Mental Health **Reform**

Promoting Improved Mental Health Services

Submission to the Department of Health on the Review of the Mental Health Act, 2001

11th October 2011

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Introduction

Mental Health Reform (MHR) welcomes this opportunity to contribute to the review of the Mental Health Act, 2001. As the national coalition advocating for improved mental health services and implementation of the Government's mental health policy *A Vision for Change*, MHR believes that changes in the law relating to mental health are necessary in order to fulfil the vision set out in Government policy. In this submission, MHR focuses on adults; we are also members of the Children's Mental Health Coalition who have made a separate submission on children and adolescents.

The Mental Health Act, 2001 provided a significant improvement in the rights of people involuntarily detained and treated in the mental health services by requiring that every involuntary detention be reviewed by an independent tribunal. It also established the Mental Health Commission as a statutory agency responsible for promoting quality mental health services and provided for the regulation of inpatient services. These provisions have had a positive impact on the nature of mental health service delivery, most obviously by reducing the number of involuntary detentions in Ireland.

However, Ireland's signing of the Convention on the Rights of Persons with Disabilities (CRPD) in 2007 provides the basis for a landmark shift in the way that people with mental health problems are treated in society both as users of mental health services and as participants in the community. The CRPD affirms that no person should be discriminated against solely on the basis of their disability, including a mental health disability. (This principle of non-discrimination is also set out in the Government's mental health policy *A Vision for Change*). The CRPD also states that people with disabilities should enjoy legal capacity on an equal basis with others in all aspects of life.[1] While the CRPD did not introduce new human rights for people with disabilities, it is being seen as strengthening existing human rights. For people with experience of a mental health difficulty in particular, the CRPD affirms their equality in such a way as to call into question existing mental health laws. If people with mental health difficulties are not to be discriminated against, then those with incapacity should have an equal right to avail of capacity legislation as any other individual.

The Mental Health Act, 2001 was also enacted before Ireland's national mental health policy *A Vision for Change* had been developed. *A Vision for Change* marks a significant departure from previous mental health policy in advocating partnership with service users at every level of care and management (the partnership principle) as well as a service underpinned by the principle of recovery. The partnership principle reflects a consensus that there is a need to redress the traditional power imbalance between mental health service users and the professionals who have authority over their detention and treatment. The recovery principle reflects service users' demands for services that are orientated towards hope and promote service user autonomy/self-determination and social inclusion. MHR welcomes the Department's decision that the scope of this review includes how legislation could support implementation of *A Vision for Change*. In addition, to have a coherent legal and policy framework, mental health legislation must be consistent with the principles of *A Vision for Change* by promoting service users' autonomy and self-determination.

Mental Health Reform believes that changes to the legislation are necessary to take account of these two major environmental factors. Mental health legislation must fully reflect the CRPD and must provide a statutory framework to drive implementation of the Government's mental health policy.

[1] Article 12(2).

Should there be a separate Mental Health Act? (Parts 1, 2, 3, 4 and Miscellaneous)

Having separate legislation that covers people who have a mental health difficulty is unhelpful to the agenda of reducing prejudice and discrimination against people with experience of a mental health difficulty because it entails treating a group differently under the law on the basis of their mental health status. The current legislation, entitled the 'Mental Health Act', is known for being concerned with 'mental health' and involuntary detention and treatment though it also covers intellectual disability and dementia. It perpetuates an association between mental health conditions and involuntary detention which is not justified by the fact that a very small proportion of people with a mental health difficulty will ever need to be involuntarily detained. In a trajectory from the 1945 Mental Treatment Act to the improvements in the 2001 Mental Health Act to revision of the 2001 Act it is a logical next step to consider how mental health legislation can be incorporated into capacity legislation.

Nevertheless, it is important that in seeking to de-stigmatise psychological and emotional distress there is no lessening of the human rights protections which have been established in the Mental Health Act, 2001. While in principle it would be best if there was no separate legislation to cover people who need involuntary detention and treatment for a mental health difficulty, such a change would require widespread consultation and careful consideration.

Recommendation: The Government should make a commitment to exploring how provisions on involuntary detention and treatment (and related provisions) in the Act could be incorporated into capacity legislation so that people impaired by a mental health condition will be covered by the same law as all people whose capacity is impaired. Government should then explore in wide consultation with stakeholders how the rights of mental health service users can be adequately protected within capacity legislation and what specific provisions are required to retain rights that protect people in need of mental health treatment from arbitrary detention and infringement of their bodily integrity.

Legislation to support the Government's mental health policy *A Vision for Change*

It is widely acknowledged that implementation of the Government's mental health policy published in 2006 has been slow, piecemeal and unevenly distributed across the country. In the current economic crisis implementation is all but grinding to a halt. With 1,000 staff having been lost in the mental health services between 2009/10 and at least a further 600 departures expected in the near future, there is a real risk that treatment for those in severe psychological or emotional distress will revert to a custodial model without community supports.

Both the White and Green Papers that preceded the Act identified the need for legislation to underpin reform of the mental health services towards community care. The Expert Group that formulated *A Vision for Change* recommended that Government consider the policy's implications for legislation and the Independent Monitoring Group for *A Vision for Change* recommended that Government consider how legislation would assist in implementation.[2]

Recommendation: Government should enact legislation to support implementation of *A Vision for Change.* Legislation should include:

- the requirement that all public mental health service be planned and provided in accordance with the principles set out in *A Vision for Change*
- an obligation on all mental health service providers to engage service users in planning their own care and to provide support for service users to make decisions about their own care where such support would enable them to do so
- a duty that the public mental health service provide community-based services

[2] Independent Monitoring Group (June, 2011) '*A Vision for Change* – the Report of the Expert Group on Mental Health Policy: Fifth Annual Report on implementation 2010'.

- a duty that the public mental health service provide a range of alternatives to medication including talking therapies, with an equitable allocation of services across the country
- an obligation on the public mental health service to develop an implementation plan for the mental health services every three years that contains specific targets, timeframes, persons responsible for each target and costings
- an obligation on the public mental health service to report annually to the Oireachtas on their progress in delivering the plan
- an extension of the standard-setting and inspection functions of the Mental Health Commission to cover community-based mental health services

Incapacitated service users who are considered voluntary

MHR is extremely concerned about mental health service users in in-patient settings who lack capacity and who currently have no protection under either the Mental Health Act or any capacity legislation because they are considered 'voluntary'. Three issues relating to these individuals must be addressed as a matter of urgency:

1. Mechanisms to review the detention of people who lack capacity and who are admitted to in-patient units for mental health treatment ("approved centres" under the Mental Health Act, 2001);
2. Mechanisms to regulate the use of restraint; and
3. Mechanisms for the review of treatment, in particular use of medication in treatment.

Under the current Mental Health Act, the definition of 'voluntary patient' includes a person who lacks the capacity to make decisions but is compliant with treatment and who is in fact detained in an approved setting. Such so-called 'voluntary patients' do not have their detention reviewed by a mental health tribunal and do not get other protections set out in the Act for 'involuntary patients'.

The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) has raised concerns about these 'so called voluntary patients' who are, in reality, deprived of their liberty, as well as issues regarding treatment and the use of restraint and seclusion.[3] While the CPT visited just two approved centres and the Central Mental Hospital, MHR is concerned that the issues raised may apply to other approved centres and to other health and social care settings. The gap in protections for "so called voluntary patients" must be addressed in the capacity legislation as well as through amending the definition of 'voluntary patient' in the Mental Health Act 2001. Appendix I contains a detailed discussion of the rationale for addressing this gap, including how the current legal framework leaves Ireland open to a claim of breaching the European Convention on Human Rights.

In making the following recommendation to ensure additional protection to people who lack capacity, MHR must emphasise that treatment under the Mental Health Act, 2001 can fall short of good practice and a great concern of many service users is the risk of loss of liberty when they agree to a voluntary admission. To quote a service user,

> "There is no such thing as involuntary or voluntary patients. All patients are involuntary. If a

[3] Report to the Government of Ireland on the visit to Ireland carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 25 January to 5 February 2010, p.60.

> voluntary patient decides not to take their medication, they are changed to involuntary. If a patient questions their treatment they are thought to lack insight and are re-graded from voluntary to involuntary".[4]

While stronger protections must be introduced for people who are currently considered voluntary and lack capacity, these must be implemented in a way that promotes the dignity, bodily integrity and autonomy of the person.

> **Recommendation:** Either the capacity or the mental health legislation should provide that people who lack capacity when they are admitted to an approved centre for mental health treatment or who become incapacitated following admission to an approved centre will get the protections and review mechanism presently afforded to 'involuntary' patients under the Mental Health Act, 2001.[5]

> **Recommendation:** The definition of 'voluntary patient' under the Mental Health Act, 2001 should be amended to refer solely to a person with the capacity to consent to admission and treatment.

