Submission from Mental Health Reform (MHR) to the Joint Committee on Children, Equality, Disability, Integration and Youth on the Assisted Decision-Making (Capacity) (Amendment) Bill 2021

21st January 2022

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Key Recommendations

- **The Assisted Decision-Making (Capacity) (Amendment) Bill 2021 and subsequent Codes of Practice must be in compliance with the UNCRPD and should also be cognisant of upcoming reform in mental health legislation.**

- **Mental Health Reform (MHR) calls for the extension of provisions to those who are involuntarily detained under Part 4 of the Mental Health Act 2001. MHR also calls for clarification on the rights of persons in prison relating to their mental healthcare.**

- **MHR recommends that provisions should be made in Part 8 of the 2015 Act for 16 and 17 year olds to consent to or refuse treatment for mental health difficulties, in line with their rights for physical health.**

- **MHR recommends that the Director of the Decision Support Service (DSS) be required to maintain a register of Advance Healthcare Directives (AHDs).**

- **MHR calls for the review of the ADMA to be aligned with a review of the Mental Health (Amendment) Bill 202X.**

- **MHR calls for a comprehensive and accessible communications campaign to ensure that people are aware of their rights under the Act.**

- **MHR calls on the Committee to recommend that a significant training, recruitment and upskilling campaign be immediately undertaken with services who will be taking on new responsibilities and providing decision-making assistance.**

- **MHR recommends that further examination is required into the provision of insurance services to people with mental health difficulties. MHR calls for the collaboration with the Minister on the review of the Equal Status Acts where these issues have been consulted on in greater detail.**

- **MHR recommends clarification on the Deprivation of Liberty Safeguards; an update on the status of the Bill and that the Committee recommend how safeguards will be in place in the interim.**

1. Introduction

Mental Health Reform (MHR) is Ireland's leading national coalition on mental health. Our vision is of an Ireland where everyone can access the support they need in their community, to achieve their best possible mental health. We drive the progressive reform of mental health services and supports, through coordination and policy development, research and innovation, accountability and collective advocacy. Together with our 76 member organisations and thousands of individual supporters, MHR provides a unified voice to the Government, its agencies, the Oireachtas and the general public on mental health issues.

MHR welcomes the opportunity to submit to this consultation on behalf of our members. MHR would like to thank our members for their continued insight, input and work in the area of mental health supports and services.

To prepare for this consultation on the General Scheme of the Assisted Decision-Making (Capacity) Act 2021, MHR hosted two, invite-only, online briefing sessions open to members and other key stakeholders in the disability sector.

MHR has been very actively involved in reviewing the Heads of Bill of the Mental Health (Amendment) Bill 202X, which is currently undergoing pre-legislative scrutiny (PLS) by the Sub-Committee on Mental Health. On the 30th of November 2021, MHR appeared before that Sub-Committee as a witness[1] and some of the issues raised are also pertinent to the General Scheme before the members of the Joint Committee on Children, Equality, Disability, Integration and Youth. MHR notes also that the Committee on Disability Matters has also discussed some of the issues relevant to the PLS of this Bill, in particular the appearance of the Decision Support Service (DSS) on May 20th, 2021[2].

[1] https://www.oireachtas.ie/en/debates/debate/joint_sub_committee_on_mental_health/2021-11-30/2/
[2] https://www.oireachtas.ie/en/debates/debate/joint_committee_on_disability_matters/2021-05-20/2/

MHR is a funded and active member of the Disability Participation and Consultation Network (DPCN). The role of DPCN is to "*provide the views and opinions of people with disabilities living in Ireland on law, policy and other important issues. Working on specific issues, this could mean, for example, attending workshops and meetings (online, or in person, having discussions with other members, or completing questionnaires)*[3]." In its first year the DPCN has positively engaged in consultation processes including those by the Department of Children, Equality, Disability, Integration and Youth (DCEDIY) and the Department of Housing, Local Government and Heritage. In its role, the DPCN has been able to advise on accessible and inclusive participation in State consultation processes as is disabled people's rights under the UN Convention on the Rights of Persons with Disabilities (UNCRPD), which was ratified by the State in 2018. Mental health difficulties may also be known as psychosocial disabilities and therefore the rights of the UNCRPD extend to those with mental health difficulties[4].

MHR was also invited to join the Assisted Decision-Making (ADM) Implementation Steering Group and the Advance Healthcare Directive (AHD) Multidisciplinary Working Group at the end of 2021 and is an active member of both.

Recommendations:

The Assisted Decision-Making (Capacity) (Amendment) Bill 2021 and subsequent Codes of Practice must be in compliance with the UNCRPD and should also be cognisant of upcoming reform in mental health legislation.

MHR urges Committee members to liaise closely with all relevant colleagues who have been working in the area of assisted decision-making and human rights.

MHR calls on the Committee to examine interlinking pieces of legislation and upcoming amending legislation to fully inform this process.

