**AMNESTY** INTERNATIONAL



# Submission to the Oireachtas Joint Committee on Justice, Defence and Equality on proposed new Capacity Law

#### August 2011

Amnesty International Ireland (AI) has a long-term strategic goal of making real in Ireland Article 12 of the International Covenant on Economic, Social and Cultural Rights which states that *"every person has the right to the highest attainable standard of physical and mental health"*. AI is a membership-based campaigning organisation which has a mission to uphold and defend human rights and has been campaigning in the area of mental health in Ireland since 2002. AI strongly welcomes the Government's decision to conduct this long over-due reform of existing legislation and the Government's intention to ratify the International Convention on the Rights of Persons with Disabilities (CRPD).<sup>1</sup>

Al welcomes this opportunity to submit its observations on the Scheme of the Mental Capacity Bill 2008 (the Scheme) to the Oireachtas Joint Committee on Justice, Defence and Equality. The focus of this submission is on the Scheme as it relates to persons with mental health problems. Al previously made submissions on the Scheme to the Department of Justice, Equality and Law Reform on 25 February 2009 and on 23 December 2009.

Al conducted original, exploratory research with individuals who may be subject to this new legislation by reason of a mental health problem, seeking their views about decision-making capacity. This research informed this submission and is available upon request. This submission was also informed by Al's Experts by Experience Advisory Group.\*

Al would welcome the opportunity to meet with the Oireachtas committee to discuss in more detail the issues raised in this submission.

\*In October 2008, AI established an advisory group of 'experts by experience' to assist in devising its campaign strategy and to provide policy advice. This group includes individuals who are at the forefront of the mental health movement in Ireland and who have direct experience of a mental health problem.

<sup>&</sup>lt;sup>1</sup> The CRPD and the CRPD Optional Protocol were adopted during the 61st Session of the General Assembly: see GA Res. 61/611, 13 December 2006, A/61/611; 15 IHRR 255.

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## **Executive Summary**

The introduction of Capacity legislation is proposed to bring Irish law in line with the Convention on the Rights of Persons with Disabilities (CRPD). The Irish Government signed the CRPD on 30 March 2007 thereby highlighting its intention to ratify it in the future. All strongly welcomes the 2011 Programme for Government commitment to review the Mental Health Act 2001 and to introduce a Capacity Bill that is in line with the CRPD. All is however concerned that the current Scheme of the Capacity Bill does not adequately adopt the changes required by Article 12 of the CRPD. The draft heads of the Mental Capacity Bill are based primarily on the recommendations of the Law Reform Commission's Consultation Papers and final Report.<sup>2</sup> The Law Reform Commission's work on legal capacity concluded just as the CRPD was finalised and since then the understanding of legal capacity has developed in international law with its adoption. While the Bill has positive aspects it needs to be reconfigured to comply with Article 12 on the right to legal capacity. Irish law must fully protect the rights of people with mental health problems.

The focus of this submission is on persons with mental health problems. Al is conscious that capacity legislation will affect persons with a range of disabilities and in a range of circumstances. Therefore, in the broader context, the concept of capacity should focus on the autonomy of the individual and how to enhance capacity to enable each individual to make a range of decisions affecting their lives. This is of particular importance having regard to Article 12 of the CRPD, which refers to the capacity of the individual in all spheres of life.

The 2008 Scheme does not provide for a system of supports that would enable people to make decisions and exercise their legal capacity. The Scheme gives undue weight to substitute decision-making and as currently worded will mean that it is unlikely Ireland would be in compliance with Article 12. AI strongly recommends that the Bill be amended to adequately provide for informal and formal supports that would support people and protect the legal capacity of people with mental health problems. AI recommends an independent capacity advocacy support. However it is important to also note that informal, cost effective supports such as carers, peer supports and families are key.

The approach in the Scheme fails to undertake the change in thinking required to move away from viewing people with disabilities as objects to be cared for to accepting people as subjects benefiting from the rule of law. Article 12 demands that we move from a model of 'best interests' to one that focuses on the potential of individuals and ensure they can enjoy legal capacity on an equal basis with others in all aspects of life. The emphasis should therefore by on the ability of a person to regain capacity to make his or her own decisions. The Bill must go further than 'taking account of' the past wishes of an individual. The Bill should provide a legislative framework for binding advance directives, instructions given by individuals specifying what actions should be taken for their health in the event that they are no longer able to make decisions due to illness or incapacity, and appoints a person to make such decisions on their behalf.

The CRPD does not mention specifically substitute decision-making and it should therefore be confined to last resort and should have appropriate safeguards and protections. Where a decision is taken to administer treatment or provide medication

<sup>&</sup>lt;sup>2</sup> "Consultation Paper on Law and the Elderly" Law Reform Commission (23) 2003; "Consultation Paper on Vulnerable Adults and the Law: Capacity" Law Reform Commission (37) 2005; "Report Vulnerable Adults and the Law" Law Reform Commission (83) 2006.

to someone who has been found to lack capacity, safeguards need to be in place, such as oversight mechanisms and independent reviews. Such a decision should only be taken where the treatment is necessary, is the least intrusive treatment appropriate to the patient's needs and is not contrary to an advance directive made by the individual.

The situation of 'incapacitated but compliant' patients needs to be urgently addressed in the Bill by providing for safeguards and review mechanisms regarding the *de facto* detention of persons who lack capacity in all inpatient and residential settings.

Al is concerned about the broad powers of informal decision-making in the hands of third parties under the Scheme. The use of informal decision-making must be restricted to *'minor or routine'* matters relating to health or personal welfare.

As the Bill will impact persons under the Mental Health Act 2001, the Bill must address the interplay of its provisions with that Act. Additionally the Bill should recognise the capacity of young people under the age of 18 to consent to admission or treatment for mental health problems.

While AI welcomes the publication of the 2008 Scheme of the Mental Capacity Bill there are a number of serious concerns about how its provisions fulfil Ireland's obligations under international human rights law, as set out in detail in this submission. We are keen to meet with relevant stakeholders to discuss in more detail our comments. Progressive legislation in this area will allow Ireland to move a step closer to the effective protection and realisation of the equal rights of persons who experience mental health problems in accordance with international human rights laws. This Bill is an important opportunity and we would strongly welcome a Bill that fully recognises the supports people need in order to enjoy legal capacity.

#### **Summary of AI Recommendations**

#### Supported decision-making

- The Bill should provide for supported decision-making as required by Article 12 CRPD and should establish a framework for supported decision-making.
- The Bill should make provision for the establishment of an independent capacity advocacy service and the appointment of capacity advocates to ensure that people with mental health problems receive the support they need to exercise their decision-making capacity in accordance with the requirements of Article 12 CRPD.<sup>3</sup>
- The Bill should identify and provide the supports necessary for people with mental health problems to exercise their legal capacity in accordance with Article 12 CRPD<sup>4</sup>.
- The Bill should be expanded to provide for Regulations or Codes of Practice on supported decision-making and should ensure that there is consultation with people affected in the preparation of such regulations or code of practice.

#### Advance Directives

• The Capacity Bill should provide a legislative framework for advance directives, including advance directives relating to mental health. This should

<sup>4</sup> With supported decision-making, individuals do not lose their legal capacity. Instead, they continue to be recognised as legal persons with rights, responsibilities and powers. This differs from substitute decision-making. Other jurisdictions have taken steps to giving a legislative basis to supported decision-making. In formulating the Capacity Bill, consideration should be given to such other models and to ways in which preferred aspects could be adopted to apply in the Irish context. By way of example, AI points to the following systems:

In British Colombia, the *Representation Agreement Act* came into effect in February 2000. The Act recognises representation agreements which are legal documents for personal planning. In making a representation agreement, an individual authorises personal supporters to assist him or her or to act on his or her behalf for health care, personal care, routine management of financial affairs and legal affairs, if the individual needs assistance due to illness, injury or disability. The individual voluntarily selects and empowers a person or group of persons (supported decision-making network) and can appoint different representatives in relation to different areas of his or her life. Most people appoint a spouse or partner, family member or friend in their Representation Agreement. They can assist, support, act or make decisions on the individual's behalf when he or she is considered not capable of making decisions independently. The Act provides for registration of such individuals or networks to secure their status in the decision-making process. Representation agreements allow for a range of decision-making assistance which do not amount to substitute decision-making.

In Manitoba, the *Vulnerable Persons Living with a Mental Disability Act* provides for an individual to take advantage of a "support network" in providing assistance to make personal care or property decisions. This limits the need to resort to substitute decision-making.

The test for capacity in the Northwest Territories *Guardianship and Trusteeship Act* recognises the role of assistance. It provides that someone has capacity where they are able 'by himself or herself or with assistance' to understand and appreciate the consequences of relevant information.

<sup>&</sup>lt;sup>3</sup> Projected cost: a 2004 report costed the provision of a personal advocacy service at around €2m. (Goodbody Economic Consultants, Developing an Advocacy Service for People with Disabilities, July 2004,

http://www.citizensinformationboard.ie/publications/social/downloads/SocialAdvocacy\_volume1Report.p df) There was a Community and Voluntary Advocacy Service in place between 2005 and 2010, which served about 5,000 clients. The budget for that service was around €3.2 million per annum. Since January 2011, the Citizens Information Board has provided a national advocacy service for people with disabilities with a particular remit for more vulnerable people with disabilities. While the extension of this advocacy service to persons admitted under the Act would entail some additional costs, such costs would not be as high as the establishment of a new advocacy service. The advocacy service could be extended on a phased basis. Initially, the existing service could be put on a statutory footing, e.g. Government will provide an advocacy service. Later, the Act could be amended to ensure that all patients have access to an advocate.

include provision for the appointment of a health care substitute decisionmaker.

- The legislative framework should provide that, where a valid advance directive exists, it should prevail in the same way as the wishes of the patient would prevail, if s/he had capacity at the time.
- The Bill should clarify that the legislative framework applies equally to patients under the Mental Health Act 2001.
- Head 1(g) and Head 3(1)(iii) should expressly state that if a person has expressed prior wishes in relation to a form of treatment, such wishes must be respected and in exceptional cases where it is proposed to depart from a person's prior wishes, approval of the Court of Protection (or other appropriate body) is required. This may require regulations and a Code of Practice to be produced.

## Safeguards around treatment in respect of people who lack capacity

- The Bill should include oversight mechanisms for treatment and medication decisions for persons who have been found to lack capacity.
- There should be a mechanism by which a person who has been found to lack capacity and in respect of whom a decision has been made about treatment can seek an independent review of a decision in respect of that treatment.
- Where a person lacks the capacity to consent to treatment, medication should only be administered,<sup>5</sup> when the following safeguards have been fulfilled (which should be expressly set out in the Bill):
  - The treatment must be necessary and constitute the least intrusive treatment or therapy appropriate to the patient's health needs; and
  - Both of these criteria should be certified by the treating consultant psychiatrist and confirmed by a second independent consultant psychiatrist.
- Consideration should be given to ways in which the Bill could adopt a multidisciplinary approach to treatment provisions.

#### Right to apply for tribunal review of proposal to administer medication

- Upon an application by a patient (or someone acting on the patient's behalf) who objects to the proposed administration of medication,<sup>6</sup> the court / tribunal should review:
  - The patient's functional capacity, and
  - The necessity of the treatment, having regard to the opinion of the treating psychiatrist, the independent psychiatrist and members of the multi disciplinary team and such other evidence or reports as are produced by the patient/his or her representative or requested by the tribunal as it sees fit.

 <sup>&</sup>lt;sup>5</sup> As regards the assessment of capacity, an independent assessment should take place with the involvement of the multi-disciplinary care team, where possible.
 <sup>6</sup> This provision would apply to a patient who has been found to lack capacity and for whom medication

<sup>&</sup>lt;sup>6</sup> This provision would apply to a patient who has been found to lack capacity and for whom medication has been recommended by his/her treating consulting psychiatrist and a second independent psychiatrist.

- Even where the above criteria are satisfied the court / tribunal shall <u>not</u> permit the administration of the proposed medication to a person if to do so would conflict with either:
  - A valid advance directive of the person as regards that medication; or
  - A valid substitute refusal by a personal guardian or a donee of an enduring power of attorney or other substitute decision-maker duly appointed under the capacity legislation.