Rights of voluntary patients (Sections 16 & 23)

Amnesty International Ireland's (AI) consultation on the Act found that there are insufficient safeguards for 'voluntary patients' in mental health inpatient services.[6] Mental Health Reform is concerned that the experience of service users is that there is very little difference between being a voluntary or involuntary patient. MHR is concerned that a weakness in the oversight of re-grading between involuntary and voluntary status is undermining the autonomy of voluntary patients. Where it is relatively easy to switch a person's status from involuntary to voluntary this can result in less protection than was envisaged in the Act since it may result in the person's original detention being un-reviewed. Where it is relatively easy to switch a person's status from voluntary to involuntary this threat can have the effect of coercing compliance in a way that contravenes a person's human right to autonomy.

MHR supports AI's recommendations to strengthen the rights of voluntary patients to leave an inpatient unit.[7] MHR is also concerned that there is no provision in the existing Act for voluntary patients to receive information as is set out for involuntary patients.

> **Recommendation:** The rights of voluntary patients to leave an inpatient unit should be strengthened as recommended by AI in its review of the Act, pages 45-46.

> **Recommendation:** Voluntary patients receiving treatment in an inpatient setting should be provided with information on the proposed treatment they will receive, the rationale for their hospitalisation, its likely duration and who they can contact for advocacy support.

> **Recommendation:** The treatment provisions of the Act should apply equally to voluntary and involuntary patients.

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[4] Quote from a speaker at the Oireachtas Cross-Party Group on Mental Health briefing on the review of the Mental Health Act, 2001 held 20th of July 2011.

[5] There is a difference between persons who are presently involuntary admitted (a core feature of which is the person is resisting admission/treatment) and that of an incapacitated but compliant person. The impact of that incapacity on the conduct of tribunal hearings is a matter which should be considered with practitioners and in the context of the review of the Mental Health Act, 2001, See C Murray 'Safeguarding the Right to Liberty of Incapable Compliant Patients with a Mental Disorder in Ireland (2007) 29 DULJ.

[6] Amnesty International Ireland (2011) 'Mental Health Act 2001: A Review: Summary Paper', p.13.

[7] Same as above reference.

Definition of mental disorder (Section 3)

Wherever the notion of capacity (or impaired judgement) exists in the Act, this should be defined in a accordance with the CRPD. Throughout the Mental Health Act including the definition of mental disorder, the functional, social model of disability approach to capacity should be used in order to fulfil the CRPD and to emphasise the temporary, decision-specific nature of incapacity for mental health service users.

MHR is also concerned that the definition of 'mental disorder' under the current section 3(1)(a) does not require that treatment be of benefit to the patient. This gap means that a person may be detained indefinitely even if their condition has not been amenable to treatment. – a highly unsatisfactory situation in terms of protecting the individual's human right to liberty.

> **Recommendation:** The functional approach to capacity should apply to all determinations of capacity under the Act.
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> **Recommendation:** Section 3(1)(a) of the Act should be amended to include a requirement that involuntary admission or detention is only justified under this ground where the person's underlying condition is amenable to or is likely to benefit from treatment.

Responsibility for assessing capacity (Sections 3, 56-60)

Government mental health policy envisages a multi-disciplinary approach to mental health care, reflecting the 'biopsychosocial' model of mental health. Evidence also shows that diagnosis is not a reliable indicator of capacity[8] and therefore the diagnostic skills of a medical professional should not necessarily be the preeminent skills used to assess capacity. This multi-disciplinary approach must be reflected in the legal provisions on assessment of capacity within the Mental Health Act, 2001.

> **Recommendation:** Where an assessment of decision-making capacity is implied in the Act, a formal assessment should be undertaken and the legislation should allow for an independent assessment being conducted by a range of qualified health and social care professionals including psychiatrists, psychiatric nurses, psychologists, occupational therapists and social workers and should ensure a minimum of three disciplines are involved in any assessment.
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> **Recommendation:** Service users who are assessed as lacking capacity should have a right to request an independent second opinion.

Best interests (Section 4)

The Mental Health Act, 2001 incorporates a principle of 'best interests' that has been interpreted paternalistically in the courts. This paternalistic interpretation does not reflect human rights to autonomy and the presumption of capacity contained in the CRPD. It is also important that the best interests principle reflects the partnership approach set out in *A Vision for Change.*

> **Recommendation:** MHR recommends that the Act be amended to reflect an autonomy-based approach to best interests using the definition of best interests set out in the proposed Scheme of the Capacity Bill.

[8] Amnesty International Ireland (2009) 'Decision-Making Capacity in Mental Health: Exploratory Research into the Views of People with Personal Experience', Dublin: Amnesty International Ireland.

Advance directives

An advance directive in the mental health context has been defined as "a legal document which provides a mechanism for individuals to stipulate, in advance, what types of psychiatric treatments they prefer or to appoint a health care agent to make such decisions for them, should they become incapacitated."[9] Advance Directives are important in order to protect the right to autonomy, dignity and bodily integrity. They allow service users to retain control over their healthcare decisions at a time when they lack capacity to make such decisions.

Psychiatric advance directives can be used to record the service user's preferences about his/her mental health care and to refuse certain treatment. They can also be used to appoint proxy decision makers who can make treatment decisions on behalf of a service user in the event that he or she loses capacity to make those decisions. Such a provision would be very helpful in the mental health context to underpin the positive role that family members and friends may play in health care decisions. Though *A Vision for Change* supports the introduction of advance care directives in mental health there is no provision for them yet in Ireland.

> **Recommendation:** Legislation should be put in place to provide a framework for advance decisions by people with a mental health condition to refuse and consent to treatment as well as advance care, social and financial arrangements. This legal framework must be binding on clinicians to the same extent as a person's wishes would be if he/she had capacity at the time. A valid advance directive should only be departed from where treatment is necessary on a life-saving emergency basis; suitable procedural safeguards must be in place to ensure compliance with this provision and any treatment given in contravention of an advance directive must be of established benefit to the recipient.

Right to advocacy and supported decision-making (Part 3)

For a person who lacks capacity, the supports that are in place to assist decision making are as much a part of enabling their capacity as is a ramp for a wheelchair user. Capacity can be impacted by the environment within which a decision is made as well as the supports available to the person to assist in the decision. An individual's capacity to make a decision may depend on whether the information about the treatment is explained by a trusted person in a way that he/she can understand. His/her capacity can be impaired by the very medical treatment received - slowing cognitive functioning and reducing mental stamina. It is important to take this view of capacity into account in legislation that concerns involuntary detention and treatment of people in mental distress. This social conception of decision making capacity must be realised in the legislation both in how their capacity to make decisions is defined and in provisions on assessment and supported decision making.

Support to assist a person with a disability to exercise their decision making capacity is a key requirement under the CRPD. Article 12 of the CRPD guarantees the right of people with impaired capacity to participate to the fullest extent possible in decisions which concern them and this entails providing assistance to enable them to do so.

A Vision for Change recognises the important role that access to advocacy plays in recovery from a mental health condition. It states that "all users of the mental health services – whether in hospitals, day centres, training centres, clinics, or elsewhere – should have the right to use the services of a mental health advocate."[10] Advocacy can play an important role in assisting treatment decisions. A wider system of supported decision making could reduce the need for involuntary admissions by facilitating individuals to be able to make decisions about their mental health treatment. Having

[9] 'Making the Most of Psychiatric Advance Directives" (2007) 24(6) Harvard Mental Health Letter 1 at 1.
[10] Expert Group on Mental Health (2006) *A Vision for Change: Report of the Expert Group on Mental Health Policy*, Dublin, Department of Health and Children, p.25.

advocacy support available in the context of capacity hearings or mental health tribunals is also important in order to promote the voice of the service user in these processes. Advocates can also support an individual to make a complaint about the service. Peer advocacy services can help to re-balance power relations within the mental health system by infusing multi-disciplinary team working with the service user perspective.

Currently peer advocacy services are funded by the Health Service Executive and provided in inpatient units however there is no statutory advocacy service for mental health service users. The law must include provisions that underpin the right of every individual who needs support in order to make decisions about their own mental health treatment to have such support, whether this is provided by a family member, trusted friend, volunteer or professional advocate.

> **Recommendation:** The legislation should provide a statutory framework for supported decision making and the right to advocacy to assist in decisions for all inpatients regardless of status.
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> **Recommendation:** The legislation should provide for regulation of supported decision making and for consultation with people with experience of a mental health condition on the regulations.
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> **Recommendation:** The legislation should provide for the right of the involuntarily detained person to have an advocate present in all hearings.

Force and restraint

The use of restraint is a restriction on a person's freedom of movement and, depending on the circumstances, may be a serious infringement of his/her rights to bodily integrity and dignity and, at an extreme, may constitute inhuman and degrading treatment. Mental Health Reform considers that as a first principle, force should not be viewed as a method for engaging service users in treatment. Force is not the way to support recovery. There is evidence that mental health services can achieve a dramatic reduction in the use of restraint where a dedicated zero-restraint programme is put in place.[11] In the context of capacity legislation and the existing Mental Health Act, 2001, the legislation must provide for the protection of users of mental health services from undue use of all forms of restraint.