[3] https://www.gov.ie/en/consultation/a3ef2-launch-of-disability-participation-and-consultation-network/
[4] https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2020/05/disabilities-inequalities-2020.pdf

1.1 Welcome Changes

The amendment and commencement of the long-awaited Assisted Decision-Making (Capacity) Act 2015 will represent a momentous change for disabled people and their rights. The 2015 Act is regarded by the State as part of the reform required to give full effect to its obligations under Article 12 of the CRPD, which requires that: "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."

MHR welcomes many of the changes in the Assisted Decision-Making (Capacity) (Amendment) Bill 2021. For example, Head 7 Amendment of section 11 of the Act of 2015 relating to persons who are not eligible to be decision-making assistants (which is reflected through other Heads in respect of the relevant sections); Head 9 which provides for Section 14 of the Act of 2015 to be amended, in subsection (1)(b), by the substitution of “assist” for “advise”; Head 11 New Section 15A - Offence in relation to decision-making assistance agreement; all of the Heads relating to the new two-step process in registering an Enduring Power of Attorney (EPA) and then notifying the Director of the DSS when the person loses capacity.

MHR welcomes, in particular, Head 27 Amendment of section 44 of the Act of 2015, which will delete subsections (5), (6), (7) and (8) relating to the use of restraints in private settings by decision supporters. Head 41 Deletion of section 62 of the Act of 2015 also deletes references to the use of restraints in private settings. MHR advocates for the move towards the Sharing the Vision policy of ‘zero restraint, zero seclusion’ in all settings.

There is much to welcome in the 2015 Act and this Amendment Bill.

2. Assisted Decision-Making & Mental Health

2.1 Decision Supports and Mental Health

The Assisted Decision Making (Capacity) Act 2015 is set to be commenced by June 2022. It is hoped that the Decision Support Service (DSS) will then be operational. The DSS is an essential new service for all adults who need support exercising their right to make decisions. This may include people with an intellectual disability, acquired brain injury, mental health difficulty or dementia. Of note is that persons may have co-morbidities, which is why MHR always calls for a holistic approach to each person with psychosocial disabilities.

The new framework will help to ensure that people are supported with decisions about their healthcare, personal welfare, property, affairs, and finances in a way that respects their individual will and preferences.

Estimates suggest that there could be as many as 200,000 people living in Ireland who have difficulties with decision-making capacity — and who may become users of the DSS. Recent research carried out by the DSS to forecast demand for the new service showed that 1 in 20 of the population may require access to it at some point in their lives. An estimated 7,408 individuals are expected to access the DSS in its first year of service, rising to 7,942 in 2026.

Among the beneficiaries of the new system will be all current adult wards of court. Almost 2,000 people have been made wards of courts since the Assisted Decision-Making (Capacity) Act 2015 was enacted. All adult wards will have their cases reviewed by the wardship court and must transition out of wardship within three years of commencement. Mental Health Reform will be calling for a shortening of this timeframe given the serious deprivation of liberty of wards.

Heads 32, 33 and 34 amend section 54 of the Act of 2015, 55 of the Act of 2015 and insert a new section 55A to the Act and all relate to wards of court and removing disparities between relevant persons and wards and to address gaps in the current provisions of the Act.

Any one of us could have difficulties with decision-making at a future point in our lives and the 2015 Act also provides tools for all adults to plan ahead by way of an enduring power of attorney (EPA) and an advanced healthcare directive (AHD). Mental Health Reform will be calling for these rights to be extended to people involuntarily detained with mental health difficulties and for 16 and 17-year-olds as are our obligations under the UN Convention on the Rights of the Child (UNCRC) and the UNCRPD.

Until stigma around mental health difficulties is reduced, it is likely that people may not plan ahead for their preferred treatments and healthcare decisions. It is possible that people will only become aware of their rights and preferences relating to mental health once they are in contact with mental health services. MHR has often called for parity of esteem between physical health and mental health and this extends now to the rights and services around assisted decision-making.

2.2 Advance Healthcare Directives (AHDs)

An Advance Healthcare Directive (AHDs) is a statement set out by someone when they have capacity to make decisions, about their will and preferences for care and treatment in the future. The Directive comes into effect, if, and when, the person becomes unwell, and no longer has decision making capacity. People can make AHDs about a broad range of issues such as the type of medication they prefer, the type of therapies that work best for them, in addition to treatment refusals (e.g. Electro-Convulsive Therapy (ECT)).