## Automatic periodic reviews of ongoing administration of medication by tribunals

 In addition, the court / tribunal should be required automatically to review the long-term administration of medication at set intervals (the three-month period foreseen by the existing section 60 Mental Health Act could be used here). Such review should also cover both (i) the capacity of the patient to consent to or refuse treatment (and whether the patient has given informed consent, where relevant) and (ii) the necessity and appropriateness of the treatment following the same format as a review of medication requested by a patient.

#### Other provisions relating to the administration of medication

- There should be a right to appeal (exercisable either by the patient, or in some cases a representative or next of kin) to the Circuit Court against any decision by the specialist court / tribunal to allow a programme of medication to be administered to a person who lacks capacity.
- The Bill should state, for the avoidance of doubt, that if a person regains capacity at any stage, the programme of medication must be discontinued unless the person gives his or her free and informed consent to its continuation.

#### **Best Interests**

• The Bill should delete the phrase 'best interests' and replace it with, for instance, the 'will and wishes' of the individual. The Bill should retain and improve the factors currently set out in Head 3 of the Scheme to consider in determining the individual's 'will and wishes'. These factors must promote the autonomy and self-determination of the individual and each individual's potential.

#### Interplay between the Scheme and the Mental Health Act 2001

- The Bill must address the interplay between its provisions and those of the Mental Health Act 2001.<sup>7</sup> The Mental Health Act should be amended to provide for supported decision-making.
- In order to maximise the autonomy of persons with mental health problems, Part 4 of the Mental Health Act (consent to treatment) should be amended to recognise the role of supported decision-makers and advance directives through which an individual can choose to appoint a substitute decisionmaker.

<sup>&</sup>lt;sup>7</sup> If the principle of 'best interests' is replaced in the Bill, the Mental Health Act 2001 should be amended to delete the 'best interests' as a guiding principle of the Act to ensure that the will and wishes, autonomy and self-determination of the individual are respected.

## **Deprivation of liberty provisions**

- The definition of "voluntary patient" under the Mental Health Act should be amended to include only those persons who have the capacity to make such a decision and who have genuinely consented to their admission to an approved centre and continue to consent.
- The Capacity Bill should include provisions to protect against any arbitrary deprivation of liberty of a person who lacks capacity but is de facto detained in inpatient or residential settings in accordance with the requirements of Article 5 ECHR as interpreted by the ECtHR in HL v the United Kingdom. In doing so the Capacity Bill should also clarify the interplay between its deprivation of liberty provisions and those of the Mental Health Act 2001.

## Informal decision-making

- The Bill must restrict the use of informal decision-making provisions to 'minor or routine' matters relating to health or personal welfare and if there is any question as to whether a particular decision is minor or not, such matter should be referred to the relevant Court of Care and Protection or Guardianship Board, as appropriate.
- Codes of Practice on informal decision-making need to be drawn up in consultation with rights holders and they need to be in place before the Bill comes into force.
- The Office of the Public Guardian should be given an express function to oversee the exercise of informal decision-making under the Bill.
- Medical professionals and others involved in care should be provided with training on the limits of informal decision-making powers.
- The role of family members should be clarified.
- The powers of the Office of the Public Guardian should be extended to include some form of oversight and supervision of the exercise of informal decision-making powers. A specific complaints procedure should also be set out in the Bill and the role of special and general visitors should be clarified.

#### Capacity assessments

- Capacity assessments in the context of decisions relating to medical treatment should be independent from the treating clinician, while allowing for consultation between the assessor(s) and the treating clinician.
- Insofar as possible, a multi-disciplinary approach should be adopted to all assessments of capacity under the Bill.

#### Title of the Bill

• The title of the Bill should be changed to 'Legal Capacity Bill'.

#### Training

• Training should be provided to all persons involved in capacity assessments so that the functional approach to capacity is applied in practice in accordance with the guiding principles and best interests principles set out in the Scheme.

### Use of force/restraint – the role of rights

- The provisions on restraint (Head 11(7) and 48(5)) should also apply to informal decision-makers and carers and the word 'or' should be replaced with 'and' at the end of subparagraph (iii) in these provisions. These provisions should also be extended to expressly state that mechanical restraint may never be used.
- As regards physical restraint, the Bill should reflect the standards set out in the Mental Health Commission Code of Practice on the Use of Physical Restraint. This should include inter alia that physical restraint should only be used for as long as necessary to prevent immediate and serious harm to the person. In addition the Bill should expressly state that physical restraint should only be used where all less intrusive measures have been exhausted.
- The Bill should emphasise that restraint may only be used for the administration of treatment in exceptional circumstances where necessary as a matter of last resort in accordance with the principle of least restriction.
- The Bill should re-iterate the individual's continuing rights to privacy and bodily integrity and the need to ensure that such rights are protected in all cases.

#### Protections from abuse and ill treatment

- The Bill should clarify that the offence of ill treatment or neglect applies equally to persons who are subject to the Mental Health Act 2001<sup>8</sup>.
- The offence of 'ill-treatment or neglect' should be extended to include 'exploitation or abuse' as well as ill-treatment or neglect.

#### Children and young people

- The Bill will need to apply to young persons below the age of 18 years to the extent that they are entitled to make decisions on their own behalf according to the law as amended from time to time.
- The Bill should provide that young persons between the age of 16 and 18 years shall be presumed to have capacity to make decisions regarding admission and treatment unless proven otherwise. This must expressly include consent to and refusal of treatment. If that presumption is rebutted and a person within that age group is found to not have such capacity, the provisions of the Bill should apply.
- Al endorses the following recommendations of the Law Reform Commission:

<sup>&</sup>lt;sup>8</sup> Al's review of the Mental Health Act 2001 includes a recommendation (recommendation 124) that specific criminal offences for the ill treatment, neglect, exploitation and abuse of mental health service users should be introduced into the Act. It also suggests that this matter be considered in the drafting of the Mental Capacity Bill.

- Legislation should provide:
  - that a 16 or 17 year old is presumed to have capacity to make an advance care directive and (ii) that where an advance care directive is being considered by or for a 16 and 17 year old a specific assessment be made by a trained and experienced health care professional of that person's capacity to understand the nature and consequences of the advance care directive<sup>9</sup>;
  - A person who is 14 years of age but less than 16 years of age could, subject to certain requirements, be regarded as capable of giving consent to and refusing health care and medical treatment, where it is established that he or she has the maturity and understanding to appreciate the nature and consequences of the specific health care treatment decision<sup>10</sup>;
  - The Bill should clarify that the recommendations concerning healthcare decision-making by persons under 16 years of age should also be applied in the context of mental health, including decisions in respect of admission and treatment under the Mental Health Act 2001; and
  - In the context of refusal of life sustaining treatment by a person under the age of 18, an application may be made to the High Court to determine the validity of the refusal. The High Court may order treatment that is necessary to save life and where this is in the best interests of the person under 18 years of age. The Commission also recommends that in any such application the person under 18 shall be separately represented.

#### Wards of Court

• The Bill should provide that all wards of court should have their cases automatically reviewed within a reasonable transitional time period. Where appropriate, personal guardians should be appointed to manage the property and affairs of wards of court.

#### Where lack of capacity is temporary

• 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.

## Codes of practice

<sup>&</sup>lt;sup>9</sup>LRC 103-2011, *Report on Children and the Law: Medical Treatment, at 4.08.* 

<sup>&</sup>lt;sup>10</sup> LRC, ibid, Recommendation 4.09. The factors recommended by the LRC in determining whether a person under 16 has the maturity and capacity to consent to and to refuse health care treatment are: (a) whether he or she has sufficient maturity to understand the information relevant to making the specific decision and to appreciate its potential consequences; (b) whether his or her views are stable and a true reflection of his or her core values and beliefs, taking into account his or her physical and mental health and any other factors that affect his or her ability to exercise independent judgement; (c) the nature, purpose and utility of the treatment; (d) the risks and benefits involved in the treatment, and(e) any other specific welfare, protection or public health considerations, in respect of which relevant guidance and protocols such as the 2011 Children First: National Guidelines for the Protection and Welfare of Children (or any equivalent replacement document) must be applied.[para 2.175 and recommendation at para 4.10]

Codes of Practice must be drafted as soon as possible and before the Bill is brought into force, in consultation with all relevant stakeholders, including in particular people with direct experience of mental health problems, their representative organisations and other groups most likely to be affected by their provisions.

### **Speicalist Board/Court**

The Bill should provide for the establishment of a specialist Board as recommended by the Law Reform Commission.

#### **Procedural safeguards**

The Bill should include necessary procedural safeguards in all hearings to adequately protect the rights of persons whose capacity is in question.

#### Marriage and sexual relations

Consideration should be given to bringing the law on marriage and sexual relations in line with the CRPD.

#### **Review of the Act**

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 passing into law.

#### Background: The Convention on the Rights of Persons with Disabilities

International human rights law is constantly evolving and the most recent statement of the rights of persons with disabilities, including persons with mental health problems, is the Convention on the Rights of Persons with Disabilities (CRPD). While Ireland has not yet ratified the CRPD, by signing the Convention it has indicated a clear intention to ratify in the future. The CRPD is seen as marking a 'paradigm shift' in attitudes and approaches to persons with disabilities, which includes persons who experience mental health problems.<sup>11</sup> The social model of disability does not focus on the individual but on the physical and social environment; it recognises that society needs to adapt to allow persons with disabilities to participate in society and enjoy their rights.<sup>12</sup> It recognises that 'disability resides in society, not in the person'.<sup>13</sup> Its provisions on legal capacity are particularly relevant in the current context as the Department of Justice acknowledged in its Regulatory Impact Assessment on the

<sup>&</sup>lt;sup>11</sup> Article 1 of the CRPD defines persons with disabilities as including "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". Although many people with a mental health problem would not consider themselves 'disabled' many would clearly be protected from discrimination under the CRPD. Further, many people with mental health problems were involved in lobbying for the CRPD and this approach to disability which takes into account societal barriers to participation. 12 Sec. 4 1/7

See A Kämpf 'The Disabilities Convention and its Consequences for Mental Health Law in Australia' in B McSherry (ed) International Trends in Mental Health Laws (Law in Context, Special Issue Volume 26 No 2) (The Federation Press, Australia, 2008), 10, p. 22. See also: A Kämpf 'Involuntary Treatment Decisions: Using Negotiated Silence to Facilitate Change?' in B McSherry and P Weller (eds) Rethinking Rights-Based Mental Health Laws (Hart Publishing, Oxford 2010) 129, pp. 133 and 137. <sup>13</sup> United Nations Disabilities – From Exclusion to Equality – Realizing the Rights of Persons with

Disabilities (2007 United Nations, New York) 4.

Scheme 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 Capacity Bill is one of the significant steps to facilitate the ratification process'.<sup>14</sup>

The CRPD recognises people with mental health problems as equal bearers of human rights and fundamental freedoms. Through Article 12 the CRPD requires people with mental health problems be presumed "legally capable of making their own decisions and having their right to self-determination respected on an equal basis with people in general health care settings".<sup>15</sup> By not referring to substitute decision-making, the CRPD implies that there is no disability-specific exception to the right to legal capacity and self-determination.<sup>16</sup> Rather, substitute decision-making is relegated to the realm of last resort, based on the circumstances of each individual case.<sup>17</sup> Moreover, any substitute decision-making mechanisms must respect the will and preferences of the person, including those expressed through advance directives.

There is a view that Article 12 leaves no place for substitute decision-making but rather that supported decision-making must replace traditional mechanisms of substitute decision-making in order to ensure compliance with the CRPD. While respecting this view, AI nonetheless recognises that there are practical difficulties to this especially given that there is an inadequate system of supports in place at present. Especially until such time as sufficient supports are in place, there remains a limited place for substitute decision-making as a last resort. Significant safeguards must be put in place to protect against the abuse of any such provision and progressive steps must be taken towards the achievement of full recognition of enjoyment by persons with mental health problems of legal capacity on an equal basis as others. Elaboration on this point from the Committee on the CRPD in the form of a General Comment on capacity will shed light on this matter.