Rules and Codes of Practice produced by the Mental Health Commission cover the use of seclusion, mechanical and physical means of restraint in inpatient services, but these provisions do not cover the use of chemical restraint or the use of restraint outside of inpatient settings. MHR is also concerned that the use of seclusion and restraint on so-called 'voluntary' in-patients may give rise to questions about whether the patient is truly voluntary.

> **Recommendation:** The Mental Health Commission's Rules and Codes of Practice on seclusion and restraint should clarify that where a "voluntary patient" is subjected to seclusion or restraint, this raises questions about whether the patient is in fact voluntary and steps should be taken to assess the person's status as a voluntary patient.
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> **Recommendation:** The definition of restraint under the Mental Health Act, 2001 should be extended to include chemical restraint. The use of chemical restraint should be governed by clear rules and subjected to the same oversight as other means of restraint.

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[11] L Ashcraft and W Anthony (2008) 'Eliminating Seclusion and Restraint in Recovery-Oriented Crisis Services' *Psychiatric Services* 59:10:1198-1202.

Recommendation: The circumstances in which seclusion and/or restraint can be used for "the purposes of treatment" should be narrowed to instances where such treatment is necessary in an emergency in order to save the life of the person concerned.

Recommendation: The Act should require that all mental health services develop and provide a programme (including appropriate staff training, policies and procedures) to minimise and where possible phase out the use of seclusion and restraint.

Medication review

There is now a substantial body of research, both in Ireland and abroad, suggesting over-prescription of high dosage medication and anti-psychotic medication as well as the over-use of polypharmacy for people with mental health conditions. The Inspector of Mental Health Services has identified the over-prescription of benzodiazepines within approved centres as well as the use of polypharmacy. For example, the Inspector found that 26% of residents in in-patient and long-stay facilities are on more than one benzodiazepine.[12]

Under the Mental Health Act 2001 (Approved Centres) (Regulations 2006SI 551 of 2006) each "resident" has an entitlement to an "individual care plan", regardless of his or her legal status. However, the Inspector of Mental Health Services has found that compliance with this aspect of the Regulations has been poor. The Mental Health Act 2001 contains no review mechanism regarding how the care plan is drawn up, how treatment decisions are made and the appropriateness of decisions.

Recommendation: The legislation should include oversight mechanisms for treatment/medication decisions for incapacitated patients in approved centres. Although the second opinion model in the Mental Health Act 2001, ss 59-60 is flawed in that it does not provide for an independent review of treatment decisions, as a first step, the model should be extended to incapacitated patients. Any amendments of the Act to extend the scope and independence of the oversight/treatment review mechanism should be extended in the same way to patients lacking capacity.

Recommendation: The requirement for an "individual care plan" for each resident currently set out in regulations should be incorporated into the Act in order to provide this requirement with a stronger statutory footing.

Consent to treatment (Sections 57-59)

Mental Health Reform believes that there is a need to strengthen provisions so that the right of the individual to make decisions about their own mental health care is respected as much as possible and more than at present. This relates to all types of treatment but is even more important when considering electro-convulsive therapy (ECT) or psycho-surgery. MHR has already proposed that people with a mental health condition should be able to avail of the capacity legislation on an equal basis with others (see MHR's submission to the Joint Oireachtas Committee on Justice and Defence on the capacity legislation, attached as Appendix I).

Recommendation: The sections of the current Act that concern administration of medication should be amended to provide that the free and informed consent of a patient shall be required in all circumstances before treatment can be administered unless the patient lacks capacity and either

[12] Inspector of Mental Health Services (2011) 'Mental Health Services 2010: Medication' report available at www.mhcirl.ie, p.7.

1) the treatment is necessary in an emergency to save the life of the patient. Where treatment is administered in an emergency, this should be for a short period of time and only where compliance with the procedures of Section 60 would cause such delay as would lead to harm to the person; or

2) the application for treatment has been reviewed independently as in the recommendation on ECT below.

Additional protections relating to Electro-convulsive Therapy (ECT) and Psycho-Surgery (Sections 58 & 59)

ECT is a controversial treatment whose benefits are far from clear-cut. A recent study in the UK for its National Health Service Research and Development Health Technology Assessment Programme found that there was little evidence that ECT is effective in the long-term and that the short-term improvement from ECT "depending on the stimulus parameters of ECT are achieved only at the expense of an increased risk of cognitive side-effects."[13]

Implementation of *A Vision for Change* should enable ECT use to be minimised, while currently psycho-surgery is not practiced in Ireland. The Government should ensure that every individual in Ireland has access to multidisciplinary community-based mental health services that provide early intervention, crisis intervention and mental health promotion so that individuals can get the mental health support they need early on in their mental health difficulty.

In Ireland a total of 373 programmes of ECT were administered in 2009, a rate of 8.8 programmes per 100,000 population. More than 70% of recipients were registered as having voluntary status. In 44 instances, ECT proceeded without the consent of the recipient. Of these, in nine instances ECT proceeded where both the treating and second opinion psychiatrist thought the recipient was unwilling. In two instances treatment proceeded where the treating psychiatrist thought the recipient was unwilling and the second opinion psychiatrist thought the recipient was unable.

MHR believes that stronger protections than those afforded in Section 57 or in the current Section 59 are required in relation to ECT. In principle, ECT should be a treatment of last resort and should not be used in an emergency. Mental Health Reform takes the view that all prescriptions of ECT should be reviewed by an independent body.

Recommendation: Starting immediately, the Mental Health Commission should review the documentation for all prescriptions of ECT in advance of treatment and should conduct an in-depth review for a minimum of ten per cent of recipients. In-depth reviews should include the input of the recipient, his/her multidisciplinary team and an independent consultant psychiatrist. All reviews should assess the capacity of the individual to make a decision, if the individual has given free and informed consent, if the treatment is necessary as a last resort and if it is the least intrusive treatment that will meet the individual's health needs.

Recommendation: In the medium term the Department of Health should consider whether all prescriptions of ECT should be subject to a tribunal review as applies for psycho-surgery.

Recommendation: In order to ensure that capable service users are not denied their right to make decisions about their own care, the term 'unwilling' should be removed from Section 59(b) of the Act so that refusals by capable service users are respected.

[13] Greenhalgh, J., Knight, C., Hind, D., Beverley, C. & Walters, S. (2005) 'Clinical and cost-effectiveness of electroconvulsive therapy for depressive illness, schizophrenia, catatonia and mania: Systematic reviews and economic modelling studies', in *Health Technology Assessment* 9:1-170.

Recommendation: It is important that second opinions for administration of ECT are seen to be independent of the treating psychiatrist. Mental Health Reform recommends that where a second opinion is sought for prescription of ECT, the person providing the second opinion should be appointed by the Commission.

Recommendation: Section 58(3) of the Act should be amended to add that where a Tribunal reviews a decision to administer psycho-surgery, the Tribunal shall review the capacity of the individual to make a decision, if the individual has given free and informed consent, if the treatment is necessary as a last resort and if it is the least intrusive treatment that will meet the individual's health needs.

Recognising the role of family members

Family members often play a valued role in supporting the recovery of their relative who has a mental health difficulty. Family members also can be impacted directly or indirectly by their relative's mental distress and the treatment he/she receives. On the other hand, many service users prefer to keep their mental health treatment private and do not disclose their circumstances to family members.

The current mental health legislation makes family members largely invisible in the process of mental health care. While continuing to respect the rights of the individual to privacy, it would be helpful if the legislation set out the duties of health service providers to provide general information to family members as well as to assess their own needs for support.

Recommendation: The legislation should place a duty on the health service to provide information of a general nature on mental health to the family members of a person with a mental health condition upon request and with the permission of the service user.

Recommendation: The legislation should place a duty on the health service to assess the support needs of family members of a person receiving treatment for a mental health condition upon request of the family member and with the permission of the service user.

Recommendation: Where the family members include children or adolescents under the age of 18, there should be a duty on the health service to assess the needs of the children and provide appropriate supports.

Preserving Tribunals

The establishment of the tribunal system of independent review provides substantially greater protection for mental health service users than existed under the 1945 Mental Health Act. The fact that such reviews are automatic is an important safeguard. The effect of the 2001 Act was an immediate and sustained reduction in the numbers of patients involuntarily detained and this is welcome.

Recommendation: The automatic entitlement to independent review of detention by a tribunal should be retained.

Preserving the Mental Health Commission

The establishment of an independent body charged with protecting the interests of patients and promoting high standards of care has been extraordinarily helpful to the Irish mental health services. The Commission stands aside from all vested interests. It is important that there continues to be an independent Commission with its existing powers to protect the interests of patients, particularly in a context where individual patients are often powerless. A specific entity is needed that is charged with

advocating for patients' interests.