2.2.1 AHD's and Mental Health

Under the Assisted Decision-Making Capacity Act, 2015 people who are detained in hospital for mental health treatment are specifically excluded from legally binding advance healthcare directives. They have no legal right to have their advance wishes respected, even though they had capacity to make decisions about their mental health care and treatment at the time of making their directive. There is no other group of individuals that are specifically excluded from this legal right. This exclusion is contrary to international human rights standards, including the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

While AHDs can be made for mental health treatment/care decisions, under Part 8 of the 2015 Act, they are not legally enforceable for persons involuntarily detained under the 2001 Act. An AHD can be taken into consideration, but it is not legally enforceable in these circumstances. The exclusion of persons detained under the 2001 Act would violate the CRPD as it discriminates on the grounds of disability. Similar legislative provisions were litigated as discriminatory under the American with Disabilities Act in the US in 2003[5]. The Assisted Decision-Making (Capacity) Amendment Bill 2019 proposed to remove this exclusion from the 2015 Act. The Bill reached Seanad stage but lapsed with the dissolution of the Dáil in March 2020. This discriminatory exclusion urgently needs to be removed from the 2015 Act. Equal access to AHDs should be provided for in both the 2015 Act and in the legislation amending the 2001 Act. AHDs are a critical support measure which should be made equally available to everyone, particularly those who are involuntarily detained under mental health legislation. The research exploring this area in Ireland suggests that the group who need AHDs the most to increase trust and respect are excluded from the legislation[6]. Therefore, it is essential that AHDs should be provided for all persons on an equal basis with others in both the legislation amending the 2001 Act and the 2015 Act

[5] Hargrave v State of Vermont, No.2: 99-CV 128 (2001); Hargrave v State of Vermont, 340 F 3d 27 (2nd Cir 2003).
[6] Fiona Morrissey, "The Introduction of a Legal Framework for Advance Directives in the UN CRPD Era: The Views of Irish Service Users and Consultant Psychiatrists" (Ethics, Medicine and Public Health: (2015) (1) 325).

This gap in the law is of great concern given reports by people who use the services that they are not sufficiently involved in their mental health care and treatment. For example, in MHR's My Voice Matters survey almost 40% of participants who use mental health services felt that they were not involved as much as they would like in decisions about the medicines they take[7]. Research shows that advance healthcare directives can reduce involuntary admissions, promote recovery and be cost effective[8].

The Expert Review Group (ERG) of the Mental Health Act, 2001 recommended that the legislation amending the 2001 Act should address in a comprehensive manner the operation of AHDs in the area of mental health[9]. The Expert Group also recommended that the legislation providing for AHDs should apply to mental health on an equal basis with general health. AHDs should be stated in clear and unambiguous terms the specific treatments to which it relates and also the particular situations in which the treatment decisions are intended to apply and that directives should be recorded in the person's recovery plan.

However, there is concern about the ERG's recommendation that a valid and applicable AHD can be overridden if at the time when it is proposed to treat the person, they are suffering from a mental illness and are detained under Part 4 of the 2001 Act and/or by the Criminal Law (Insanity) Act 2006. The blanket denial of a person's will and preferences and concerns when they are detained involuntarily on mental health grounds is unjust, particularly at the moment such AHDs arguably become most important.

Recommendation:

Involuntary patients do not have the right to have their advance wishes about treatment respected. MHR calls on the Committee to recommend the extension of provisions of this Act to those who are involuntarily detained under Part 4 of the Mental Health Act 2001.

[7] https://www.mentalhealthreform.ie/wp-content/uploads/2019/03/SU-EXEC-SUMMARY-WEB.pdf
[8] Morrissey F., "Advance Directives in Mental Health Care: Hearing the Voice of the Mentally Ill", (2010) 16 (1) Medico-Legal Journal of Ireland 21.
[9] https://www.gov.ie/en/publication/637ccf-report-of-the-expert-group-review-of-the-mental-health-act-2001/

2.2.2 Proposed under The Mental Health (Amendment) 202X[10] Heads

The Mental Health (Amendment) 202X[11] Heads of Bill notes that section 85(7) and section 136 of the 2015 Assisted Decision-Making (Capacity) Act will need to be amended to ensure provisions around designated healthcare representatives can operate and will ensure parity of treatment for those with mental health difficulties. Therefore, the intention in the Heads of Bill to reform the 2001 Mental Health Act is to provide parity in terms of the application of AHDs to both voluntary and involuntary categories. However, MHR would like to bring to the committee's attention that there is a lack of clarity on how this gap will be addressed in the interim.

As part of MHR's ongoing campaign to 'Reform the Mental Health Act 2001', a human rights analysis piece on the heads of bill to reform the Mental Health Act 2001 was commissioned last year. The comprehensive analysis by Dr Charles O'Mahony and Dr Fiona Morrissey of NUIG has been shared with relevant Ministers, Department Officials and Committee members. Of interest and of relevance to this Committee is a section in the paper on AHDs as they relate to mental health[12]. We have copied or paraphrased some of the information below for ease of access for Committee members and the paper in full is available on our website[13].