Article 12(2) of the CRPD expressly states that 'persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life'. The Convention then goes on to clarify and expand upon the measures States Parties are required to take to ensure that persons with disabilities may exercise their capacity to the fullest extent possible, while being safeguarded against abuse.

<sup>&</sup>lt;sup>14</sup> Available at:

http://www.justice.ie/en/JELR/Regulatory%20Impact%20Assessment.doc/Files/Regulatory%20Impact% 20Assessment.doc. <sup>15</sup> Kämpf (2010) p. 141.

<sup>&</sup>lt;sup>16</sup> Kämpf (2010) p. 144.

<sup>&</sup>lt;sup>17</sup> There is a view that Article 12 leaves no place for substitute decision-making but rather that supported decision-making must replace traditional mechanisms of substitute decision-making in order to ensure compliance with the CRPD. (See, for example, International Disability Alliance Submission to the UN Committee on the Rights of Persons with Disabilities on Functional Capacity (June 2010) available at: http://www.internationaldisabilityalliance.org/wp-content/uploads/2010/07/IDA-submission-on-functionalcapacity.doc.) When it ratified the Convention, Canada entered a declaration and reservation in relation to Article 12 CRPD as follows: "Canada recognises that persons with disabilities are presumed to have legal capacity on an equal basis with others in all aspects of their lives. Canada declares its understanding that Article 12 permits supported and substitute decision-making arrangements in appropriate circumstances and in accordance with the law. To the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Canada reserves the right to continue their use in appropriate circumstances and subject to appropriate and effective safeguards. [emphasis added] With respect to Article 12 (4), Canada reserves the right not to subject all such measures to regular review by an independent authority, where such measures are already subject to review or appeal." On the other hand, despite the fact that the U.K. provides for substitute decisionmaking in its laws, the U.K. did not deem it necessary to enter a declaration or reservation in this regard. (source: http://www.un.org/disabilities/default.asp?id=475.)

Article 12(3) requires States to put supports in place to assist persons with disabilities in making decisions for themselves, thereby maximising the autonomy of the person and placing substitute decision-making processes such as guardianship to the realm of last resort. In Article 12(4), the Convention 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 the 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 proportionate, 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'. Such safeguards are to be "proportional to the degree to which such measures affect the person's rights and interests".

## Some specific concerns with the Scheme of the Mental Capacity Act 2008

#### Supported decision-making and substitute decision-making as a last resort

Al welcomes the fact that the Government has acknowledged the need for access to supports where required to exercise capacity in its Regulatory Impact Assessment on the Scheme. This is in line with Article 12 of the CRPD, which places an obligation on States Parties to "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity". However, the Scheme does not fulfil this objective and as proposed, would not adequately meet the requirements in the CRPD to ensure the availability of appropriate supports for decision-making. The CRPD requires that the autonomy of the person is maximised and that substitute decision-making processes such as guardianship are placed to realm of last resort (Article 12(3)). The Government must take steps to establish a framework of supported decision-making for all persons who lack capacity and the role of supported decision-making must be recognised in the Bill. Thus the CRPD "requires a transformation in decision-making practices in mental health".<sup>18</sup>

While the Scheme touches on the concept of supported decision-making under the Guiding Principles and Best Interests Heads, where for example "a person shall not be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success", its main focus is on systems of substitute decision-making. The Scheme does not set out a framework for supported decision-making and accordingly fails to adequately protect the right of the individual to autonomy and self-determination in accordance with Article 12 of the CRPD. A system of supported decision-making would also help to underpin that section of the proposed capacity definition, which refers to a person communicating his or her decision by "any other means" insofar as this could include communicating through the assistance of an advocate or other person. The Bill should be expanded to provide for Regulations or Codes of Practice on supported decision-making.

#### Advocacy service

The appointment of an independent advocate would be one obvious method of providing support in decision-making.<sup>19</sup> Arguably this would prevent or at least minimise subsequent challenges to capacity decisions where these were brought on the grounds that the individual did not have the maximum opportunity to demonstrate that he or she had capacity. It should not be assumed that the National Advocacy

<sup>&</sup>lt;sup>18</sup> Weller (2008) p. 102.

<sup>&</sup>lt;sup>19</sup> Projected cost: a 2004 report costed the provision of a personal advocacy service at around €2m. Goodbody Economic Consultants, Developing an Advocacy Service for People with Disabilities, July 2004,

http://www.citizensinformationboard.ie/publications/social/downloads/SocialAdvocacy\_volume1Report.p df There was a Community and Voluntary Advocacy Service in place between 2005 and 2010, which served about 5.000 clients. The budget for that service was around €3.2 million per annum. Since January 2011, the Citizens Information Board has provided a national advocacy service for people with disabilities with a particular remit for more vulnerable people with disabilities. While the extension of this advocacy service to persons admitted under the Act would entail some additional costs, such costs would not be as high as the establishment of a new advocacy service. The advocacy service could be extended on a phased basis. Initially, the existing service could be put on a statutory footing, e.g. Government will provide an advocacy service. Later, the Act could be amended to ensure that all patients have access to an advocate.

Service for People with Disabilities established under the Citizens Information Act 2007 will necessarily be sufficient for the purposes of the capacity legislation.<sup>20</sup>

It would be preferable to insert provisions similar to sections 35-41 of the Capacity Act 2005 (England and Wales), which require that where there is no one to support the individual in their decision-making (other than someone engaged in providing care or treatment for the person lacking capacity in a professional capacity or for remuneration) and a serious decision has to be made for that person regarding the administration of serious medical treatment or the provision of residential accommodation, an independent capacity advocate (IMCA) must be appointed to them. The function of the IMCA is to ensure the fullest possible participation of the person lacking capacity in the decision-making process. This includes obtaining relevant information, ascertaining the person's wishes, beliefs and values, ascertaining alternative courses of action and, if relevant, obtaining further medical opinions regarding treatment.<sup>21</sup>

The Mental Health (Care and Treatment) (Scotland) Act 2003 provides that individuals with mental health problems have a right of access to an independent advocate and the responsibility is placed on each local authority and each Health Board to secure the availability of independent advocates and to ensure that the individual concerned has access to them (Section 259). "Advocacy services" are defined in the Scottish legislation as "services of support and representation made available for the purpose of enabling the person to whom they are available to have as much control of, or capacity to influence, that person's care and welfare as is, in the circumstances, appropriate". This right to access advocacy applies to all mental health service users, not just to people who are subject to powers under the new Act and it applies whatever the person's need for advocacy and whether or not the person lacks capacity or has communication difficulties.<sup>22</sup> The independent advocate's role empowers people to influence decisions about their care and treatment and enables people to know and understand their rights, review their available options and express their needs and wishes.<sup>23</sup> The Mental Welfare Commission for Scotland also recognises that advocacy plays an important part in helping professionals fulfil their duties under mental health and incapacity law.<sup>2</sup>

#### Independent support persons

The Bill should make provision for independent support persons to be available to assist individuals to make decisions. In the context of the current economic constraints, this could be developed on a gradual basis starting with those individuals who face decisions in relation to their property, financial affairs or medical care and who do not have any individual within their relationship circle to provide such support.

#### Informal supports

Some persons may prefer a more informal type of support and mechanisms that would allow for this also need to be considered. It is also important that safeguards be included to avoid abuse and that the legal obligations of those providing support be clarified in accordance with Article 12(4) of the CRPD.

<sup>&</sup>lt;sup>20</sup> For a discussion of the different approach required in relation to capacity advocates see M Donnelly, 'Legislating for Incapacity: Developing a Human Rights-Based Framework' (2008) 30 Dublin University Law Journal 395 (2008) 434.

<sup>&</sup>lt;sup>21</sup> Section 36(2) Mental Capacity Act 2005 (England and Wales).

<sup>&</sup>lt;sup>22</sup> See: <u>http://www.mwcscot.org.uk/web/FILES/Working with independent advocacy.pdf</u> p.2.

 <sup>&</sup>lt;sup>23</sup> ibid, p.3.
 <sup>24</sup> ibid, p.3.

#### Other jurisdictions

It is Al's understanding that other jurisdictions, in addition to the UK, (and in particular the province of British Columbia in Canada)<sup>25</sup> are making progress towards incorporating supported decision-making into their laws, policy and practice and Al believes that valuable lessons could be learned from experts in those jurisdictions. The Swedish organisation PO-Skåne provides a 'personal ombudsman' service to support people with mental health problems in decision-making. This service primarily offers supported decision-making for people with severe mental health problems and maintains long term relationships with its clients, based on mutual trust and strict confidentiality.<sup>26</sup> The Irish Government should look into ways in which similar services could be made available in Ireland.

**RECOMMENDATIONS:** The Bill should provide for supported decision-making as required by Article 12 CRPD and should establish a framework for supported decision-making.

The Bill should make provision for the establishment of an independent capacity advocacy service and the appointment of capacity advocates to ensure that people with mental health problems receive the support they need to exercise their decision-making capacity in accordance with the requirements of Article 12 CRPD.

The Bill should identify and provide the supports necessary for people with mental health problems to exercise their legal capacity in accordance with Article 12 CRPD<sup>27</sup>.

The Bill should be expanded to provide for Regulations or Codes of Practice on supported decision-making and should ensure that there is consultation with people affected in the preparation of such regulations or code of practice.

<sup>&</sup>lt;sup>25</sup> See From Exclusion to Equality: Realizing the Rights of Persons with Disabilities (Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol) UN/UNOHCHR/IPU Handbook No. 14-2007, page 90, available at

http://www.un.org/disabilities/documents/toolaction/ipuhb.pdf accessed on 20 February 2009. <sup>26</sup> See presentation by Maths Jesperson to the EFC/EDF Symposium on the legal capacity of persons with disabilities in light of the UN Convention on the Rights of Persons with Disabilities, held on 4 June 2009 (available at: http://www.efc.be/ftp/public/Disability/Consortium/lectures%20papers/PO-Sk%C3%A5ne%20and%20supported%20decision-making.doc). <sup>27</sup> With supported decision-making, individuals do not loss their legal capacity light of the light o

<sup>&</sup>lt;sup>27</sup> With supported decision-making, individuals do not lose their legal capacity. Instead, they continue to be recognised as legal persons with rights, responsibilities and powers. This differs from substitute decision-making. Other jurisdictions have taken steps to giving a legislative basis to supported decision-making. In formulating the Capacity Bill, consideration should be given to such other models and to ways in which preferred aspects could be adopted to apply in the Irish context. By way of example, Al points to the following systems:

In British Colombia, the *Representation Agreement Act* came into effect in February 2000. The Act recognises representation agreements which are legal documents for personal planning. In making a representation agreement, an individual authorises personal supporters to assist him or her or to act on his or her behalf for health care, personal care, routine management of financial affairs and legal affairs, if the individual needs assistance due to illness, injury or disability. The individual voluntarily selects and empowers a person or group of persons (supported decision-making network) and can appoint different representatives in relation to different areas of his or her life. Most people appoint a spouse or partner, family member or friend in their Representation Agreement. They can assist, support, act or make decisions on the individual's behalf when he or she is considered not capable of making decisions independently. The Act provides for registration of such individuals or networks to secure their status in the decision-making process. Representation agreements allow for a range of decision-making assistance which do not amount to substitute decision-making.

In Manitoba, the *Vulnerable Persons Living with a Mental Disability Act* provides for an individual to take advantage of a "support network" in providing assistance to make personal care or property decisions. This limits the need to resort to substitute decision-making.

## Advance Directives

Advance Directives provide a method of ascertaining a person's wishes in advance of loss of capacity or during a lucid period and thereby help to limit infringements of their autonomy and bodily integrity by the imposition of treatments to which they would not have consented, had they the capacity to make such decision at the appropriate time.

Given the fact that substitute decision-making can be flawed in that the decisions of the substitute decision-maker may not necessarily reflect the views of the individual,<sup>28</sup> advance directives play a potentially vital role in maximising the circumstances where an individual's personal choice is respected.