> **Recommendation:** The Mental Health Commission should be preserved with its existing powers.

Independent complaints mechanism

Currently the Act does not provide a right of the individual to complain directly to the Mental Health Commission. This has meant that the default route for an individual to make a complaint about their detention or treatment in the mental health services is through the HSE's non-statutory *Your Service, Your Say* complaints procedure. For mental health service users who are vulnerable to involuntary detention this is a highly dissatisfactory situation. In practice it means that a person may be required to submit their complaint to a staff member who could involuntarily detain and treat them or prolong their involuntary detention and treatment. It is not surprising, then, that there are extremely few complaints made by current service users about the mental health services.

Mental health service users must have a safe means of making a complaint that is independent of the service itself.

> **Recommendation:** The legislation should provide a complaints mechanism independent of the service provider. The Mental Health Commission should be given a direct role in receiving, investigating and resolving complaints about mental health service delivery. The legislation should also provide for advocacy support in making a complaint and for a proxy decision-maker to be able to make a complaint on behalf of an incapacitated person.

Protection from abuse

The previous mental health legislation of 1945 included a section (253) which criminalised the ill treatment or neglect of a patient in a psychiatric institution. The current Mental Health Act repealed this section and omitted any replacement. MHR sees no rationale for the repeal of this provision. In light of the history of abuse in various institutions in Ireland, it is important that provision is made in legislation to emphasise the unacceptability of abusive behaviour.

> **Recommendation:** Specific criminal offences for the ill treatment, neglect, exploitation or abuse of mental health service users should be introduced into the Act.

Future review of the Act as CRPD evolves

The CRPD is a relatively new document in human rights terms. Over time the UN Committee on the Rights of Persons with Disabilities will interpret the Convention in a way that will explain how the Convention applies to people with a mental health disability. This may have implications for legislation that covers people with a mental health disability in Ireland in the future.

> **Recommendation:** Government should commit to reviewing the Mental Health Act in the light of interpretation of the CRPD by the UN Committee on the Rights of Persons with Disabilities.

Conclusion

While the Mental Health Act, 2001 was a welcome improvement on previous mental health legislation, the human rights and policy environments have substantially changed since its enactment and these changes need to be reflected in the review of the Act.

Currently there is inadequate protection for voluntary patients who lack capacity, a dearth of rights for voluntary patients and family members, weaknesses in the protections of an individual's human rights to autonomy and bodily integrity and a lack of statutory support for Government mental health policy.

Mental Health Reform hopes that the above recommendations will assist Government in revising the legislation so that it complies with up-to-date human rights law and provides an appropriate framework for delivery of *A Vision for Change*.

We are available to meet with the Department of Health to discuss this submission and to answer any questions that might arise during the course of this consultative process.

About Mental Health Reform
Mental Health Reform's vision is for an Ireland where people with mental health difficulties can recover their good health and live their lives to the fullest. Mental Health Reform promotes a model of health and social care where all citizens have equal access to affordable, sustainable and high quality primary care and specialist mental health services.

The views and active participation of people who experience mental health difficulties, their families and friends are important to achieve best outcomes in public mental health services delivery and integrated services at local community level are the best setting to attain these outcomes.

Mental Health Reform's members:

- Amnesty International Ireland
- Bodywhys
- Cork Mental Health Foundation
- Grow
- Inclusion Ireland
- The Irish Advocacy Network
- The Irish Refugee Council
- Shine
- Simon Communities of Ireland
- Slí Eile Housing Association
- STEER
- Suicide or Survive

For further information, pleasen't hesitate to contact Orla Barry, Director, Mental Health Reform, 6-9 Trinity Street, Dublin 2, 01 612 14 22 or by email: obarry@mentalhealthreform.ie.

Appendix I:

Mental Health **Reform**
Promoting Improved Mental Health Services

Submission to Mental Capacity Law in Ireland
Oireachtas Committee on Justice, Defence and Equality
19th August 2011

Executive Summary

Mental Health Reform, the national coalition promoting improved mental health services, makes the following recommendations for inclusion in the capacity legislation:

1. The capacity legislation should provide a statutory framework for supported decision making and the right to advocacy to assist in decisions. This is a key requirement under the Convention on the Rights of Persons with Disabilities (CRPD). Article 12 of the CRPD protects the right to equal recognition before the law of all persons with disabilities. This requires a legal framework to guarantee the right of people lacking capacity to participate to the fullest extent possible in decisions which concern them and the provision of assistance to enable them to do so. The Scheme of the Mental Capacity Bill 2008 does not provide the appropriate emphasis on supported decision making that would reflect the CRPD; it overly focuses on guardianship and regularises substitute decision making rather than supported decision making. If the legislation takes the same approach as the Scheme it is not likely to be compliant with the CRPD.
2. The capacity legislation should provide for regulation of supported decision making and for consultation with people with experience of a mental health condition on the regulations.
3. The capacity legislation should include necessary procedural safeguards in all hearings to promote the voice of the person whose capacity is in question.
4. The capacity legislation should include a complaints mechanism independent of the service provider. It should also provide for advocacy support in making a complaint and for a proxy decision-maker to be able to make a complaint on behalf of an incapacitated person.
5. The provisions of the capacity legislation must apply equally to the decision making capacity of people with a mental health condition and with equal reference to mental health as to physical health. The capacity legislation should make amendments to the Mental Health Act, 2001 so that the Act fully reflects the provisions of the capacity legislation.
6. The Capacity legislation should provide that people who lack capacity when they are admitted to an approved centre for mental health treatment, or who become incapacitated following admission to an approved centre, will get the protections and review mechanism presently afforded to 'involuntary' patients under the Mental Health Act, 2001.[14] This needs to be reflected in the context of the review of the Mental Health Act, 2001.
7. The definition of voluntary patient under the Mental Health Act, 2001 should be amended such that the term 'voluntary patient' refers to a person with the capacity to consent to admission and treatment only.
8. With regard to informal decision making, capacity legislation must ensure that individuals' right to make decisions about their daily lives including patterns of living, usage of their financial resources and relationships is protected.
9. Where a formal assessment of decision making capacity is required, the legislation should allow for an independent assessment to be conducted by a range of qualified health and social care professionals including psychiatrists, psychiatric nurses, psychologists, occupational therapists and social workers and should ensure a minimum of two disciplines including a health and social care professional is involved in any assessment.

[14]There is a difference between persons who are presently involuntary admitted (a core feature of which is the person is resisting admission/treatment) and that of an incapacitated but compliant person. The impact of that incapacity on the conduct of tribunal hearings is a matter which should be considered with practitioners and in the context of the review of the Mental Health Act, 2001, See C Murray 'Safeguarding the Right to Liberty of Incapable Compliant Patients with a Mental Disorder in Ireland (2007) 29 DULJ.

10. The capacity legislation should provide a legal framework for advance decisions to refuse and consent to treatment as well as advance care, social and financial arrangements. This legal framework must be binding on clinicians to the same extent as a person's wishes would be if he/she had capacity at the time. A valid advance directive should only be departed from where treatment is necessary on a life-saving emergency basis; suitable procedural safeguards must be in place to ensure compliance with this provision and any treatment given in contravention of an advance directive must be of established benefit to the recipient. The advance decision provisions must apply equally to people with a mental health condition as to others and must apply to treatment for mental and physical health.

11. The capacity legislation should include a general provision about the use of restraint that sets out the nature of restraint and de-limits the circumstances in which restraint may be used. The model provided by the UK's Mental Capacity Act 2005, section 6 would appear to provide a useful starting point in this regard.

12. The definition of restraint should include "chemical restraint". The use of chemical restraint should be governed by clear rules and subjected to the same oversight as other means of restraint.

13. The capacity legislation and the Mental Health Act should include oversight mechanisms for treatment/medication decisions for incapacitated patients in approved centres and other care facilities. Although the second opinion model in the Mental Health Act 2001, ss 59-60 is flawed in that it does not provide for an independent review of treatment decisions, as a first step, the model should be extended to incapacitated patients. Any amendments of the MHA 2001 to extend the scope and independence of the oversight/treatment review mechanism should be extended in the same way to patients lacking capacity.

14. The Bill should strengthen Guiding Principle 1(b) so that where a person is likely to regain capacity no intervention should take place unless it is necessary and cannot be postponed until the person in question is expected to regain capacity.

15. The capacity legislation should provide that existing Wards of Court have their capacity reviewed as soon as possible after enactment of the legislation.

16. The Bill should require periodic reviews of the Act which should cover not only the operation or functioning of the Act but also whether the Act has succeeded in fulfilling the objectives and aims sought to be achieved by its enactment.

Introduction

Mental Health Reform (MHR) welcomes this opportunity to contribute to the formulation of proposals on capacity legislation. We are available to meet with the Committee to discuss this submission and to answer any questions that might arise during the course of this consultative process.