AHDs are considered a critical support to enable people to exercise their capacity in treatment/care decisions and avoid the need for coercion and non-consensual treatment, which is prohibited under the CRPD. The research suggests the process of developing an AHD confers recovery and capacity building benefits for the person[14]. An international systematic review reported that AHDs reduced involuntary admissions by 23%[15]. AHDs are also associated with a reduced need for readmission

[10] https://www.gov.ie/en/publication/47068-draft-heads-of-a-bill-to-amend-the-mental-health-act-2001/
[11] https://www.gov.ie/en/publication/47068-draft-heads-of-a-bill-to-amend-the-mental-health-act-2001/
[12] https://www.mentalhealthreform.ie/wp-content/uploads/2021/11/Legal-analysis-MH-Act-28-October-1.pdf
[13] https://www.mentalhealthreform.ie/wp-content/uploads/2021/11/Legal-analysis-MH-Act-28-October-1.pdf
[14] Marvin Swartz & Jeffrey Swanson, 'Commentary: Psychiatric Advance Directives and Recovery-Oriented Care' (2007) 58 Psychiatric Services 1164.
[15] Mark de Jong and others, "Interventions to Reduce Compulsory Psychiatric Admissions: A Systematic Review and Metaanalysis" (JAMA Psychiatry: (2016) 73 (7) 657)

into hospital[16], and enhanced recovery[17]. This is particularly relevant in the Irish mental health system where 60% of admissions are readmissions[18].

Recommendation:

MHR calls for the amendment of sections 85(7) and 136 of the 2015 Act to be amended to ensure parity of treatment for those with mental health difficulties.

2.2.3 Register of Advance Healthcare Directives (AHDs)

MHR calls for the Decision Support Service (DSS) to maintain a register of Advance Healthcare Directives (AHDs). In cases of emergency or urgent situations, where a person has lost capacity due to a mental health crisis, MHR would be concerned on how, at a practical level, a treating healthcare professional would be aware that an AHD exists without such a register. Furthermore, without a record of an AHD having been made MHR would express concerns that there is a risk that a person's will and preferences will not be known, respected and their human rights upheld[19] During a session with the Committee on Disability Matters on the 20th of May 2021, Ms Áine Flynn, Director of the DSS confirmed that such a register would beneficial.

Ms Flynn stated:

Part 8 states that the Minster for Health may make regulations to provide for the notification of the making of an advance healthcare directive to the director of the Decision Support Service and for the director to maintain a register of advance healthcare directives. It is the view of the DSS that these regulations would enhance the operation of Part 8 and would benefit the person and healthcare professionals

[16] Claire Henderson and others, "Effect of Joint Crises Plans on Use of Compulsory Treatment in Psychiatry: Single Blind Randomised Controlled Trial" (British Medical Journal, (2004) 329, 13); Chris Flood and others, "Joint Crisis Plans for People with Psychosis: Economic Evaluation of a Randomised Controlled Trial" (British Medical Journal: (2006) 333. 729).

[17] Marvin Swartz & Jeffrey Swanson, "Commentary: Psychiatric Advance Directives and Recovery-Oriented Care" (Psychiatric Services: (2007) 58, 1164).

[18] There were 16,710 admissions to Irish psychiatric units and hospitals in 2019. 60 per cent of these were readmissions and 14 per cent were involuntary. Health Research Board, "National Inpatient Reporting System Bulletin"), (Dublin: Health Research Board, 2020).

[19] https://decisionsupportservice.ie/services/decision-support-arrangements/advance-healthcare-directive

alike. However, we are informed by the Department of Health that the absence of unique health identifiers is an obstacle that must be overcome before these regulations can be written[20].

Recommendations:

The validity of AHDs should apply equally between both general health care and mental health care. The Heads of Bill should explicitly provide that AHDs are enforceable in respect of voluntary, intermediate, and involuntary categories. The 2021 Amendment Bill must be amended accordingly.

MHR calls on the Committee to ensure that the required amendments are brought forward in this amendment bill as the reform of the 2001 Act will take some time before being enacted, commenced and implemented.

The Committee has an opportunity now to address this lacuna and extend this human right to persons detained under Part 4 of the 2001 Mental Health Act.

MHR also calls for clarification on persons detained in prison or forensic facilities and their rights to have AHDs respected.

MHR recommends that the Director of the Decision Support Service (DSS) be required to maintain a register of Advance Healthcare Directives (AHDs).

3. The need for specific provisions on the capacity of 16 and 17-year-olds to give consent in a mental health context

Currently, people aged 16 and 17 can consent to or refuse physical healthcare decisions, but this right does not apply to mental healthcare decisions. Under Irish law (i.e. the Non-Fatal Offences Against the Person Act, 1997) 16 and 17 year olds can consent to treatment for physical health care. This includes any surgical, medical or dental issues, including for example, treatment for cancer. However, 16 and 17 year olds do not have any right to consent or refuse mental health treatment. This includes consent or refusal of admission to hospital. This means that 16 and 17 years olds accessing mental health services cannot make decisions about their own mental

[20] https://www.oireachtas.ie/en/debates/debate/joint_committee_on_disability_matters/2021-05-20/2/

health care and treatment. For example, a 16 or 17-year-old cannot refuse a particular course of treatment such as electro-convulsive therapy (ECT), even if they wish to refuse. This situation is made worse by the fact there is no national advocacy service for people under the age of 18 who are accessing mental health services.

