2009:

(i) The Nursing Home Support Scheme Act 2009 is yet further legislation that was enacted prior to the Assisted Decision-Making (Capacity) Act 2015. It makes provision for the appointment of a person defined as a 'care representative' to be appointed when a person lacks capacity to make an application for financial support for the payment of long term care. The necessary legislative provisions - the Guiding Principles, functional construction of capacity, the respecting of a person's autonomy in so far as possible and the choosing by them of whatever support arrangements are necessary to take account of the different levels of capacity - are all contained in the Assisted Decision-Making (Capacity) Act 2015. Further gaps in the 2009 Act relate to non-representation of a person who lacks capacity in a court application, no provision for the review of capacity and no appropriate safeguarding provisions. Therefore, the appointment of any person to act on behalf of a person who lacks capacity for the purpose of being able to avail of the provisions of the Nursing Home Support Scheme Act 2009, should be done within the provisions of the Assisted Decision-Making (Capacity) Act 2015.

(ii) Safeguarding Ireland suggests that Section 21 of the Nursing Home Support Scheme Act 2009 be replaced with the following provision:

Where a person whose capacity is in question or may shortly be in question or who lacks the capacity to make an application for a care needs assessment or to make an application for ancillary State support, the provisions of the Assisted Decision-Making (Capacity) Act 2015 shall apply.

Conclusion:

The Oireachtas Committee will be very aware of the lengthy pre legislative scrutiny that took place over a number of years in relation to the enactment of the Assisted Decision-Making (Capacity) Act 2015. This was necessary in order to replace and reform our existing archaic legislation with a modern legal framework as to how decision-making capacity is to be construed and assessed and to ensure that the State is enabled to fully comply with its international human rights obligations. Therefore, statutes which do not take account of the UNCRPD and/or predate the Assisted Decision-Making (Capacity) Act 2015 and fall short of respecting an individual's human rights or do not have appropriate safeguarding provisions in relation to persons whose capacity is at issue must be amended or replaced. Also where gaps in the Assisted Decision-Making (Capacity) Act 2015 itself have been identified as needing amendment or clarification these should be dealt with and accommodated at this stage thus avoiding unnecessary and costly applications to court on the full commencement of the Act.

Finally, Safeguarding Ireland **urges the full commencement the Assisted Decision-Making (Capacity) Act 2015** as soon as possible. It reiterates, the need for the **immediate commencement** of Sections 3, Section 8 which is Part 2 and Part 8 dealing with Advance Healthcare Directives. In addition, it asks that serious consideration be given to the inclusion in Part 8 of a 'place of care' decision to enable a person to express their will and preferences with regard to where they wish to receive care if that eventuality should arise.

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