Ireland's signing of the Convention on the Rights of Persons with Disabilities (CRPD) provides the basis for a landmark shift in the way that people with mental health problems are treated in society both as users of mental health services and as participants in the community. The CRPD sets out that no person should be discriminated against solely on the basis of their disability, including a mental health disability. (This principle of non-discrimination is also set out in the Government's mental health policy *A Vision for Change*). The CRPD also states that people with disabilities should enjoy legal capacity on an equal basis with others in all aspects of life.[15] This implies that people with incapacity on the basis of a mental health condition should have an equal right to avail of the capacity legislation as any other individual. *A Vision for Change* states that, "The human rights of individuals with mental health problems must be respected at all times" and it is crucial that capacity legislation reflects this.

Capacity legislation that reflects the CRPD should also help to underpin other principles of *A Vision for Change* including the principle of community care which emphasises the delivery of services in the community, partnership with and respect for service users, and the recovery approach which emphasises the ability of individuals with a mental health problem to recover and regain valued roles in the community.

The importance of capacity legislation for implementing the CRPD was acknowledged by the Department of Justice and Law Reform in its Regulatory Impact Assessment on the Scheme of the Mental Capacity Bill 2008 when it stated that *"[t]he next step towards ratification of the Convention is to ensure that Ireland complies with obligations under the Convention. The Mental Capacity Bill is one of the significant steps to facilitation the ratification process"*[16]. In MHR's view, the capacity legislation must fulfil the spirit as well as the letter of the CRPD with regard to people with a mental health condition by ensuring that they can avail of the same legal provisions as anyone else.

Ideas about the capacity of a person with a mental health condition are changing: In the past, certain diagnoses, such as schizophrenia or any psychotic condition, would have been presumed to entail a lack of capacity. Today, we know that the evidence contradicts these assumptions. Most people with a mental health problem retain capacity even when receiving inpatient treatment.[17]Even where an individual does lose capacity to make decisions, this is likely to be for only a short period of time. People with a mental health problem can maintain their capacity to make some decisions even when they are unable to make others. Thus the traditional approaches of basing capacity assessments on diagnosis, which in turn result in global capacity determinations for indefinite lengths of time, are no longer acceptable.

The CRPD is premised on the 'social model' of disability, or the idea that society disables people who have impairments. The social model of disability recognises that capacity is not solely an attribute of

[15]Article 12(2).

[16]Art 12 (4) calls for safeguards to be put in place to prevent abuse. It recognises that a lack of capacity does not equate with a loss of rights and demands that rights, will and preferences of the person be respected. It also requires protections against conflicts of interest and undue influence, as well as requiring that any interventions on grounds of incapacity be proportional, adapted to the individual's needs and applicable for the shortest possible time period, as well as being subject to regular review by a 'competent, independent and impartial authority or judicial body'.

[17] Amnesty International Ireland, *Decision-Making Capacity in Mental Health: Exploratory Research into the Views of People with Personal Experience* (Dublin: Amnesty International Ireland, 2009), p.13.

the individual. For a person who lacks capacity, the supports that are in place to assist decision making are as much a part of enabling their capacity as is a ramp for a wheelchair user. Capacity can be impacted by the environment within which a decision is made as well as the supports available to the person to assist in the decision. In the context of mental health this is a very significant development. An individual's capacity to make a decision may depend on whether the information about the treatment is explained by a trusted person in a way that he/she can understand. This social conception of decision making capacity must be realised in the legislation, both in its definition of capacity and in provisions on assessment, supported decision making, etc.

It is also important to recognise that places in which people who lack capacity receive treatment and care are diverse. People may receive treatment in an approved centre governed by the Mental Health Act, 2001, but many mental health service users lacking capacity will continue to live at home and attend day services in the community. Others will live in community residences with high levels of support. Still others may live in public or private nursing home facilities with specialist services for age-related conditions such as dementia. Others again will receive treatment and support in specialist services such as those required by persons who have a dual diagnosis of intellectual disability and a mental health condition. Also, the reality is that people who lack capacity may be placed in general hospitals or other facilities unsuited to their needs in the absence of appropriate alternative options.

With this background in mind, Mental Health Reform makes the following specific recommendations to the Joint Oireachtas Committee on Justice, Defence and Equality for inclusion in the capacity legislation.

Supported decision making

Support to assist a person with a disability to exercise their decision making capacity is a key requirement under the CRPD. Article 12 of the CRPD protects the right to equal recognition before the law of all persons with disabilities. This requires a legal framework to guarantee the right of people with impaired capacity to participate to the fullest extent possible in decisions which concern them and the provision of assistance to enable them to do so. The Scheme of the Bill does not provide the appropriate emphasis on supported decision making that would reflect the CRPD; it overly focuses on guardianship and regularises substitute decision making rather than supported decision making. If the legislation takes the same approach as the Scheme it is not likely to be compliant with the CRPD.

A Vision for Change recognises the important role that access to advocacy plays in recovery from a mental health condition. It states that "all users of the mental health services – whether in hospitals, day centres, training centres, clinics, or elsewhere – should have the right to use the services of a mental health advocate."[18] Advocacy can play an important role in assisting treatment decisions. A wider system of supported decision making could reduce the need for involuntary admissions by facilitating individuals to be able to make decisions about their mental health treatment. Having advocacy support available in the context of capacity hearings or mental health tribunals is also important in order to promote the voice of the service user in these processes. Advocates can also support an individual to make a complaint about the service. Currently peer advocacy services are funded by the Health Service Executive and provided in inpatient units however there is no statutory advocacy service for mental health service users. The capacity legislation must include provisions that underpin the right of every individual who needs support in order to make decisions about their own mental health treatment to have such support.

[18]Department of Health and Children, A *Vision for Change: Report of the Expert Group on Mental Health Policy* (2006), p. 25.

1. **Recommendation: The capacity legislation should provide a statutory framework for supported decision making and the right to advocacy to assist in decisions.**

2. **Recommendation: The capacity legislation should provide for regulation of supported decision making and for consultation with people with experience of a mental health condition on the regulations.**

3. **Recommendation: The capacity legislation should include necessary procedural safeguards in all hearings to promote the voice of the person whose capacity is in question.**

4. **Recommendation: The capacity legislation should include a complaints mechanism independent of the service provider. It should also provide for advocacy support in making a complaint and for a proxy decision-maker to be able to make a complaint on behalf of an incapacitated person.**

Interplay with the Mental Health Act

The CRPD affirms the principle of non-discrimination on the basis of a mental health disability and the need for equal treatment before the law of people with a mental health condition as compared with others. This means that the decision making capacity of a person with a mental health condition should be addressed in an equal manner to anyone else. Currently Ireland has a separate Mental Health Act that includes some provisions relating to the capacity or incapacity of a person with a 'mental disorder'. On foot of the CRPD, there can no longer be one set of standards for people with a mental health condition and another set of standards for people with physical conditions. The same standards must apply to both groups. Stated simply, MHR is of the view that all of the provisions of the capacity legislation must apply equally to people with a mental health condition at all times.

5. **Recommendation: The provisions of the capacity legislation must apply equally to the decision making capacity of people with a mental health condition and with reference to mental health as to physical health. The capacity legislation should make amendments to the Mental Health Act 2001 so that the Act fully reflects the provisions of the capacity legislation.**

Incapacitated service users who are considered voluntary

MHR is extremely concerned about mental health service users in in-patient settings who lack capacity and who currently have no protection under either the Mental Health Act, 2001 or any capacity legislation as they are considered 'voluntary patients'. The following three issues relating to these individuals must be addressed:

1. Mechanisms to review the detention of people who lack capacity and who are admitted to in-patient units for mental health treatment ("approved centres" under the Mental Health Act, 2001);

2. Mechanisms to regulate the use of restraint; and

3. Mechanisms for the review of treatment, in particular use of medication in treatment.

Under the current Mental Health Act, 2001 the definition of 'voluntary patient' includes a person who is incapacitated but compliant and who is in fact detained in an approved setting. Such so-called 'voluntary patients' do not have their detention reviewed by a mental health tribunal and do not get other protections set out in the Act for 'involuntary patients'.

Similar concerns have been raised in the recent report of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT). This submission reflects concerns raised by the CPT about these "so-called 'voluntary' patients"[19] who are, in reality, deprived of their liberty, as well as issues regarding treatment and the use of restraint and seclusion. While the CPT visited just two approved centres and the Central Mental Hospital, MHR is concerned that the issues raised may apply to other approved centres and to other health and social care settings. The gap in protections for "so-called 'voluntary patients" must be addressed in the capacity legislation as well as through amending the definition of 'voluntary patient' in the Mental Health Act 2001. Appendix I contains a detailed discussion of the rationale for addressing this gap, including how the current legal framework leaves Ireland open to a claim of breaching the European Convention on Human Rights.