In the absence of an advocacy service, there is a risk that young people are not having their voices heard about their mental health care and treatment. In addition, there is no review of 16 and 17 year olds who have been admitted to inpatient mental health services on a voluntary basis. This is a big concern given that 16 and 17 years do not have a legal right to refuse or consent to admission. Their admission is categorised as voluntary based on their parent's or guardian's consent.

3.1 Gap being addressed through interlinking legislation

MHR notes that there are attempts to address this gap through provisions included in a standalone Part 8 in the Heads of Bill to Reform the Mental Health Act 2001. Part 8 outlines all provisions for those under 18, with specific references to 16 and 17 year olds with capacity; 16 and 17-year-olds whose capacity might be in question; under 16s with capacity; and under 16s whose capacity might be in question. These changes will reflect our obligations under the UNCRC and UNCRPD.

However, MHR would like to once more highlight a concerning lacuna between the Heads of Bill to Reform the Mental Health Act 2001 and the Assisted Decision Making (Capacity) Act 2015. As mentioned, Part 8 of the Mental Health (Amendment) Bill is set to provide for 16 and 17 year olds to give or withdraw consent to treatment in mental health services if they are deemed to have capacity. The Heads of Bill state that the Assisted Decision Making (Capacity) Act 2015 would apply for the purposes of conducting the necessary capacity assessments. However, the Act doesn't provide for decision supports for under 18s. Mental Health Reform has written to all relevant Ministers highlighting this lacuna and we hope that this Committee will find a remedy as a matter of urgency.

It is regrettable that the 2015 Act excluded persons aged under 18 to avail of the supports it provides. In particular, the exclusion of 16- and 17-year-olds from the scope of the 2015 Act is of concern as it serves to impede young persons from exercising their legal capacity under the revised mental health legislation.

3.2 ECT and 16/17-year-olds

The World Health Organization has criticised the use of Electro-Convulsive Therapy (ECT) on children and young people and has recommended that the use of ECT should be prohibited by legislation[21]. Section 106 in the Heads of Bill to reform the 2001 Mental Health Act contains a specific provision for the administration of ECT to children. It states that a programme of electro-convulsive therapy should not be administered to a child aged 16 years or older unless the child gives their consent in writing to the administration of the programme of therapy. Subsections of the Heads provide that where a child aged 16 years or older has been deemed to lack capacity or where a child is aged under 16 years of age, or a child in respect of whom an order is in force, a programme of ECT should not be administered in any circumstances to the child without the explicit approval of the court. The explanatory notes for this subsection explain that the HSE advised that provision for ECT for children should be retained in the revised Act as it continues to be prescribed occasionally.

3.3 The DSS and 16/17-year-olds

MHR believe that it's imperative to ensure that young people can be confident that their will and preference regarding accessing services and supports are respected in the same manner as for those aged over 18 years of age. That is the thrust of Part 8 and amending legislation but it seems to have been overlooked up to this point. We further understand that for the HSE's National Consent Policy to be robust, issues around capacity need to be set on a statutory footing.

[21] World Health Organization, "WHO Resource Book on Mental Health, Human Rights and Legislation Stop Exclusion: Dare to Care" (Geneva: 2005), at page 64.

When the issue of extending the legislation to cover 16 and 17-year olds during the session of the Committee on Disability Matters, Ms Áine Flynn, Director of the Decision Support Service (DSS) stated:

"I will not comment greatly on the 16 or 17-year-olds. They are identified otherwise as a separate cohort in legislation. In answer to an earlier question, however, it has not been part of the conversation here yet specifically on capacity legislation but it has certainly been the subject of comment and is something to watch with interest. We would have to be responsive to any changes that will come down the tracks as far as these younger people are concerned[22]."

MHR note the DSS comments on 16 and 17-year-olds and welcome the recognition of the issue. MHR is concerned that there is no agency specifically responsible for ensuring the capacity of 16 and 17-year-olds is addressed and therefore that this lacuna will remain. Is the DCEDIY looking at how the rights of 16 and 17-year olds will be respected in regards to their legal capacity and their possible need for decision-making supports? MHR requests that the Committee seek clarification on this matter and include recommendations to the responsible Minister and Department and highlight the need for gaps to be addressed in interlinking legislation.

Recommendations:

MHR recommends that provisions should be made in Part 8 of the 2015 Act for 16 and 17 year olds to consent to or refuse treatment for mental health difficulties, in line with their rights for physical health.

The Assisted Decision-Making (Capacity) (Amendment) Bill 2021 should provide for detail on the supported decision-making provisions for 16- and 17-year-olds subject to the mental health legislation and address the lacuna highlighted by MHR.

MHR requests that such a recommendation be included in a Committee report and that members engage with their counterparts on the Sub-Committee on Mental Health and Committee on Disability Matters.

[22] https://www.oireachtas.ie/en/debates/debate/joint_committee_on_disability_matters/2021-05-20/2/

4. Clarification on other issues

4.1 Guiding Principles and Interveners

The Guiding Principles of the 2015 Act are designed to change how we legislate for decision-making. The UNCRPD specifically prohibits substitute decision-making and a sea-change is required in how we treat people with psychosocial disabilities and potential capacity issues.