Advance directives have a role in ensuring that mental health services adopt a recovery approach, as is advocated by *A Vision for Change* by creating space for the individual service user to have a greater role in charting their personal course to recovery. A recent report on personal experiences of recovery in Ireland found that being listened to and developing relationships of trust are important for the recovery process.<sup>29</sup>

Legal recognition of psychiatric advance directives is in line with the CRPD, which affirms that persons with disabilities (including persons with mental health problems) enjoy legal capacity on an equal basis with others and calls on States Parties to ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person and are free of conflict of interest and undue influence.

Article 17 CRPD expressly recognises the right to respect for physical and mental integrity on an equal basis with others. When read together with Article 12 and Article 25 CRPD (the right to the highest attainable standard of health), the right to respect for physical and mental integrity on the same basis as others implies that a person with a mental health problem should only be subject to treatment without consent if they lack capacity in accordance with Article 12, and the treatment is strictly necessary to protect their health or to prevent harm to them or to others. To accord with Article 12(4) the wishes and feelings of the person deemed to lack capacity should be respected. This would include affording respect to advance statements requesting particular treatment, and recognising the binding nature of valid and applicable advance decisions and lasting powers of attorney refusing treatment for mental health problems.<sup>30</sup>

The European Committee of Ministers adopted a recommendation of the European Committee on Legal Cooperation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity<sup>31</sup> which states in Principle 1:

The test for capacity in the Northwest Territories *Guardianship and Trusteeship Act* recognises the role of assistance. It provides that someone has capacity where they are able 'by himself or herself or with assistance' to understand and appreciate the consequences of relevant information.

 <sup>&</sup>lt;sup>28</sup> Law Reform Commission Report *Bioethics: Advance Care Directives* (LRC 94-2009) p. 12.
 <sup>29</sup> Y Kartalova-O'Doherty and D Tedstone Doherty *Reconnecting with Life: personal experiences of*

recovering from mental health problems in Ireland (HRB Research Series 8, Health Research Board Dublin 2010) pp.31-33.

<sup>&</sup>lt;sup>30</sup> Phil Fennell paper (unpublished) 'What does the Convention on the Rights of Persons with Disabilities mean for Mental Health Laws?' delivered at a seminar co-hosted by Amnesty International Ireland and the Centre for Disability Law and Policy NUIG at the Fitzwilliam Hotel Dublin, 22 November 2010. <sup>31</sup> Recommendation Cm/Rec(2009)11Of The Committee Of Ministers To Member States

On Principles Concerning Continuing Powers Of Attorney And Advance Directives For Incapacity

- 1. States should promote self-determination for capable adults in the event of their future incapacity, by means of continuing powers of attorney and advance directives.
- 2. In accordance with the principles of self-determination and subsidiarity, states should consider giving those methods priority over other measures of protection.32

Recommendation (2009)11 of the Council of Europe provides that continuing powers of attorney and advance directives can apply to health as well as other personal matters and did not make any distinction between the application of advance directives to decisions relating to physical health or mental health.

Taking into account Ireland's international obligations under this Recommendation<sup>33</sup> and the provisions of the CRPD, as well as Irish case law,<sup>34</sup> the Law Reform Commission recommended that an appropriate legislative framework should be enacted for advance care directives as part of the reform of the law on capacity, but excluded advance care directives relating to mental health from the scope of its report.<sup>35</sup> AI recommends that the legislative framework for advance directives proposed by the Law Reform Commission should apply equally to advance directives relating to mental health.

There are compelling reasons for the recognition of advance directives in the context of mental health care. 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.<sup>3</sup>

The WHO has pointed out that the negotiation of a joint crisis plan among patients and mental health teams, including the preparation of advance directives specifying treatment preferences, can result in reduced involuntary admissions in patients with severe mental disorders.<sup>37</sup> Morrissey also argues that by reducing re-admission rates and reducing lengths of hospitalisation, advance directives can have significant economic benefits in mental health care.38

To ensure that advance directives are used effectively in practice. Morrissey points out that they must be "accessible, easily executable and include appropriate support from professionals, family and advocates in the mental health context". 36

A number of jurisdictions provide for advance care directives in relation to mental health in their laws, including Ontario<sup>40</sup>, many states in the US, Scotland<sup>41</sup> and

and Its Explanatory Memorandum as adopted by the Committee of Ministers at the 1073<sup>rd</sup> Meeting of the Ministers' deputies, CDCJ (2009) 34, 9 December 2009. =

Emphasis added.

<sup>&</sup>lt;sup>33</sup> Recommendation (2009)11 was only in draft form at the time of the LRC's report.

<sup>&</sup>lt;sup>34</sup> In particular In Re a Ward of Court (1996).

<sup>&</sup>lt;sup>35</sup> Law Reform Commission Report *Bioethics: Advance Care Directives* (LRC 94-2009) recommendation

<sup>5.02. &</sup>lt;sup>36</sup> F Morrissey 'Advance Directives in Mental Health Care: Hearing the Voice of the Mentally III' (2010) 16(1) Medico-Legal Journal of Ireland (2010) p. 9. <sup>37</sup> WHO Resource Book (2005) p. 56, referring to C Henderson et al 'Effect of joint crisis plans on use of

compulsory treatment in psychiatry: Single blind randomised control trial' (2004) British Medical Journal 329, p.136. <sup>38</sup> Morrissey (2010) p. 9.

<sup>&</sup>lt;sup>39</sup> ibid p. 17.

<sup>&</sup>lt;sup>40</sup> Ontario Substitute Decisions Act 1992, s.46, s.50. This provides for anticipatory treatment refusal, which enables capable patients to bind their future preferences through powers of attorney.

England and Wales<sup>42</sup>, although the extent to which they are legally binding varies between jurisdictions.

The Bamford Report recommends the recognition of advance decisions to refuse treatment and, in addition, advance statements about preferred treatment in the context of mental health care.43

Under the Scheme, statements about preferences for specific types of treatment would have to be taken into account. This is a welcome step. However, a requirement that advance directives be "taken into account" when determining what treatment is in a person's best interests is not sufficient to ensure respect for the person's autonomous wishes and to move away from a system dominated by paternalism and deference to medical expertise.<sup>44</sup> In order to privilege the will and preference of the individual as is required by the CRPD, psychiatric advance directives must be given the same weight and legal validity as advance directives in general medicine.45 It is imperative that the Capacity Bill, when published, goes further than the Scheme and provides a legal framework for advance directives, including those relating to treatment for mental health problems. The Bill should specify that its provisions apply equally to patients under the Mental Health Act.

**RECOMMENDATIONS:** The Capacity Bill should provide a legislative framework for binding advance directives, including advance directives relating to mental health. This should include provision for the appointment of a health care substitute decisionmaker.

The legislative framework should provide that, where a valid advance directive exists, it should prevail in the same way as the wishes of the patient would prevail, if s/he had capacity at the time.

The Bill should clarify that the legislative framework applies equally to patients under the Mental Health Act 2001.

Head 1(g) and Head 3(1)(iii) should expressly state that if a person has expressed prior wishes in relation to a form of treatment, such wishes must be respected and in exceptional cases where it is proposed to depart from a person's prior wishes, approval of the Court of Protection (or other appropriate body) is required. This may require regulations and a Code of Practice to be produced.

## Treatment

#### Informed consent to treatment

Article 17 CRPD expressly recognises the right to respect for physical and mental integrity on an equal basis with others. It does not clarify whether involuntary treatment is ever permissible under the Convention. It is important to remember that, even where a person lacks capacity and cannot exercise his or her autonomy, s/he retains the right to privacy and physical and mental integrity.<sup>46</sup> This is particularly

<sup>&</sup>lt;sup>41</sup> Sections 275 and 276 of The Mental Health (Care and Treatment) (Scotland) Act 2003, s. 275 and 276. provide for the making, withdrawal and effect of Advance Statements. <sup>42</sup> See Mental Capacity Act 2005 and Mental Health Act 2007.

<sup>&</sup>lt;sup>43</sup> Bamford Review para 6.5.

<sup>&</sup>lt;sup>44</sup> P Weller (2010) p. 63.

<sup>&</sup>lt;sup>45</sup> See P Weller (2008) pp. 103 and 105.

<sup>&</sup>lt;sup>46</sup> See judgment of the ECtHR in *Storck v Germany* (2005) 43 EHRR 96 and discussion in M Donnelly (2008) pp. 51-57.

relevant in situations where a person who has been found to lack capacity to make a treatment decision actively resists the administration of treatment. To accord with Article 12(4) the wishes and feelings of the person deemed to lack capacity should be respected. This would include affording respect to advance statements requesting particular treatment, and recognising the binding nature of valid and applicable advance decisions and lasting powers of attorney refusing treatment for a mental health problems.<sup>47</sup>

## Procedural safeguards around treatment

The Bill should introduce safeguards around treatment, including a mechanism for review and oversight of treatment / medication decisions in respect of persons who lack capacity. Head 14 of the Scheme of the Bill provides for decisions on capacity to be subject to review at regular intervals. This provision needs to be extended to cover treatment / medication administered to persons who have been found to lack capacity. The maximum length of interval – 36 months, should be reduced to better protect the individual.

The WHO in its guidance has called for safeguards in mental health laws relating to treatment including that a second, *independent*, accredited mental health practitioner confirms the treatment plan and, preferably, that the treatment plan be sanctioned by an independent authority, which should examine, not only whether the proposed treatment is in the patient's best interests, but also that the patient him/herself does indeed lack the capacity to consent to or refuse the treatment.<sup>48</sup> The treatment should have a therapeutic aim and be likely to entail a real clinical benefit and should not be given for longer than is necessary. In addition, it should be systematically reviewed by the treating clinician and periodically by an independent review body.<sup>49</sup>

Article 6 ECHR (right to a fair trial) provides a right to certain procedural safeguards in the context of determinations of capacity or incapacity and treatment decisions.<sup>50</sup> This includes primarily the right to a "fair and public hearing within a reasonable time by an independent and impartial tribunal established by law" (Article 6 ECHR).<sup>51</sup>

Dr Mary Donnelly points to three main goals that should underpin reviews of treatment decisions, all of which have a basis in the international (and in some cases the national) human rights framework. These goals are:

- to protect individuals against violations of their human rights. This includes the right to be free from inhuman or degrading treatment, and the rights to privacy, bodily integrity and autonomy;
- to ensure the delivery of the most appropriate treatment. This should involve an assessment of whether there are other more appropriate treatment options available and how these could be delivered – it has a medical or therapeutic aspect, but also involves social and psychological factors. This goal is in line with the right to the highest attainable standard of physical and mental health (Article 12 ICESCR and Article 25 CRPD) and the right to rehabilitation (Article 26 CRPD); and

<sup>&</sup>lt;sup>47</sup> Phil Fennell paper (unpublished) 'What does the Convention on the Rights of Persons with Disabilities mean for Mental Health Laws?' delivered at a seminar co-hosted by Amnesty International Ireland and the Centre for Disability Law and Policy NUIG at the Fitzwilliam Hotel Dublin, 22 November 2010. <sup>48</sup> WHO Resource Book (2005) pp.53-54.

<sup>&</sup>lt;sup>49</sup> ibid p. 54.

<sup>&</sup>lt;sup>50</sup> Bartlett, Lewis and Thorold (2007) pp. 134-135.