In making the following recommendation to ensure additional protection to people who lack capacity, MHR must emphasise that treatment under the Mental Health Act, 2001 can fall short of good practice and a great concern of many service users is the risk of loss of liberty when they agree to a voluntary admission. To quote a service user, "There is no such thing as involuntary or voluntary patients. All patients are involuntary. If a voluntary patient decides not to take their medication, they are changed to involuntary. If a patient questions their treatment they are thought to lack insight and are re-graded from voluntary to involuntary".[20] While stronger protections must be introduced for people who are currently considered voluntary and lack capacity, these must be implemented in a way that promotes the dignity, bodily integrity and autonomy of the person.

6. **Recommendation: The capacity legislation should provide that people who lack capacity when they are admitted to an approved centre for mental health treatment or who become incapacitated following admissionto an approved centre will get the protections and review mechanism presently afforded to 'involuntary' patients under the Mental Health Act, 2001.[21] This needs to be reflected in the context of the review of the Mental Health Act, 2001.**

7. **Recommendation: The definition of voluntary patient under the Mental Health Act 2001 should be amended such that the term 'voluntary patient' refers to a person with the capacity to consent to admission and treatment only.**

Incapacitated residents in supported accommodation and informal decision making

As of 2007, almost two and a half thousand people with a mental health condition were long-stay residents of health service community accommodation.[22] With the closure of old psychiatric institutions, more mental health service users will be residing in supported accommodation provided by the HSE and other agencies. Many adults with a long-term mental health condition also live with their parents or other family members. Mental Health Reform has received anecdotal reports of

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19 Report to the Government of Ireland on the visit to Ireland carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 25 January to 5 February 2010, p. 60

20 Quote from a speaker at the Oireachtas Cross-Party Group on Mental Health briefing on the review of the Mental Health Act, 2001 held 20th of July 2011.

21 There is a difference between persons who are presently involuntary admitted (a core feature of which is the person is resisting admission/treatment) and that of an incapacitated but compliant person. The impact of that incapacity on the conduct of tribunal hearings is a matter which should be considered with practitioners and in the context of the review of the Mental Health Act, 2001, See C Murray 'Safeguarding the Right to Liberty of Incapable Compliant Patients with a Mental Disorder in Ireland (2007) 29 DULJ.

22 Health Service Executive (2008) 'The Efficiency and Effectiveness of Long-Stay Residential Care for Adults within the Mental Health Services: Evaluation report prepared under the Value for Money and Policy Review Initiative', p.17.

instances where health service staff are making decisions for residents to a greater extent than seems necessary. For example, staff overly controlling the patterns of residents' daily lives, their money and their relationships may be depriving individuals of decision making capacity unnecessarily. The capacity legislation can provide an important support to the recovery ethos set out in *A Vision for Change* by ensuring that informal substitute decision making occurs only where necessary and that the capacity of the individual to make their own decisions about their daily living is maximised.

8. **Recommendation: With regard to informal decision making, capacity legislation must ensure that individuals' right to make decisions about their daily lives including patterns of living, usage of their financial resources and relationships is protected.**

Responsibility for assessing capacity

Government mental health policy envisages a multi-disciplinary approach to mental health care, reflecting the 'biopsychosocial' model of mental health. This model recognises that mental health is a result of a "complex interaction" between biological, psychological and social factors. Evidence also shows that diagnosis is not a reliable indicator of capacity[23] and therefore the diagnostic skills of a medical professional should not be the preeminent skills used to assess capacity. This multi-disciplinary approach must be reflected in the legal provisions on assessment of capacity.

9. **Recommendation: Where a formal assessment of decision making capacity is required, the legislation should allow for an independent assessment being conducted by a range of qualified health and social care professionals including psychiatrists, psychiatric nurses, psychologists, occupational therapists and social workers and should ensure a minimum of two disciplines including a health and social care professional involved in any assessment.**

Advance directives

An advance directive in the mental health context has been defined as "a legal document which provides a mechanism for individuals to stipulate, in advance, what types of psychiatric treatments they prefer or to appoint a health care agent to make such decisions for them, should they become incapacitated."[24] In our understanding an agent is not necessarily a medical professional. Advance Directives in the healthcare context are important in order to protect the right to autonomy, dignity and bodily integrity. They allow service users to retain control over their healthcare decisions at a time when they lack capacity to make such decisions. In the mental health arena it is common practice that Psychiatric Advance Directives (PADs) may be overridden if a person is a danger to themselves and is subject to involuntary admission.[25]

Advance directives have a particular importance in the area of mental health treatment as they can have a therapeutic benefit for service users by building self-esteem, reducing stress and leading to improved communication between doctor and patient. Morrissey has argued that because of the episodic nature of many mental health problems, many people become experts in their own care, in the sense that they know what works and what does not work for them in a time of crisis. Advance directives provide a mechanism to harness patient expertise and thereby improve decision making quality in mental health care. Views expressed in a small study conducted in Ireland illustrate the value of advance directives for mental health service users:

[23] Amnesty International Ireland, *Decision-Making Capacity in Mental Health: Exploratory Research into the Views of People with Personal Experience* (Dublin: Amnesty International Ireland, 2009.)
[24] 'Making the Most of Psychiatric Advance Directives" (2007) 24(6) Harvard Mental Health Letter 1 at 1.
[25] F Morrissey 'Advance Directives in Mental Health Care: Hearing the Voice of the Mentally Ill' (2010) 16(1) Medico-Legal Journal of Ireland (2010).

> "I do think it would be helpful. I know that there is a lot of debate and discussion about this, but I do think it would be helpful because nobody knows your mental health better then you."
>
> "And in a lucid moment I've turned around and said I do not want to take this certain medication because they have had adverse effects on me - for instance I would refuse to take lithium ever again because it gave me severe psoriasis which is troubling me all my life … so I would want to be able to sign an advance directive to say that because of the adverse effects I have experienced I do not want to take lithium."
>
> "I wouldn't want people experimenting on me with new drugs, certainly not when I wasn't capable of making the decision."[26]

Psychiatric advance directives can be used to record the service user's preferences in relation to his/her mental health care and to refuse certain treatment. They can also be used to appoint proxy decision makers who can make treatment decisions on behalf of a service user in the event that he or she loses capacity to make those decisions. Such a provision would be very helpful in the mental health context to underpin the positive role that family members and friends may play in health care decisions. Moreover, an advance directive can also list the service user's wishes in relation to choice of hospital, choice of healthcare professionals, financial arrangements and arrangements for care of family members and pets. However, few service users may prepare an advance directive unless they are facilitated to prepare one[27] so it would be important to provide information and support to assist individuals in preparing an advance directive.

Despite the many benefits of psychiatric advance directives, there is no statutory framework for advance directives of any kind in Ireland and Ireland lags behind other jurisdictions which have already instituted relevant legal provisions. Legal provision for advance directives already exists in Ontario, many states in the US, Scotland, England and Wales. This lacuna in Irish law needs to be addressed in order for the voice of those with mental health conditions to be heard.

A Vision for Change supports the introduction of advance care directives and states that:

> "a person centred approach to the delivery of care will both highlight and moderate these conflicting rights, offering measures such as advance directives that can be put into effect at times when the user may not be well enough to make informed decisions".

Morrissey notes that despite the direct reference to advance directives in AVFC there has been little implementation of this. She notes that the implementation of advance care directives "can contribute significantly to the recovery and person-centred care espoused in the policy framework".[28]

Advance directives can contribute to fulfilment of the CRPD as part of "measures relating to the exercise of legal capacity respect the rights, will and preferences of the person and free of conflict of

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[26] Amnesty International Ireland, *Decision-Making Capacity in Mental Health: Exploratory Research into the Views of People with Personal Experience* (Dublin: Amnesty International Ireland, 2009), p. 50.
[27] See J. Swanson, et al., (2006) 'Facilitated Psychiatric Advance Directives: a Randomized Trial of an Intervention to Foster Advance Treatment Planning Among Persons with Severe Mental Illness' 163(11) *American Journal of Psychiatry* 1943 at 1943.
[28] F. Morrissey, (2010) 'Advance Directives in Mental Health Care: Hearing the Voice of the Mentally Ill'16(1) *Medico-Legal Journal of Ireland* 21.

interest and undue influence".[29] The Committee of Experts on Family Law of the Council of Europe has also recently recommended that States "promote self-determination for capable adults in the event of their future incapacity, by means of continuing powers of attorney and advance directives".[30]

The Scheme of the Mental Capacity Bill 2008 provides that prior wishes should be taken into account in accordance with the guiding principles and best interests provisions of the proposed new capacity legislation but it does not set out a legal framework for advance directives.