The range of decision supporters, as provided for by the 2015 Act, are called "interveners" and only interveners are required to adhere to the guiding principles.

Guiding principles

> **8.** (1) The principles set out in *subsections (2)* to *(10)* shall apply for the purposes of an intervention in respect of a relevant person, and the intervener shall give effect to those principles accordingly[23].

At an appearance before the Joint Committee on Disability Matters, Ms Áine Flynn, Director of the DSS, recommended that the remit of the guiding principles be extended for general application across the Act and not just applied to those defined as "interveners".

"Why are we taking these guiding principles, which also govern how we even assess capacity, and narrowing them down to quite a fixed category of people doing fixed things? If this is about ushering in a new ethos and approach, why is it not just how we all do things in the future, relative to somebody who may have an issue with their decision-making capacity? That is an idea that has gone back and forth a bit, and while I do not want to speak out of turn, ***it may be addressed in the amending legislation***[24]***".****[emphasis added]*

[23] https://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/print.html
[24] https://www.oireachtas.ie/en/debates/debate/joint_committee_on_disability_matters/2021-05-20/2/

Recommendations:

MHR supports the DSS calls for the guiding principles to be applied across the Act and not just to interveners.

MHR calls for the guiding principles to be informed by a person's human rights.

4.2 Advocates

It is crucial that children and adults who are in hospital for mental health treatment have direct access to professionals whose role it is to provide independent information about their rights when in hospital, assist and help to make decisions or to voice any concerns they may have. Currently, there are significant gaps in advocacy supports for people with mental health difficulties, including those in hospital. For example, people who are involuntarily detained do not have a legal right to have an advocate present at a review of their detention.

Chapter 3 | Service Access, Coordination and Continuity of Care Domain of our mental health policy published in 2020, Sharing the Vision, states:

"AVFC [A Vision For Change], in Recommendation 3.2, recommended that 'advocacy should be available as a right to all patients in all mental health services in all parts of the country'. However, the research and engagement for Sharing the Vision showed that there are gaps in access to advocacy supports and that some needs are unmet. Challenges include a lack of awareness of existing advocacy supports. This is particularly relevant for people with mental health difficulties living in the community, relative to those being supported in acute units and longer-stay facilities. The right to advocacy needs to be re-emphasised and the development of additional advocacy services pursued. There is also a need for research to determine the advocacy needs of people with a mental health difficulty living in the community, as knowledge of the scale and nature of need in this area is limited. When the Assisted Decision-Making

(Capacity) Act is commenced, adults with a mental health condition will have the option to appoint an assistant to help them in making decisions in relation to their mental health treatment and in making Advance Care Directives in relation to anticipated future treatment[25].”

Recommendations 54, 65 and 92 in the implementation roadmap of Sharing the Vision all highlight the importance of advocacy for persons with mental health difficulties. Recommendation 92 states:
Make available a range of advocacy supports including both peer and representative advocacy as a right for all individuals involved with the mental health services. A range of advocacy supports including both peer and representative advocacy should be available as a right for all individuals involved with the mental health services.

MHR has long been a proponent of the need for funded, accessible, independent advocacy services for children and adults. Therefore, MHR calls for a definition of independent advocacy to be included in the amendment bill. MHR recommends that an explicit right of access to an independent advocate be put on a statutory footing. Advocates must also be entitled to access all necessary information, with the relevant person’s consent, in order to allow them assist the person effectively.

MHR has also called for a funded, independent advocacy service to be made available to under 18s.

Recommendations:

MHR support the National Advocacy Service calls for a definition of independent advocacy and the subsequent rights afforded to them to be included in the final Act.

MHR call for the provision for the establishment or appointment of a publically funded, independent advocacy service for adults and children accessing the mental health services.

[25] https://adhdireland.ie/wp-content/uploads/2020/06/Sharing-the-Vision-Mental-Health.pdf

4.3 Codes of Practice

The Assisted Decision-Making (Capacity) Amendment Bill 2021 sets out requirements for the DSS to develop codes of practice and the necessary forms required for the implementation of the service. Before Christmas the DSS opened Phase 1 of its public consultation on 6 draft codes of practice and this phase closed on January 7th 2022[26]. Phase 2 of the public consultation on 8 draft codes of practice is currently open until February 18th 2022[27].

Many of the Heads of the Amendment Bill 2021 contain changes to the 2015 Act to provide for the Director of the DSS to develop codes and forms *"rather than requiring them to be prescribed by regulations made by the Minister. Providing for forms relating to the Act to be specified by the Director is considered to be consistent with the provisions of the Mental Health Act 2001 (No. 25) which requires forms relating to that Act to be specified by the Mental Health Commission[28]".*

Recommendations:

MHR calls for a comprehensive and accessible communications campaign to ensure that people are aware of their rights under the Act. Prior to this, accessible and inclusive consultation processes must be followed in accordance with the UNCRPD.