<sup>&</sup>lt;sup>51</sup> A hearing need not be public where the privacy rights of the one of the parties is at stake, as is often the case in hearings relating to persons with mental health problems where intimate personal information regarding a person's mental health problem is relevant.

to ensure respect for the values of dignity, fairness and participation in the decision-making process. This accords to the right to fair procedures set out in Article 6 ECHR and Article 12(3) (legal capacity) and 13 (access to justice) CRPD. In addition, a process that is based on values of fairness and participation not only has a better chance of delivering the best decision for the patient, but is also leads to higher levels of compliance with treatment and better therapeutic outcomes.<sup>52</sup>

One of the key aims of the treatment must be to restore the patient's capacity and when this occurs involuntary treatment should be stopped.<sup>53</sup> In addition to providing patients and their families with information of their rights and involving them in treatment planning even where they lack capacity, patients and their families or personal representatives must have a right to appeal to a review body, tribunal and/or court against the imposition of involuntary treatment.<sup>54</sup>

Under the Mental Health Act, no safeguards in relation to treatment apply to voluntary patients, even if they lack capacity.<sup>55</sup> This system has been criticised by a number of expert legal commentators<sup>56</sup> and observed by the CPT.<sup>57</sup> In addition, it would appear to be out of step with the requirements of the ECHR which Professor Phil Fennell has summarised as follows:

"The ECtHR emphatically rejected the argument that a compliant incapacitated patient should be treated on the same basis as a capable consenting patient in relation to deprivations of liberty under Article 5 of the European Convention (i.e. that no formal procedure was required where a person did not object to admission). The same principle must apply to interferences with physical integrity. It is too important to be lost simply because a person has given themselves up to the intervention, especially if he or she lacks the capacity to consent to treatment." 58

## **RECOMMENDATIONS:**

The Bill should include oversight mechanisms for treatment and medication decisions for persons who have been found to lack capacity.

There should be a mechanism by which a person who has been found to lack capacity and in respect of whom a decision has been made about treatment can

<sup>&</sup>lt;sup>52</sup> See M Donnelly (2010), 'Review of Treatment Decisions: Legalism, Process and the Protection of Rights' in B McSherry and P Weller (editors) Rethinking Rights-Based Mental Health Laws (Hart Publishing, Oxford 2010) pp. 277-279, citing from a variety of other sources.

<sup>53</sup> ibid. <sup>54</sup> ibid.

<sup>&</sup>lt;sup>55</sup> The only exception being section 69 (seclusion and restraint), which applies to both involuntary and voluntary patients.

See, for example, Donnelly (2008) p. 401.

<sup>&</sup>lt;sup>57</sup> CPT, 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) CPT, Report on Ireland, p. 60.

<sup>&</sup>lt;sup>58</sup> See P Fennell 'Institutionalising the Community: The Codification of Clinical Authority and the Limits of Rights-Based Approaches' in B McSherry and P Weller (2010).

seek an independent review of a decision in respect of that treatment.

Where a person lacks the capacity to consent to treatment, medication should only be administered,<sup>59</sup> when the following safeguards have been fulfilled (which should be expressly set out in the Bill):

- The treatment must be necessary and constitute the least intrusive treatment or therapy appropriate to the patient's health needs; and
- Both of these criteria should be certified by the treating consultant psychiatrist and confirmed by a second independent consultant psychiatrist.

Consideration should be given to ways in which the Bill could adopt a multidisciplinary approach to treatment provisions.

#### Right to apply for tribunal review of proposal to administer medication

Upon an application by a patient (or someone acting on the patient's behalf) who objects to the proposed administration of medication,<sup>60</sup> the court / tribunal should review:

- a. The patient's functional capacity; and
- b. The necessity of the treatment, having regard to the opinion of the treating psychiatrist, the independent psychiatrist and members of the multi disciplinary team and such other evidence or reports as are produced by the patient/his or her representative or requested by the tribunal as it sees fit.

Even where the above criteria are satisfied the court / tribunal shall <u>not</u> permit the administration of the proposed medication to a person if to do so would conflict with either:

- c. A valid advance directive of the person as regards that medication; or
- d. A valid substitute refusal by a personal guardian or a donee of an enduring power of attorney or other substitute decision-maker duly appointed under the capacity legislation.

# Automatic periodic reviews of ongoing administration of medication by tribunals

In addition, the court / tribunal should be required automatically to review the longterm administration of medication at set intervals (the three-month period foreseen by the existing section 60 Mental Health Act could be used here). Such review should also cover both (i) the capacity of the patient to consent to or refuse treatment (and whether the patient has given informed consent, where relevant) and (ii) the necessity and appropriateness of the treatment following the same format as a review of medication requested by a patient.

#### Other provisions relating to the administration of medication

There should be a right to appeal (exercisable either by the patient, or in some cases a representative or next of kin) to the Circuit Court against any decision by the specialist court / tribunal to allow a programme of medication to be administered to a

 <sup>&</sup>lt;sup>59</sup> As regards the assessment of capacity, an independent assessment should take place with the involvement of the multi-disciplinary care team, where possible.
 <sup>60</sup> This provision would apply to a patient who has been found to lack capacity and for whom medication

<sup>&</sup>lt;sup>50</sup> This provision would apply to a patient who has been found to lack capacity and for whom medication has been recommended by his/her treating consulting psychiatrist and a second independent psychiatrist.

person who lacks capacity.

The Bill should state that, for the avoidance of doubt, if a person regains capacity at any stage, the programme of medication must be discontinued unless the person gives his or her free and informed consent to its continuation.

## **Best interests**

Significant difficulties have arisen in relation to the application of the 'best interests principle' as the principal consideration in the 2001 Mental Health Act because a paternalistic approach tends to have been adopted by the courts in interpreting the principle. Currently, the 'best interests' principle is used in the legal system in relation to decisions concerning children who, unlike adults with mental health problems or other disabilities, are presumed to lack legal capacity. There are therefore negative connotations to the term 'best interests' both in the application of the law and the approach that guides the law.

Al welcomes the provisions in Head 3 of the Scheme which require that the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him or her when he or she had capacity) be considered insofar as they are reasonably ascertainable. However, it is our view that this provision does not go far enough to promote the autonomy of the person and there are dangers associated with a narrow interpretation of best interests. This is also relevant to the need to establish a system for the recognition of advance directives.

There is a difficulty in balancing the "best interests" of the person in question with a model of advocacy that empowers people with disabilities.<sup>61</sup> While the CRPD does not directly address the conflict between 'best interests' and empowerment, the focus of article 12 is clearly on personal autonomy and article 12(2) expressly addresses the right of people with disabilities to enjoy full legal capacity on an equal basis with others. The Preamble of the Convention also states that 'Persons with disabilities should have the opportunity to be actively involved in decision-making processes...including those directly concerning them'.

The Bill should adopt a more appropriate and useful phrase than 'best interests' that promotes the will and wishes of the individual and is in keeping with the CRPD's focus on the autonomy of the individual. Al recommends using a phrase such as 'will and wishes' instead of 'best interests'. In addition, the Bill should provide for relevant factors and circumstances which inform consideration by a third party of an individual's 'will and wishes'. The factors set out in Head 3 of the Bill should be retained and improved. Factors, such as respect for personal autonomy, support for autonomous decision making, and promotion of choice and empowerment should be taken into account to protect against the potential for subjective views of professionals or advocates to influence the decision or course of action being taken. Factors should also include taking a course of action which is least restrictive of a person's freedom and autonomy.62

<sup>&</sup>lt;sup>61</sup> Flynn, E., "A Socio-Legal Analysis of Advocacy for People with Disabilities – Competing Concepts of 'Best Interests' and Empowerment in Legislation and Policy on Statutory Advocacy Services" (2010) 32(1) *Journal of Social Welfare and Family Law.* <sup>62</sup> *Ibid*, p.33

The issues to be considered in relation to any 'best interest' determination should include taking a course of action which is least restrictive of a person's freedom and autonomy. Other factors, such as respect for personal autonomy, support for autonomous decision making, and promotion of choice and empowerment should be taken into account to protect against the potential for subjective views of professionals or advocates to influence the decision or course of action being taken.

The Bill should adopt a more appropriate and useful phrase which takes the above into account. Al recommends using a phrase other than 'best interests' or the phrase 'will and wishes' and providing for relevant factors and circumstances which inform consideration by a third party of an individual's 'will and wishes'.

The CRPD clearly calls for an autonomy based approach in its General Principles (Article 3), in its provisions relating to legal capacity (Article 12) and in its reiteration of the right to health (Article 25), which obliges States to:

"[r]equire health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, *inter alia*, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care."

## **RECOMMENDATION:**

The Bill should delete the phrase 'best interests' and replace it with, for instance, the 'will and wishes' of the individual. The Bill should retain and improve the factors currently set out in Head 3 of the Scheme for consideration in determining the individual's 'will and wishes'. These factors must promote the autonomy and self-determination of the individual and each individual's potential.

#### Interplay between the Scheme and the Mental Health Act 2001

The issue of capacity is hugely relevant in the context of the Mental Health Act 2001, which deals with the involuntary admission, detention and treatment of persons with mental health difficulties. Firstly, the definition of 'mental disorder' in the 2001 Act includes a reference to impaired judgement of the person concerned. This would appear to be a reference to incapacity. Secondly, Part 4 of the Mental Health Act 2001 (Consent to Treatment) refers to capacity<sup>63</sup> in the definition of 'consent' for the purposes of that section. However, the Scheme is silent on how its provisions will operate vis-à-vis the Mental Health Act 2001.

Empirical studies have demonstrated that a sizeable majority of people with mental health difficulties, including persons diagnosed as having schizophrenia and clinical depression, are no less competent to make decisions regarding medical treatment than the general public.<sup>64</sup> Thus lack of capacity should not be assumed in individuals with a psychiatric diagnosis, even those undergoing inpatient care. This point is reinforced by the CRPD, which requires as a starting point, a presumption of capacity. The recent ECHR case of *Shtukaturov v Russia* also confirmed that the

<sup>&</sup>lt;sup>63</sup> It uses the phrase 'capable of consenting' rather than capacity.

<sup>&</sup>lt;sup>64</sup> T Grisso and P Appelbaum 'The MacArthur Treatment Competence Study III: Abilities of Patients to Consent to Psychiatric and Medical Treatments' (1995) 19(2) Law and Human Behaviour 149, cited in P Bartlett, O Lewis and O Thorold *Mental Disability and the European Convention on Human Rights* (Martinus Nijhoff Publishers, Leiden 2007) 152.

existence of a mental disorder, even a serious one, cannot be the sole reason to justify full incapacitation.  $^{\rm 65}$ 

Al welcomes the fact that the Scheme adopts a functional and time specific approach to capacity and contains a presumption of capacity<sup>66</sup>. However, Al is concerned that the Scheme does not address the important interplay between its provisions and those of the Mental Health Act 2001.

It is no longer acceptable for the State to allow persons diagnosed with a mental disorder to be treated differently than others, nor to allow their rights to be more readily interfered with. By emphasising the principles of non-discrimination and equality before the law, the CRPD requires the State to justify on objective grounds any interference with the rights of persons with disabilities, including persons with mental health problems.

Article 12(2) of the CRPD requires States Parties to recognise "that persons with disabilities [including persons who experience mental health problems] enjoy legal capacity *on an equal basis with others in all aspects of life*".<sup>67</sup> Accordingly, if Ireland is to comply with Article 12 of the CRPD, it is crucial that the presumption of capacity, and the time-specific and issue-specific functional approach to capacity and the guiding principles and definition of 'best interests' set out in the Scheme (which seek to promote the autonomy of the individual to the greatest extent possible) apply equally to all persons, including those involuntarily admitted to approved centres under the provisions of the 2001 Act.

In addition, in order to maximise the autonomy of persons disabled by a mental health problem, the role of substitute decision-makers such as personal guardians or donees of an Enduring Power of Attorney must be recognised by the Mental Health Act 2001. It seems from a review of the mental health laws in civil law jurisdictions in Europe that they give a greater role to substitute decision-makers (usually guardians) in decisions about treatment where a person is found to lack capacity.<sup>68</sup> Respecting the past and present wishes of the person as to who should make important decisions on their behalf where they lack capacity is an important means by which the law can maximise the autonomy of the individual.

<sup>&</sup>lt;sup>65</sup> Case no. 44009/05 27 March 2008. This case involved a man with a history of mental health problems whose mother had applied for him to be subject to guardianship without his knowing and had then had him admitted to psychiatric institution. The Court confirmed that the existence of a mental disorder, even a serious one, cannot be the sole reason to justify full incapacitation – the 'mental disorder' must be 'of a kind or degree' warranting such a measure. The Court went on to refer to the principles formulated in Recommendation No. R (99)4 of the Committee of Ministers of the Council of Europe, which while they do not have the force of law, define a common European standard in this context. Contrary to these principles, the Russian legislation did not provide for a 'tailor-made response' and as a result the applicant's rights were limited more than strictly necessary.