10. **Recommendation: The capacity legislation should provide a legal framework for advance decisions to refuse and consent to treatment as well as advance care, social and financial arrangements.** This legal framework must be binding on clinicians to the same extent as a person's wishes would be if he/she had capacity at the time. A valid advance directive should only be departed from where treatment is necessary on a life-saving emergency basis; suitable procedural safeguards must be in place to ensure compliance with this provision and any treatment given in contravention of an advance directive must be of established benefit to the recipient. **The advance decision provisions must apply equally to people with a mental health condition as to others and must apply to treatment for mental and physical health.**

Force/restraint

The use of restraint is a restriction on a person's freedom of movement and, depending on the circumstances, may be a serious infringement of his/her rights to bodily integrity and dignity and, at an extreme, may constitute inhuman and degrading treatment. Mental Health Reform considers that as a first principle, force should not be viewed as a method for engaging service users in treatment. Force is not the way to support recovery. There is evidence that mental health services can achieve a dramatic reduction in the use of restraint where a dedicated zero-restraint programme is put in place.[31]

MHR considers the promotion of no force as indicative of the kind of cultural change that is required to create a humane mental health service, where the service user's experience of treatment and care is positive.

In the context of capacity legislation and the existing Mental Health Act, 2001, the legislation must provide for the protection of users of mental health services from undue use of restraint.

The use of restraint may implicate Articles 3 and 8 of the ECHR as well as the constitutional protections afforded to these rights. The protection of individual rights does not require that restraint may never be used.[32]However, it does require a clear definition of restraint and a clear set of circumstances in which restrictions may be used and the methods of restraint employed.

In respect of in-patient services in approved centres, the use of restraint is regulated by Section 69 of the Mental Health Act, which provides that both seclusion and the application of mechanical means of bodily restraint must follow the rules laid down by the Mental Health Commission. The Mental Health Commission's Code of Practice on physical restraint also provides some regulation of this practice, while falling short of human rights standards.[33]However, as noted above, many persons with a mental health difficulty and the majority of persons who are incapacitated will receive care

[29] Amnesty International Ireland, *Submission to the Department of Health and Children on the need for a substantive review of the Mental Health Act 2001'* (Dublin: Amnesty International Ireland), p.52.
[30] Ibid.
[31] L Ashcraft and W Anthony, 'Eliminating Seclusion and Restraint in Recovery-Oriented Crisis Services' *Psychiatric Services* 59(10) (2008), pp.1198-1202.
[32] See *Trust A and Trust B* v *H (An Adult Patient)* [2006] EWHC 1230 (Fam), [27].
[33] Amnesty International Ireland, 'Submission to the Department of Health and Children on the need for a substantive review of the Mental Health Act 2001', pp.108-113.

and treatment outside of an approved centre. It is therefore necessary that the capacity legislation addresses the issue of restraint.

The Scheme of the Mental Capacity Bill 2008 restricts the power of personal guardians and attorneys to restrain. However, it does not contain any restriction on the use of restraint more generally – i.e. by a party other than the guardian/attorney. This would seem to be a clear omission from the Scheme which must be addressed in the Bill.

11. **Recommendation: The capacity legislation should include a general provision about the use of restraint that sets out the nature of restraint and de-limits the circumstances in which restraint may be used. The model provided by the UK's Mental Capacity Act 2005, section 6 would appear to provide a useful starting point in this regard.**

12. **Recommendation: The definition of restraint should include "chemical restraint". The use of chemical restraint should be governed by clear rules and subjected to the same oversight as other means of restraint.**

Medication Review

There is now a substantial body of research, both in Ireland and abroad, suggesting over-prescription of high dosage medication and anti-psychotic medication as well as the over-use of polypharmacy for people with mental health conditions. The Inspector of Mental Health Services has identified the over-prescription of benzodiazepines within approved centres as well as the use of polypharmacy. For example, the Inspector found that 26 per cent of residents in in-patient and long-stay facilities are on more than one benzodiazepine.[34] In its recent report the CPT drew attention to the use of 'chemical restraint' and noted "*the CPT's delegation met with patients who had been administered medication for behaviour control rather than for decreasing symptoms of their disease, notably after an incident which involved physical violence. At present such use of "chemical restraint" does not qualify as a means of restraint under Irish law and is therefore not subject to oversight".*[35]

There is no data in respect of prescription practices in care homes which are not subject to the review of the Inspector of Mental Health Services. In the UK, an independent study of medication practices in respect of people with dementia found that approximately 180,000 people with dementia (up to a quarter of all such people) are being treated with antipsychotic medication[36]. This is in spite of evidence that antipsychotic drugs 'show minimal efficiency' in treatment for behavioural and psychological symptoms in dementia (BPSD) such as agitation, aggression, wandering, shouting, depression, sleep disturbance and psychosis.

Under the Mental Health Act 2001 (Approved Centres) (Regulations 2006SI 551 of 2006) each "resident" has an entitlement to an "individual care plan", regardless of his or her legal status. However, the Inspector of Mental Health Services has found that compliance with this aspect of the Regulations has been poor. The Mental Health Act, 2001 contains no review mechanism regarding how the care plan is drawn up, how treatment decisions are made and the appropriateness of decisions. In respect of incapacitated patients in all settings, the common law rules apply in respect of treatment. If the patient lacks capacity, treatment is determined on the basis of his or her best

[34] Inspector of Mental Health Services (2011) 'Mental Health Services 2010: Medication' report available at www.mhcirl.ie, p.7.
[35] Report to the Government of Ireland on the visit to Ireland carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 25 January to 5 February 2010, at paragraph 132 of the report.
[36] S. Banerjee: The Use of Antipsychotic Medication for People with Dementia: Time for Action (London: Department of Health, 2009.

interests with no mechanism for review of decisions made or for external oversight of medication levels.

13. **Recommendation: The capacity legislation and the Mental Health Act should include oversight mechanisms for treatment/medication decisions for incapacitated patients in approved centres and other care facilities. Although the second opinion model in the Mental Health Act 2001, ss 59-60 is flawed in that it does not provide for an independent review of treatment decisions, as a first step, the model should be extended to incapacitated patients. Any amendments of the MHA 2001 to extend the scope and independence of the oversight/treatment review mechanism should be extended in the same way to patients lacking capacity.**

Guiding Principles

The Scheme of the Mental Capacity Bill published in 2008 included a principle that "no intervention is to take place unless it is necessary having regard to the needs and individual circumstances of the person, including whether the person is likely to increase or regain capacity" (Head 1(b)). It is important to recognise that lack of capacity arising from a mental health condition is often temporary. Mental Health Reform is concerned that the draft wording in the Scheme of the Bill does not go far enough to prevent undue interference with a person's bodily integrity where there is a possibility that the individual will regain capacity. Every effort should be afforded to allow the individual to regain capacity before making a treatment decision on their behalf unless there is an objective reason why the treatment cannot be postponed. In order to strengthen this protection, MHR recommends the following:

14. **Recommendation: The Bill should strengthen Guiding Principle 1(b) so that where a person is likely to regain capacity no intervention should take place unless it is necessary and cannot be postponed until the person in question is expected to regain capacity.**

Transition arrangements (Wards of Court)

While the numbers are unknown, it would be expected that there are long-stay residents in psychiatric institutions and high-support accommodation who may currently be Wards of Court. It will therefore be important to make provision in the capacity legislation for existing Wards of Court to have their capacity assessed as soon as possible after enactment.

15. **Recommendation: The capacity legislation should provide that existing Wards of Court have their capacity reviewed as soon as possible after enactment of the legislation.**

Review of the legislation

This capacity legislation marks a significant shift in Ireland's approach to people whose capacity is impaired. As a major new departure in Irish law, it is important that not only the operation but the fulfilment of the law's intentions is safeguarded by a statutory review process.

16. **Recommendation: The Bill should require periodic reviews of the Act which should cover not only the operation or functioning of the Act but also whether the Act has succeeded in fulfilling the objectives and aims sought to be achieved by its enactment.**

Conclusion

People with a mental health condition have an equal right to protection under capacity legislation. The capacity legislation must give effect to this right and affirm the position of people with a mental

health condition as equal citizens in Ireland. This will require amendment to the Mental Health Act, 2001 at a minimum, so that it fully reflects the capacity legislation provisions.

The Capacity legislation must protect the rights of mental health service users in in-patient settings who lack capacity and who currently have no protection under either the Mental Health Act or capacity legislation as they are considered 'voluntary patients'. This will require specific provision in the legislation to independently review the detention of incapacitated but 'compliant' patients. Further specific provision is required to ensure limitations and guidance on the use of restraint and to underpin a culture of zero restraint. Specific measures are also required to ensure adequate review on the use of medication.

The Scheme of the Capacity Bill sets out a wide scope for informal decision making. The capacity legislation must ensure that people who lack capacity are adequately protected from abuse through informal decision making by narrowing the scope of such decisions and ensuring independent oversight.