MHR recommends that a significant training, recruitment and upskilling campaign be immediately undertaken with services who will be taking on new responsibilities and providing decision-making assistance.

[26] https://decisionsupportservice.ie/public-consultation/public-consultation-phase-1
[27] https://decisionsupportservice.ie/public-consultation/public-consultation-phase-2
[28] https://www.oireachtas.ie/en/press-centre/press-releases/20211220-joint-committee-on-children-equality-disability-integration-and-youth-seeks-submissions-on-the-assisted-decision-making-capacity-amendment-bill-2021/

5. Part 3 – Amendment of Other Enactments

MHR notes and welcomes the 11 Heads relating to other enactments. In the interest of brevity, MHR welcomes the necessary creation of the statutory basis for IHREC's role as the UNCRPD monitoring framework; the necessary changes to legislation allowing for decision-making assistants and others to access the relevant provisions / legal rights.

The following are the 11 Heads covered by Part 3 of the Bill:

- Head 77 Amendment of schedule to Freedom of Information Act 2014
- Head 78 Amendment of section 42 of Freedom of Information Act 2014
- Head 79 Amendment of section 7 of Juries Act 1976
- Head 80 Amendment of section 41 of Electoral Act 1992
- Head 81 Amendment of National Disability Authority Act 1999
- Head 82 Amendment of Equal Status Act 2000
- Head 83 Amendment of section 46 of Disability Act 2005
- Head 84 Amendment of section 47 of Disability Act 2005
- Head 85 Amendment of Human Rights and Equality Commission Act 2014
- Head 86 Amendment of Social Welfare Consolidation Act 2005
- Head 87 Amendment of Part 4 Nursing Homes Support Scheme Act 2009

MHR welcomes the increase to 6% for disabled people to be employed by public bodies. MHR notes that this could be much higher and that supports are needed for people with psychosocial disabilities in employment.

MHR would like to draw the Committee's attention to the Review of the Equal Status Acts which took place in the run-up to Christmas 2021. The public consultation phase is now closed and under review but disability stakeholders did raise a number of very important issues and changes. One of note relates to the provision of insurance services to people with mental health difficulties. There is anecdotal evidence of

individuals being denied insurance services because of their experience of mental health difficulties. MHR would have concerns in relation to this discrimination under the UNCRPD. While outside the scope of this amendment bill, MHR wishes to highlight the matter because of the amendments to other enactments as provided for in Part 3.

The Review of the Equality Acts also included recommendations around widening the definitions of gender, the inclusion of socio-economic status and the accessibility to employment and training for people with psychosocial disabilities.

Recommendation:

MHR recommends that further examination is required into the provision of insurance services to people with mental health difficulties. MHR calls for the collaboration with the Minister on the review of the Equal Status Acts where these issues have been consulted on in greater detail.

6. Part 4 - Miscellaneous

Head 88 Review of Act of 2015

MHR is concerned that five years is too long to wait to review the Act. These concerns are due to the changes in the UNCRPD, the need to ratify the Optional Protocol of the UNCRPD and upcoming reform to the interlinked Mental Health Act 2001. In MHR's Human Rights Analysis on the Heads to Reform the Mental Health Act 2001 these concerns are addressed. The detached reviews along separate timelines across two government departments runs the risk of a fragmented approach. To minimise this risk, it is proposed that the review of the mental health legislation should coincide with the review of the 2015 Act. This will minimise the risk of a fragmented approach and ensure that policy makers undertake a meaningful and holistic review of the mental health and capacity laws.

Given the delays in the commencement of the 2015 Act and the reform of the Mental Health Act it would be desirable for these reviews to take place 3 years after the commencement of both pieces of legislation. At that point Ireland should have completed the first cycle of reporting to the UN Committee on the Rights of Persons with Disabilities on how the rights enshrined in the CRPD are being implemented. This review process will be essential in responding to the Committee's Concluding Observations and recommendations and in preparation for the second cycle of reporting[29]. A timely, holistic, and coordinated approach to review of the mental health and capacity legislation is essential.

Recommendations:

MHR calls for the review of the ADMA to be aligned with a review of the Mental Health (Amendment) Bill 202X.

The coordinated review of the mental health and capacity legislation should take place 3 years after the commencement of both pieces of legislation.

7. Deprivation of Liberty Safeguards

A final area of concern for MHR is that of the Protection of Liberty Safeguards or Deprivation of Liberty Safeguards (often referred to as DoLs). This is another area considered in MHR's Human Rights Analysis on the Heads to Reform the Mental Health Act, which is again inextricably linked with the 2015 Act and Amendment Bill 2021 before the Committee.