<sup>&</sup>lt;sup>ob</sup> There is a view that the CRPD requires an irrebuttable assumption of capacity in law. If this is the case, there would be no place in law for any form of substitute decision-making. Consideration should be given to this view and to any General Comments from the Committee that interprets the CRPD in this regard. Bach and Kerzner state that the CRPD provides for an equal right to legal capacity: "No longer should legal capacity legislation identify a 'presumption of capacity,' for which procedures are outlined about how to remove legal capacity when a person is found without the requisite [mental] capacity. Rather, legal capacity legislation should incorporate an 'assumption' of legal capacity as articulated in the principle above." M. Bach and L. Kerzner ' A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' Prepared for the Law Reform Commission of Ontario, October 2010, p.95 (http://www.lco-cdo.org/disabilities/bach-kerzner.pdf)

<sup>&</sup>lt;sup>67</sup> Emphasis added.

<sup>&</sup>lt;sup>68</sup> Dawson and Kämpf 'Incapacity Principles in Mental Health Laws in Europe' (2006) 12(3) Psychology, Public Policy and Law 310-331.

**RECOMMENDATION:** The Bill must address the interplay between its provisions and those of the Mental Health Act 2001. In order to comply with Article 12 CRPD the Mental Health Act 2001 must be amended to delete the 'best interests' as a guiding principle of the Act and to ensure that the will and wishes, autonomy and selfdetermination of the individual are respected. The Act must be amended to provide for supported decision-making.

In order to maximise the autonomy of persons with mental health problems, Part 4 of the Mental Health Act (consent to treatment) should be amended to recognise the role of supported decision-makers and advance directives through which an individual can choose to appoint a substitute decision-maker.

#### **Deprivation of liberty provisions**

The European Court of Human Rights has stressed that the situation of vulnerability and powerlessness of persons detained in mental health institutions requires special vigilance on the part of the authorities.<sup>69</sup> This requirement for 'special vigilance' applies both to persons detained under the formal provisions of the Mental Health Act 2001 and those 'voluntary' patients who are in fact detained.

It is possible that a substantial number of people who are 'voluntarily' admitted to approved centres (within the meaning of the Mental Health Act 2001) and other inpatient/residential care settings are *de facto* detained, that is deprived of their liberty. The reality for these 'voluntary' patients who lack the capacity to consent to their admission is that if they attempted to leave the hospital or care setting, they would be prevented from doing so. However because, for whatever reason, they are not formally detained under the Mental Health Act 2001, they do not have the benefit of safeguards such as automatic reviews of their detention by Mental Health Tribunals under that Act. It seems that while they do not have the capacity to consent to admission, such persons are often admitted as voluntary patients because they do not object to admission (so called 'Bournewood' cases or compliant incapacitated patients).<sup>70</sup>

A fundamental issue in relation to the deprivation of liberty of "incapacitated but compliant" patients became very apparent in the case of *EH v St. Vincent's Hospital and Others.*<sup>71</sup> This case concerned a woman who lacked capacity and who was detained as an 'involuntary patient' under the Mental Health Act. An order to extend her detention was not renewed by the relevant mental health tribunal for technical reasons and, the applicant's status reverted to 'voluntary'. On 22 December the woman attempted to leave the hospital and was prevented from doing so as the powers to prevent a voluntary patient from leaving an approved centre were invoked. She was then detained as an 'involuntary patient' on foot of successive renewal orders.

In *habeas corpus* proceedings in the High Court and Supreme Court, the applicant's lawyers argued that, because the applicant lacked capacity she could not have been a 'voluntary patient' during the period from 10 to 22 December. They submitted that

<sup>&</sup>lt;sup>69</sup> See Herczegfalvy v Austria (1992) 15 E.H.R.R. 437.

<sup>&</sup>lt;sup>70</sup> See G Richardson 'Coercion and Human Rights: A European Perspective' (2008) 17(3) Journal of Mental Health 245, 247.

<sup>&</sup>lt;sup>/1</sup> [2009] 2 I.L.R.M. 149.

the term 'voluntary patient' should be given a narrow and literal interpretation in accordance with the applicant's rights under the ECHR.

The applicant's lawyers drew upon the ECtHR judgment in *HL v the United Kingdom* (the "Bournewood Gap" case).<sup>72</sup> That case involved a patient with autism who lacked capacity to consent to admission to hospital but was treated as an informal patient rather than being formally detained under the Mental Health Act 1983 (England and Wales). He was found by the ECtHR to have been *de facto* deprived of his liberty as he was in the "effective and unqualified control" of his health care professionals. The following statement sums up the Court's position:

"The Court reiterates that the right to liberty is too important in a democratic society for a person to lose the benefit of Convention protection for the single reason that he may have given himself up to be taken into detention (see *De Wilde, Ooms and Versyp v. Belgium*, judgment of 18 June 1971, Series A no. 12, p. 36, §§ 64-65), especially when it is not disputed that that person is legally incapable of consenting to, or disagreeing with, the proposed action."<sup>73</sup>

The ECtHR held that the processes under the English common law were not sufficient and this absence of procedural safeguards failed to protect against arbitrary deprivations of liberty on grounds of necessity and amounted to a violation of Article 5(1). The ECtHR also found the UK in breach of Article 5(4) as the applicant did not have available to him a procedure which satisfied the requirements of that Article; thus a more formal process for reviewing the detention of such patients was required. This has led to the recent introduction of the Deprivation of Liberty Safeguards in the England and Wales in April 2009.<sup>74</sup>

However, in the case of EH v St. Vincent's Hospital and Others, the Irish Supreme Court, based on the view that the Act was paternalistic in intent, refused the various reliefs sought and dismissed the appeal. In doing so, the Court made the following statement in relation to the meaning of "voluntary patient" under the Act.

"The terminology adopted in s.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 or renewal order. This definition cannot be given an interpretation which is *contra legem*."<sup>75</sup>

The Irish Human Rights Commission has expressed concern at this definition, "where neither capacity nor consent are relevant factors to determining the status of a patient" and has stated that it has implications for Ireland's compliance with its international human rights law obligations. In particular, the Commission is

 <sup>&</sup>lt;sup>72</sup> Application No. 45508/99 judgment of the European Court of Human Rights, 5 October 2004.
 <sup>73</sup> ibid, para 90.

<sup>&</sup>lt;sup>75</sup> [2009] 2 I.L.R.M. 149.

concerned that the apparent absence of any procedural protections afforded to incapacitated compliant patients and wards of court under the Mental Health Act may not conform with international human rights standards including in particular the requirements of Article 5 ECHR vis-à-vis compliant incapacitated patients as set out by the ECtHR in *HL v United Kingdom*.<sup>"76</sup>

Accordingly, the Commission made the following recommendations:

- That the Government take steps to remedy the current lack of protection from deprivation of liberty afforded to incapacitated compliant patients and wards of court in the context of an admission to an approved centre within the terms of the [Mental Health] Act. Specifically, the definition of a voluntary patient in the Act should be amended to include only those persons who have the capacity to make such a decision and who have genuinely consented to their admission to a psychiatric institution and continue to consent. Ideally, such amendment should occur at the same time as the enactment of a comprehensive Capacity Bill.
- In the event that there is any doubt whether a person has capacity to consent or object to their admission to an approved centre, the question of the person's capacity should be referred for determination pursuant to appropriate capacity legislation, under an expedited procedure if necessary.
- That care be taken in assessing one's capacity to ensure that the presumption of one's capacity (rather than incapacity) occurs and that unnecessary categorisations of "deprivation of liberty" and referrals to Mental Health Tribunals are avoided where possible.
- That all persons who have been declared to lack legal capacity to make medical decisions, and are considered to be in need of psychiatric detention, should be admitted to approved centres in a similar manner to involuntary patients under the Act with all the ensuing safeguards necessary to ensure their lawful detention under the Constitution and Article 5 of the ECHR.

Insofar as AI is aware, there is no data on the numbers of so-called compliant incapacitated patients within the Irish mental health services. A study of patients admitted to three psychiatric wards in inner London between February 2006 and June 2007 gives some idea of the number of people who fall might into this category.<sup>77</sup> Of a total of 200 patients interviewed, 120 were informal and 80 were formal. Of the informal patients, 47 were found to lack capacity (that is approximately 39 per cent of the informal patients surveyed). These statistics suggest that there could be a high number of compliant incapacitated patients in the mental health services in Ireland whose rights are not being adequately protected.

If Ireland is to comply with the requirements of Article 5 ECHR as applied by the ECtHR in *HL v the United Kingdom*, it is imperative that the definition of 'voluntary patient' be amended in line with the recommendations of the Irish Human Rights Commission set out above. However, the wider issue of persons who are *de facto* detained in places other than approved centres (for example in care homes for older people or residential settings for people with intellectual disabilities) must also be addressed in the Bill. This was not adequately addressed in the Scheme. The Bill also needs to stipulate how such deprivation of liberty safeguards will interplay with the provisions of the Mental Health Act.

<sup>&</sup>lt;sup>76</sup> IHRC (2010) p. 33.

<sup>&</sup>lt;sup>77</sup> G Richardson 'Mental Capacity at the Margin: The Interface Between Two Acts' (2010) 18(56) Medical Law Review 1, p. 3

Accordingly, it is clear that the Bill needs to provide safeguards for persons who lack capacity, but while they do not fall within the criteria for detention under the Mental Health Act 2001, are *de facto* deprived of their liberty. These provisions must comply with the European Convention on Human Rights<sup>78</sup> (ECHR) and other applicable international human rights law, including in particular the CRPD. Accordingly they must ensure that any such deprivation of liberty is not arbitrary, is proportionate to its legitimate aim, is for the shortest period necessary and is reviewed periodically by an independent body.

**RECOMMENDATIONS:** The definition of 'voluntary patient' under the Mental Health Act 2001 should be amended to include only those persons who have the capacity to make such a decision and who have genuinely consented to their admission to an approved centre and continue to consent.

The Capacity Bill should include provisions to protect against any arbitrary deprivation of liberty of a person who lacks capacity but is de facto detained in inpatient or residential settings in accordance with the requirements of Article 5 ECHR as interpreted by the ECtHR in HL v the United Kingdom. In doing so the Capacity Bill should also clarify the interplay between its deprivation of liberty provisions and those of the Mental Health Act 2001.

## Informal decision-making

While AI acknowledges the need for provisions allowing for informal decision-making to reflect the day-to-day reality for carers, AI has serious concerns about the scope of the informal decision-making provisions as currently set out in Head 16 of the Scheme. While the Scheme assigns jurisdiction to the Circuit and High Courts<sup>79</sup> to decide questions of capacity (Head 5), it does not require that the Court assess a person's capacity in all circumstances. Thus it seems that many assessments of capacity and decision-making' provisions. Under those provisions a person involved in the care and treatment of another person whose decision-making capacity is in doubt is effectively tasked with assessing capacity and deciding the best course of action, except in the limited circumstances set out in Head 17 (Heads 16 and 17).<sup>80</sup>

While the Scheme requires informal decision-makers to act in accordance with the Guiding Principles and in the person's best interests (as per Head 3 of the Scheme), it appears that the Scheme leaves it largely to codes of practice to determine the criteria for invoking formal court assessments of capacity and substitute decision-making procedures, including in the context of decisions regarding medical treatment.

Recommendation 99(4) of the Council of Europe foresees informal procedures being used *only* in the case of 'minor or routine' decisions relating to health or personal

<sup>&</sup>lt;sup>78</sup> Convention for the Protection of Human Rights and Fundamental Freedoms, 4 November 1950 CETS 005.

<sup>&</sup>lt;sup>79</sup> to be known as the Circuit and High Courts of Care and Protection.