The capacity legislation provides an opportunity to put a statutory advocacy process in place – any person who needs to make significant decisions about their mental health treatment and whose capacity is in question should have the right to access advocacy support. Without such a provision, the legislation is unlikely to comply with the CRPD. It is also imperative to introduce provisions for advance decisions that can support the recovery ethos in mental health care and individuals' human rights.

Mental Health Reform

Mental Health Reform's vision is for an Ireland where people experiencing mental health difficulties achieve and enjoy the highest attainable standard of mental (and physical) health. Mental Health Reform promotes a model of health and social care where all citizens have equal access to affordable, sustainable and high quality primary care and specialist mental health services.

The views and active participation of people who experience mental health difficulties, their families and friends are important to achieve best outcomes in public mental health services delivery and integrated services at local community level are the best setting to attain these outcomes.

A Vision for Change, the national policy for reforming Ireland's mental health services, published in 2006, proposes a radical change in ethos and approach to the provision of mental health care. The recovery model, which lies at the heart of AVFC, challenges the traditional power base in the current mental health system in Ireland. We will develop the capacity of our member organisations and service users through information, education, support and training to secure implementation of AVFC by its outside target date of 2016:

The Work of Mental Health Reform

Mental Health Reform will work with its members through education, information, support and training to take the necessary steps to deliver structural and cultural reform in line with existing policy.

Structural reform is about setting in place the policies, model of service, funding, accountabilities, partnerships and legislation that will lead to the adoption and effective implementation of a progressive, comprehensive and holistic mental health system in Ireland.

Cultural change requires a programme of education for mental health professionals, service users, family members and communities to engender new attitudes and expectations in mental health. Training programmes for mental health professionals should be re-shaped to be in line with the person –centred, recovery focussed approach set out in *A Vision for Change*.

Bridging policy to practice: Mental Health Reform is calling on the Government to move to comprehensive community based services, as set out in Ireland's mental health services reform policy, A Vision for Change. Since the introduction of the policy in 2006, implementation has been slow. At the current rate of progress, it will not be implemented even by the outset target of 2016.

Improving mental health services is an essential part of political and social reform in Ireland, as the quality of mental health services impacts on all of our lives: one in four people experience a mental health difficulty during their lives. Nonetheless, mental health funding is at its lowest level in modern history at just 5% of the HSE budget and community mental health services, the cornerstone of a modern mental health service, are poorly resourced.

Background to Mental Health Reform

Formerly the Irish Mental Health Coalition, Mental Health Reform was founded by five founding members in response to the need to create a focal point for national-level mental health promotion.

The founding members of Mental Health Reform are:

- Amnesty International Ireland
- Bodywhys – The Eating Disorders Association
- Grow
- The Irish Advocacy Network
- Shine (formerly Schizophrenia Ireland).

For further information, please don't hesitate to contact Orla Barry, Director, Mental Health Reform, 6-9 Trinity Street, Dublin 2, 01 612 14 22 or by email: obarry@mentalhealthreform.ie.

Appendix I
Incapacitated service users who are considered voluntary

The right to liberty is a fundamental human right. It may only be interfered with in limited circumstances, provided such interference is necessary, proportional to the legitimate aim for which it is carried out and is carried out in accordance with a procedure set out in law.

The majority of persons accessing mental health services do so through community mental health services and as such the issue of detention does not arise.

The Mental Health Act, 2001 governs the admission and treatment of persons to approved centres for in-patient treatment. Persons receiving treatment in approved centres under the Mental Health Act 2001 are categorised as 'voluntary' or 'involuntary' admissions. Involuntary admissions account for approximately 10% of admissions to approved centres. Persons who are involuntarily admitted to approved centres are by definition deprived of their liberty. Consequently, to protect the rights of patients and to comply with our constitutional and international legal obligations, all involuntary admissions are periodically reviewed by an independent Mental Health Tribunal. Specific safeguards are also in place in reviewing the treatment afforded to involuntary patients.

Under the 2001 Act, 'voluntary patients' do not have their admission to an approved centre independently reviewed. This is because it is commonly understood that a voluntary patient is not being detained against their will, and have given consent to their treatment and so do not require an independent mechanism to protect their right to liberty.

The difficulty is that the definition of 'voluntary patient' includes persons who are incapacitated but compliant and who are in fact detained in an approved setting. Section 2 of the 2001 Act defines a voluntary patient as "*a person receiving care and treatment in an approved centre who is not the subject of an admission order or a renewal order*". The Supreme Court considered the definition in the case of *EH* v *St Vincent's Hospital and Ors*[2009] IESC 46and held that "*the terminology adopted in Section 2 of the Act of 2001 ascribes a very particular meaning to the term "voluntary patient". It does not describe such a person as one who freely and voluntarily gives consent to an admission order. Instead the express statutory language defines a "voluntary patient" as a person receiving care and treatment in an approved centre who is not the subject of an admission order or a renewal order..."*

Thus under Irish law a patient who is 'incapacitated but compliant' is defined as a voluntary patient and any detention or deprivation of liberty of that patient is not subject to independent review. Such a position leaves Ireland open to a claim of breach of the European Convention on Human Rights. Arising from the decision in *EH* and the Court's interpretation of Section 2, the Irish Human Rights Commission, in its "*Policy Paper concerning the definition voluntary patient under s, 2 of the Mental Health Act, 2001*" has stated that "*This understating of s. 2 ... is of concern to the IHRC insofar as it has implications for the State's compliance with its international human rights obligations*".

The European Court of Human Rights considered the matter in decision of *HL V United Kingdom* HRC MRLR (2005) 40 EHRR 761 [2004] 1 MHLR 236, identifying the gap in the protections offered to incapacitated but compliant patients in what has become known as "the Bournewood Gap".

The facts in the Bournewood case were as follows: The applicant was 48 years of age and autistic and 'profoundly mentally retarded'. He was unable to speak and his understanding was limited. He was frequently agitated and had a history of self harm. On 22 July, 1997, HL was at a day centre. He

was agitated, hitting himself on the head and banging his head against the wall. He was taken to A& E and from there to the local psychiatric unit in Bournewood as an informal patient. His carers were not allowed to visit him. Ultimately the matter was heard by the European Court of Human Rights, with the applicant claiming *inter alia* that the manner of his admission and continued detention breached Art 5 of the European Convention on Human Rights. [i]

In the Bournewood case, the ECtHR held that:

> *"the Court considers the key factor in the present case to be that the health care professionals treating and managing the applicant exercises complete and effective control over his care and movements from the moment he presented acute behavioural problems on 22 July 1997 to the date he was compulsorily detained on 29 October 1997*". In finding the detention unlawful the court went on to comment "*the Court finds striking the lack of any fixed procedural rules by which the admission and detention of compliant incapacitated persons is conducted...In particular the Court notes the lack of any formalised admission procedures which indicate who can propose admission, for what reasons and on the basis of which kind of medical and other assessment and consultation. There is no requirement to fix the exact purpose of admission (e.g. treatment and admission) and, consistently, no limits in terms of time, treatment or care attach to that admission. Nor is there any specific provision requiring a continuing clinical assessment of the persistence of a disorder warranting detention."*

The Bournewood decision lead to the introduction of the Deprivation of Liberty Safeguards in England and Wales in April, 2009[ii], legislation was introduced in the UK to provide independent review of the admission of incapacitated but compliant patients to in-patient mental health services. In the UK system, this provision is addressed in the Mental Capacity Act 2005. The procedure is different to that applying to persons involuntarily detained.

It appears clear that if Ireland is to comply with the requirements of Article 5 of the ECHR as applied by the ECtHR in *UL V the United Kingdom* and address the Bournewood Gap, then the definition of "voluntary patient" in the Mental Health Act, 2001 will have to be amended.

More recently the issue was identified by the CPT report "*the CPT delegation observed that many so called 'voluntary' patients were in reality deprived of their liberty; they were accommodated in closed units from which they were not allowed to leave and, in at least certain cases, were returned to hospital if they left without permission. Further if staff considered it necessary, these patients could also be subjected to seclusion and could be administered medication for prolonged period against their wish"*[iii]It is not clear whether the patients referred to in its report are incapacitated.

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[i]Art 5 states "No one shall be deprived of his liberty save in the following cases and in according with a procedure prescribed by law'. It goes on to stipulate that persons of unsound mind may be detained lawfully i.e. in accordance with a procedure prescribed by law.

[ii]See section 50 of the Mental Health Act 2007 (England and Wales) which inserts additional provisions into the Capacity Act 2005. There has been some comment on the efficacy of the approach arguing the Safeguards as introduced are complex and "arguably... yields little in terms of actual protections, especially in relation to treatment and care decisions for the person once she has been admitted". See M Donnelly "Legislating for Incapacity: Developing a Human Rights Based Framework' (2008) 30 Dublin University Law Journal 395, p.433.

[iii] Report to the Government of Ireland on the visit to Ireland carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 25 January to 5 February 2010, at paragraph 117