The CRPD Committee has interpreted Article 14 of the CRPD as a key non-discrimination provision that is particularly relevant for persons with psychosocial disability, who are at increased risk of deprivation of liberty[30]. The Committee, in its guidelines on Article 14, emphatically state that involuntary detention on healthcare grounds violates the absolute ban on deprivation of liberty and the principle of free and

[29] States must report initially within two years of ratifying the Convention and, thereafter, every four years. The Committee examines each report and makes suggestions and general recommendations on the report.
[30] See CRPD Committee, "Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with disabilities" (Geneva: Adopted during the CRPD Committee's 14th session, September 2015).

informed consent of the person to healthcare under Article 25 of the CRPD. The Committee has consistently stated that States Parties to the CRPD need to repeal provisions that permit the involuntary detention of "persons with disabilities in mental health institutions based on actual or perceived impairments"[31]. The Committee has noted that involuntary detention in mental health services results in the denial of legal capacity to make a range of decisions about healthcare, treatment, and admission to a hospital, and as such violates Article 12 (legal capacity / equal recognition before the law) in conjunction with Article 14 (the right to liberty)[32].

The amending legislation to reform the 2001 Mental Health Act provides for a new category of persons to be known as "intermediate" who would not be detained but would have similar review rights and safeguards as a detained person (this is relating to capacity for those who fall between the voluntary categories and do not meet the requirements for involuntary detention). Detailed guidelines will have to be produced for this category to which the Mental Health Commission and Head of the Decision Support Service (DSS) under the 2015 Act should contribute[33]. There are concerns that these safeguards are still not in place.

The Minister for State at the DOH at the time, Jim Daly, emphasised that any change regarding the voluntary person in the 2018 Act could not be commenced until other relevant sections of the 2015 Act are introduced "due to the interconnected nature of many of the changes to be made…[34]" The Expert Review Group of the 2001 Mental Health Act emphasised the importance of having the 2015 Act fully commenced to ensure the appropriate support is available to assist in making these decisions.

[31] See CRPD Committee, "Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with disabilities" (Geneva: Adopted during the CRPD Committee's 14th session, September 2015); at para 10
[32] Ibid.
[33] Department of Health, "Report of the Expert Group on the Review of the Mental Health Act 2001" (Dublin: 2015), at page 84
[34] Dáil Debates 14th July 2017 (Report and Final stage).

Information provided to the Dáil by the Minister of State for Mental Health and Older Persons, Mary Butler, on the status of the deprivation of liberty safeguards from November 2020 and May 2021 are copied below:

Heads of Bill to provide legislative clarity on the issue of deprivation of liberty safeguards are at a relatively advanced stage. A number of complex legal and policy issues which have arisen during the drafting process remain to be resolved.
Work on the Heads of Bill has been paused due to the diversion of resources, as part of the response to COVID-19[35]*.*

Heads of Bill to provide legislative clarity on the issue of deprivation of liberty safeguards are at a relatively advanced stage. A number of complex legal and policy issues which have arisen during the drafting process remain to be resolved[36]*.*

Recommendation:

MHR recommends that the Committee obtain clarification on the Deprivation of Liberty Safeguards; an update on the status of this Bill and that the Committee ascertains what safeguards will be in place in the interim.

8. Conclusion

It has been a long 7 years since the enactment of the 2015 Assisted Decision-Making (Capacity) Act. This is a once in a generation opportunity to ensure the failures of the past are never revisited where people with psychosocial disabilities have had their liberty deprived, their will and preferences ignored and their voices silenced. This Committee has the opportunity to ensure that our amended decision-making legislation is about putting people's will and preferences at the centre of the decisions affecting their lives.

[35] https://www.oireachtas.ie/en/debates/question/2020-11-26/405/ PQ reply from Minister Butler to Deputy O'Dowd, November 2020
[36] https://www.oireachtas.ie/en/debates/question/2021-07-27/2668/#pq-answers-2668 PQ reply from Minister Butler to Deputy Cairns, July 2021

The UNCRPD was developed with the mantra of 'Nothing About Us, Without Us' and it is imperative that this philosophy is carried forward through legislation relating to young people and adults with psychosocial disabilities. To make this philosophy a reality we need the legislation and subsequent culture change to reflect our new person-centred, human-rights compliant, models of treatment, access to treatment and rights to consent to or refuse treatments. Reforming the Mental Health Act 2001 and the commencement of the Assisted Decision-Making (Capacity) Act 2015 and Amendment Bill are pieces of an overall picture of the application of human rights of people with mental health difficulties.

MHR welcomes the opportunity to participate in the Committee's consultation process and looks forward to the progression of this Bill through PLS. MHR is delighted to be a member of the HSE ADM Implementation Steering Group and will work diligently with our peers to ensure that the voices of people with psychosocial disabilities are heard and respected. MHR would also like to take this opportunity to commend Ms Áine Flynn, Director of the DSS, and her team for the amount of work that has been done to date. MHR also acknowledges all of those who have been involved in bringing this sea-change legislation to fruition over many years, in particular we acknowledge the work of those with lived experience who bravely made their voices heard. MHR looks forward to the Committee's PLS and report.

For more information on any of the above content please contact Ber Grogan, Policy and Advocacy Coordinator at bgrogan@mentalhealthreform.ie or at 083-089 4186.

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