<sup>&</sup>lt;sup>80</sup> Head 17 provides that an informal decision-maker is not authorised to do any act which (a) would require a court order or (b) would conflict with a decision of a donee of an EPA or a personal guardian. Major healthcare decisions concerning non-therapeutic sterilisation, withdrawal of artificial life-sustaining treatment and organ donation are confined to the jurisdiction of the High Court under Head 21. However, it is not clear to what extent informal capacity assessments and substitute decision-making are otherwise regulated by the Scheme.

welfare.<sup>81</sup> If the scope of the informal decision-making provisions of the Bill is not clearly limited to minor or routine matters, there is a real risk that the Bill will not comply with this Council of Europe Recommendation. Furthermore this may lead to an unacceptable situation whereby only decisions relating to property and financial affairs of the incapacitated person will require an independent and thorough hearing as to the person's capacity and who should be tasked with making decisions on their behalf, whereas important decisions regarding such matters as where the person should live or what treatment they should receive would be left to be dealt with under informal mechanisms, which by their nature are less likely to safeguard the rights and interests of the individual.

Al acknowledges that the Bill must seek to strike a balance between the need to protect the rights and interests of persons who lack capacity and the need to avoid over-formalising the capacity process to the extent that it becomes unworkable. However, Al is strongly of the view that some situations, including in particular significant healthcare decisions, require a greater degree of control and supervision than is contemplated by the Scheme.<sup>82</sup>

It is instructive at this juncture to re-iterate the requirements of Article 12(4) CRPD, particularly with reference to protection from abuse, which provides:

"States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective *safeguards* to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity *respect the rights, will and preferences of the person, are free of conflict of interest and undue influence,* are *proportional and tailored to the person's circumstances,* apply for the shortest time possible and are *subject to regular review by a competent, independent and impartial authority or judicial body.* The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests."<sup>83</sup>

It is difficult to see how broad informal decision-making powers could comply with the requirements of Article 12(4). In particular, such informal mechanisms could involve conflicts of interest (where the treating clinician is essentially wearing two hats, that of the treating clinician and that of the substitute decision-maker). While the Office of the Public Guardian could and should be given an express function to oversee the exercise of informal decision-making under the Bill, it is difficult to envisage how broad informal decision-making powers could be subjected to adequate review as required by the CRPD.

It is critical that the Bill restricts the use of informal procedures to 'minor or routine' matters relating to health or personal welfare and if there is any question as to whether a particular decision is minor or not, such matter should be referred to the relevant Court of Care and Protection or specialist Board, as appropriate.

The Public Guardian's powers should be extended to include some form of oversight and supervision of the exercise of informal decision-making powers. In our view, the

<sup>&</sup>lt;sup>81</sup> Recommendation No. R(99) 4, adopted by the Committee of Ministers on 23 February 1999, Principle 2(8). Emphasis added.

<sup>&</sup>lt;sup>82</sup> See also M Donnelly 'Legislating for Incapacity: Developing a Human Rights-Based Framework' (2008) 30 Dublin University Law Journal 395, p. 426.

<sup>&</sup>lt;sup>83</sup> Emphasis added.

Office of the Public Guardian should also be given a similar function in respect of persons providing support in decision-making. Al queries whether the reporting obligations which apply to Personal Guardians and Donees of Enduring Powers of Attorney under the Scheme are adequate and would ask the Department to clarify these obligations and to consider whether more detailed regulations are required in this regard.

A specific procedure for complaints to be made to the Public Guardian concerning the exercise of substitute or supported decision-making roles should also be established under the Bill.

Furthermore, the Scheme is quite unclear as to the role of special and general visitors, which needs to be clearly defined in the Bill.

**RECOMMENDATIONS:** The Bill must restrict the use of informal decision-making provisions to 'minor or routine' matters relating to health or personal welfare and it there is any question as to whether a particular decision is minor or not, such matter should be referred to the relevant Court of Care and Protection or Guardianship Board, as appropriate.

Codes of Practice on informal decision-making need to be drawn up in consultation with rights holders and they need to be in place before the Bill comes into force.

The Office of the Public Guardian should be given an express function to oversee the exercise of informal decision-making under the Bill.

Medical professionals and others involved in care should be provided with training on the limits of informal decision-making powers.

The role of family members should be clarified.

The powers of the Office of the Public Guardian should be extended to include some form of oversight and supervision of the exercise of informal decision-making powers. A specific complaints procedure should also be set out in the Bill and the role of special and general visitors should be clarified.

#### Who should assess capacity?

Where an application has been made to the Court of Care and Protection, it will make a declaration as to whether a person lacks capacity to make a specified decision or decisions. In carrying out such assessments of capacity, the Court may 'request expert reports for the court by such experts as it considers necessary, whether medical (including reports concerning cognitive ability), social and health care (including care in the community) or financial (including reports on valuation of property)' (Head 13). Thus, where the Court is tasked with assessing capacity, a multidisciplinary approach is provided for.

However, in situations where no application has been made to the Court of Care and Protection, the Scheme does not specify who should be tasked with assessing capacity.

Al's Research Report on Capacity shows that participants had a strong preference for a neutral party to conduct capacity assessments. Indeed four participants expressed concern that the power inequality between patients and mental health professionals would impact on the assessment of a person's capacity.

There is also some acknowledgement in the literature of potential bias by mental health professionals in carrying out capacity assessments. Among a small group of service users and carers, Manthorpe, et al. found that there was concern that professionals would not be able to live up to the ideal of a presumption of capacity.<sup>84</sup> In their study of the reliability of the MacArthur Assessment Tool for Competence to Treatment, Cairns, et al. acknowledged that there was probably a bias towards finding that the patient had capacity where the patient agreed with treatment.<sup>85</sup> Okai's systematic review of capacity in inpatients with mental health problems found a higher likelihood that clinicians would find patients have capacity and speculated that this was due to clinicians presuming capacity where the patient agrees with treatment.<sup>86</sup> Significantly, US law generally requires that the capacity assessment must be carried out by someone other than the patient's own doctor.<sup>87</sup> Furthermore, Dawson and Kämpf make the point that the move to the functional approach (and the move away from a status approach that was dependent on the existence of 'mental disorder') potentially means that psychologists as well as psychiatrists will have a role in assessments of capacity.88

While the views of those who know the individual concerned well, including the individual's treating clinician, can assist in producing an accurate assessment, there is a need to ensure the independence of the capacity assessment process. The need for such an approach is reinforced by the requirement of Article 12(4) CRPD that measures relating to the exercise of legal capacity be free of conflict of interest.

In order to address these concerns AI would urge the Department to amend the Scheme so as to ensure that the person who carries out the capacity assessment in the context of decisions relating to medical treatment is independent from the treating clinician, while allowing for consultation between the assessor and the treating clinician. This approach should be followed save in emergency circumstances where life-saving treatment is required. This should apply to any informal capacity assessments under the Bill where the decision concerned relates to medical treatment, and to capacity assessments under the Mental Health Act 2001. Also, the multi-disciplinary approach set out in the Scheme in relation to formal assessments of capacity by the Court of Care and Protection should apply to all capacity assessments in relation to medical treatment.

**RECOMMENDATIONS**: Capacity assessments in the context of decisions relating to medical treatment should be independent from the treating clinician, while allowing for consultation between the assessor(s) and the treating clinician.

<sup>50</sup> D Okai, G Owen, H McGuire, S Singh, R Churchill and M Hotopf (2007) 'Mental Capacity in <u>P</u>sychiatric Patients: Systematic Review', *British Journal of Psychiatry* 191:291-7.

<sup>&</sup>lt;sup>84</sup> Manthorpe, JJ Rapaport and N Stanley (2008) 'Expertise and Experience: People with Experiences of Using Services and Carers' Views of the Mental Capacity Act 2005', *British Journal of Social Work* 1-17.
<sup>85</sup> R Cairns, C. Maddock, A. Buchanan, A.S. David, P. Hayward, G. Richardson, G. Szmukler and M.
Heter (2005) 'Beliability of Montel Capacity Accessing in Payability in Payability of Montel Capacity Accessing Contents in Payability and Accessing Contents in Payability and Accessing Contents in Payability and Capacity Accessing Conten

Hotopf (2005) 'Reliability of Mental Capacity Assessments in Psychiatric In-Patients', *British Journal of Psychiatry* 187:372-378. <sup>86</sup> D Okai, G Owen, H McGuire, S Singh, R Churchill and M Hotopf (2007) 'Mental Capacity in

<sup>&</sup>lt;sup>87</sup> M Donnelly 'Treatment for Mental Disorder: The Mental Health Act 2001, Consent and the Role of Rights' (2005) 40 Irish Jurist 220, 233.

<sup>&</sup>lt;sup>88</sup> J Dawson and A Kämpf 'Incapacity Principles in Mental Health Laws in Europe' (2006) 12(3) Psychology, Public Policy and Law 326.

Insofar as possible, a multi-disciplinary approach should be adopted to all assessments of capacity under the Bill.

## Title of Bill

The title, 'Scheme of the Mental Capacity Bill' or 'the Mental Capacity Act', when enacted, could contribute to prejudicial attitudes and discrimination met by persons who will be subject to the Act's provisions. Consideration should be given to changing the title of the Bill to 'Legal Capacity Bill' to better reflect what the object and purpose of the Bill and in order to avoid further entrenchment of prejudicial attitudes.

## **RECOMMENDATION**: The title of the Bill should be changed to 'Legal Capacity Bill'.

## <u>Training</u>

There is no doubt that assessments of capacity are difficult and require specific skills and training. Grisso and Appelbaum describe capacity assessment as 'one of the most challenging tasks facing clinicians today'.<sup>89</sup> Without a doubt it requires specific training, in particular to ensure that in practice assessments adopt a functional approach – which is quite a change from the status or outcome approaches often adopted to date.

**RECOMMENDATION:** Training should be provided to all persons involved in capacity assessments so that the functional approach to capacity is applied in practice in accordance with the guiding principles and best interests principles set out in the Scheme.

#### <u>Use of force/restraint – the role of rights</u>

While it is undoubtedly positive that Article 12 of the CRPD and accordingly the Scheme has created a focus on the autonomy rights of the individual, it is important that sight is not lost of the importance of the other rights of persons with disabilities, which continue to exist even in cases where they lack the capacity to make certain decisions about their lives.<sup>90</sup>

The rights to dignity, privacy and bodily integrity are central to the CRPD and are reinforced by the provisions of the MI Principles and Council of Europe Recommendation 2004(10).<sup>91</sup> In the case of *Storck v Germany*<sup>92</sup> the European Court held that Article 8 (right to privacy) was breached by the administration of medication

 <sup>&</sup>lt;sup>89</sup> T Grisso and P Appelbaum Assessing competence to consent to treatment (Oxford University Press NewYork 1998) v. cited in Dawson and Kämpf 326.
 <sup>90</sup> So, for example, the European Court of Human Rights has found that a person does not have to be

<sup>&</sup>lt;sup>90</sup> So, for example, the European Court of Human Rights has found that a person does not have to be legally capable to feel degraded within the meaning of Article 3 ECHR (*Herczegfalvy v Austria* (1992) 15 E.H.R.R. 437). Similarly in *Glass v UK* ((2004) 39 EHRR 15), the Court found that the right of physical integrity (Article 8 ECHR) is not restricted to people with capacity.

<sup>&</sup>lt;sup>91</sup> CRPD: Article 3 (General Principles), Article 15 (prohibition on torture or to inhuman or degrading treatment), Article 17 (respect for physical and mental integrity on an equal basis with others) and Article 22 (right to respect for privacy). MI Principles 1(2), 1(3), 13(1)(b), 14(1)(a), 18(7),. Council of Europe Recommendation 2004(10) Articles 1(1), 11(2)(i), 32(3), 37(3)(1).

<sup>&</sup>lt;sup>92</sup> European Court of Human Rights Application No 61603/00, judgment 16 June 2005.

to the applicant against her will while she was detained in a private psychiatric hospital. Whether or not the patient had capacity was not central to the court's decision. Rather its finding made clear that treatment cannot be imposed against a person's will simply because they lack capacity.<sup>93</sup> This means that the use of restraint to administer treatment to a patient who, although s/he lacks capacity to make the treatment decision, nevertheless actively resists the treatment, must be seriously guestioned.

Thus, safeguards must be in place to ensure that the person's rights to dignity, privacy and personal integrity are fully protected.

Al welcomes the provision in the Guiding Principles of the Scheme that 'due regard must be given to the need to respect the right of a person to his or her dignity, bodily integrity, privacy and autonomy' and the statement that 'regard must be taken of the views of the person's past and present wishes ...'. Al also acknowledges the provisions of Heads 11(7) and 48(5) (applicable to personal guardians and donees of enduring powers of attorney respectively) which place restrictions on the use of restraint. Al notes that where these provisions state that "the act is a proportionate response to the likelihood of the donor suffering harm or the seriousness of that harm" the word 'or' should be replaced with 'and'. Furthermore these provisions should also be inserted into the restrictions on informal decision-makers, as is the case under section 6 of the Mental Capacity Act 2005 (England and Wales). These provisions should also be extended to expressly state that mechanical restraint may never be used. As regards physical restraint, the Bill should reflect the standards set out in the Mental Health Commission Code of Practice on the Use of Physical Restraint. This should include inter alia that physical restraint should only be used for as long as necessary to prevent immediate and serious harm to the person. In addition the Bill should expressly state that physical restraint should only be used as a last resort where all less intrusive measures have been exhausted.

**RECOMMENDATIONS:** The provisions on restraint (Head 11(7) and 48(5)) should also apply to informal decision-makers and carers and the word 'or' should be replaced with 'and' at the end of subparagraph (iii) in these provisions. These provisions should also be extended to expressly state that mechanical restraint may never be used.

As regards physical restraint, the Bill should reflect the standards set out in the Mental Health Commission Code of Practice on the Use of Physical Restraint. This should include inter alia that physical restraint should only be used for as long as necessary to prevent immediate and serious harm to the person. In addition the Bill should expressly state that physical restraint should only be used where all less intrusive measures have been exhausted.

The Bill should emphasise that restraint may only be used for the administration of treatment in exceptional circumstances where necessary as a matter of last resort in accordance with the principle of least restriction.

The Bill should re-iterate the individual's continuing rights to privacy and bodily integrity and the need to ensure that such rights are protected in all cases.

<sup>&</sup>lt;sup>93</sup> See: M Donnelly 'From Autonomy to Dignity: Treatment for Mental Disorders and the Focus for Patient Rights' in B McSherry (Editor) *International Trends in Mental Health Laws* (Law in Context Special Issue, Federation Press, NSW, 2008), 37-57,56.

## Protections from abuse and ill treatment

Inhuman and degrading treatment and torture are absolutely prohibited under various international human rights instruments.<sup>94</sup> This not only prohibits the State or its agents from subjecting anyone to inhuman or degrading treatment or torture but also places a *positive* obligation on States to conduct effective investigations into and, where appropriate, prosecute allegations of inhuman or degrading treatment and torture. In addition to reiterating the prohibition on torture and inhuman and degrading treatment in Article 15, Article 16 of the CRPD requires States Parties to take all appropriate legislative, administrative, social, educational and other measures to protect persons with mental health problems from all forms of exploitation, violence and abuse, including their gender-based aspects. This includes preventative measures such as ensuring that protective services, people with disabilities and their families are given information to help them avoid, recognise and report instances of abuse in a manner that is age, gender and disability specific. Under article 16(5) CRPD, States are required to "put in place effective legislation and policies" to ensure that instances of violence, exploitation and abuse are identified, investigated and, where appropriate, prosecuted.

Serious consideration needs to be given to how Ireland's legislation could be made more robust so that instances of abuse of vulnerable persons, including people with mental health problems, can be effectively identified and investigated.

In order to deter such offences and in the interest of clarity and certainty of the law, the offence should be extended to include 'exploitation or abuse' as well as ill treatment or neglect.

#### **RECOMMENDATIONS:**

The Bill should clarify in the Bill that the offence of ill treatment or neglect applies equally to persons who are subject to the Mental Health Act 2001<sup>95</sup>.

The offence of 'ill-treatment or neglect' should be extended to include 'exploitation or abuse' as well as ill treatment or neglect.

#### **Children and Young People**

As the Department will be aware, the Law Reform Commission published a consultation paper and a report entitled Children and the Law: Medical Treatment<sup>96</sup>, which makes recommendations to reduce the age of consent to medical treatment below 18 years. The Report sets out a Draft Health (Children and Consent to Health Care Treatment) Bill 2011 and an Outline Scheme of Mental Health (Amendment) Bill. To the extent that the age of consent for healthcare decisions is reduced below 18 years, the capacity law will need to reflect this. The Law Reform Commission has made a number of recommendations in relation to young people and capacity in its report on *Children and the Law: Medical Treatment*. Al endorses these recommendations and submits that consideration should be given to the interplay between the Mental Capacity Bill and the Draft Mental Health (Amendment) Bill and the Draft Health (Children and Consent to Health Care Treatment) Bill as proposed.

<sup>&</sup>lt;sup>94</sup> These include Article 7 ICCPR, Article 3 ECHR and Article 15 CRPD.

<sup>&</sup>lt;sup>95</sup> Al's review of the Mental Health Act 2001 includes a recommendation (recommendation 124) that specific criminal offences for the ill treatment, neglect, exploitation and abuse of mental health service users should be introduced into the Act. It also suggests that this matter be considered in the drafting of the Mental Capacity Bill.

<sup>&</sup>lt;sup>96</sup> Available at <u>http://www.lawreform.ie/</u>.

#### Capacity to consent and young people between 14 and 18 years of age

Neither the Mental Health Act nor the Scheme of the Capacity Bill recognises the capacity of a young person under the age of 18 years to consent to admission or treatment for mental health problems.

Under the Mental Health Act, parental consent is determinative of a young person's status (voluntary or involuntary) regardless of their age or maturity. It is our understanding that this raises a particular issue in the case of children and young people who are in state care because, according to HSE policy, any such children or young people who require inpatient care must be involuntarily detained under the provisions of the Act. Social workers cannot consent in *loco parentis* to psychiatric treatment for children and young people in the care of the HSE. The amendments proposed below, whereby children and young people of sufficient age and maturity could legally consent to admission and or treatment would address this issue.

#### Young people aged 16 to 18 years

The consent of a young person aged 16 years or over is effective for any surgical, medical or dental treatment (i.e. the ensuing treatment will not be an offence against the person) under section 23 of the Non-Fatal Offences Against the Person Act 1997 (the 1997 Act). However, there is an inconsistency between this provision and the Mental Health Act (which defines a child as anyone under the age of 18 other than a person who is or has been married) and the MHC in its guidance has stated that parental consent is determinative of the status of a child (i.e. voluntary or involuntary) under the Mental Health Act.<sup>97</sup>

The Convention on the Rights of the Child (CRC) is not prescriptive as to the age at which young people should be presumed capable of making treatment decisions. However, it does require that there be no discrimination in the choice and application of age limits. Accordingly, any right to consent to treatment for persons over 16 years should apply to all young persons equally, including those who experience mental health problems.

Section 23 of the 1997 Act does not give a right to consent to treatment as such; rather it is a defence to any subsequent charge of assault. Therefore it needs to be clarified and expressly stated that young people between the age of 16 and 18 years have the right to consent to treatment. The corollary of the right to consent to treatment is the right to refuse treatment; the former is arguably rendered meaningless without the latter.<sup>98</sup> Accordingly, when setting out the age of consent to treatment, legislation needs to expressly state that this includes the corollary right to refuse treatment.

The Law Reform Commission has recommended that a person of 16 years of age or older should be presumed in law to have capacity to consent to health care and medical treatment. This proposal would mark a welcome development in addressing the inconsistency between section 23 of the 1997 Act and the Mental Health Act as regards the age at which a young person may legally consent to or refuse medical treatment. Al welcomes the fact that the LRC sees no reason to differentiate between issues of capacity and consent in relation to physical and mental health (paragraph 1.45 Report and paragraph 6.123 Consultation Paper). This is in line with the human rights principle of non-discrimination as reiterated most recently in the CRPD.

<sup>&</sup>lt;sup>97</sup> Mental Health Commission Code of Practice Relating to the Admission of Children under the Mental Health Act 2001 (1 November 2006), para 2.7.

<sup>&</sup>lt;sup>98</sup> See, for example, Report of the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover UN Doc. A/64/150 (10 August 2009) para 28.

This recommendation is also in line with the CRC principle that the evolving capacities of the child/young person be respected and that such views be given due weight in accordance with the age and maturity of the child/young person (Article 12 CRC).

As is the case with adults, in order to consent to admission and/or treatment a young person must have the necessary functional capacity to do so. Where the capacity of a young person between the age of 16 and 18 years is in question, the provisions of the Bill would apply.

Also, as is set out in the Scheme of the Mental Capacity Bill 2008,<sup>99</sup> a young person should not be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success. This is in line with Article 12 of the CRPD, which places an obligation on States Parties to "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity".<sup>100</sup> It is important that effective mechanisms are put in place to ensure that children and young people are given the necessary support to exercise their capacity as is required under Article 12 CRPD. Specialist child and adolescent advocates could have an important role to play in this regard.

#### Under 16 year olds

Competence in relation to children and young people below the age of 16 years is a matter of fact, which differs from child to child depending on the individual child's maturity, and an age of consent would not appear to be appropriate for this age group.

Al would support the introduction of the 'mature minor rule', which effectively depends on satisfaction of a functional test of capacity in relation to children and young people under the age of 16 years. The tiered approach, which has been put forward by the Law Reform Commission, would seem to be appropriate in this regard. It must be stressed that *all* children and young people who are capable of forming their own views (a threshold which should be far lower than that of functional capacity) must be allowed to express their views freely and it is only when deciding what weight is to be assigned to those views that functional capacity comes into play. It should be noted that there have been criticisms of the mature minor rule in the sense that it places young patients entirely in the hands of the medical professional who determines whether or not the young person is capable. Accordingly, thought needs to be given as to who should be tasked with determining whether the child is in fact capable and whether a multi-disciplinary team might be more suitable to perform this assessment.

#### Children and young people with capacity

Where a child or young person has capacity to make a treatment decision, then his or her right to refuse treatment should be respected. If a situation arises where a young person refuses treatment which is life sustaining, the Bill should provide that an application may be made to the High Court to determine the validity of the refusal as is recommended by the LRC.<sup>101</sup>

#### Child or young person lacking capacity

Where a child or young person does not have capacity to make a treatment decision, safeguards must be put in place so that such treatment is subject to an effective

<sup>&</sup>lt;sup>99</sup>Available at: <u>http://www.inis.gov.ie/en/JELR/Pages/Scheme of Mental Capacity Bill 2008</u>.

<sup>&</sup>lt;sup>100</sup> See AI Submission on the Scheme of the Mental Capacity Bill 2008 (available at http://amnesty.ie/reports/submission-department-justice-equality-and-law-reform-scheme-mental-capacity-bill-2008), pp.10 and 11.

<sup>&</sup>lt;sup>101</sup> LRC 102-2011, Report on Children and the Law: Medical Treatment, Para 2.160

independent review at regular intervals. The same safeguards should apply as are recommended in relation to adults.

**RECOMMENDATIONS:** The Bill will need to apply to young persons below the age of 18 years to the extent that they are entitled to make decisions on their own behall according to the law as amended from time to time.

The Bill should provide that young persons between the age of 16 and 18 years shall be presumed to have capacity to make decisions regarding admission and treatment unless proven otherwise. This must expressly include consent to and refusal of treatment. If that presumption is rebutted and a person within that age group is found to not have such capacity, the provisions of the Bill should apply.

Al endorses the following recommendation of the Law Reform Commission:

#### Legislation should provide:

(i) that a 16 or 17 year old is presumed to have capacity to make an advance care directive and (ii) that where an advance care directive is being considered by or for a 16 and 17 year old a specific assessment be made by a trained and experienced health care professional of that person's capacity to understand the nature and consequences of the advance care directive.<sup>102</sup>

- A person who is 14 years of age but less than 16 years of age could, subject to certain requirements, be regarded as capable of giving consent to and refusing health care and medical treatment, where it is established that he or she has the maturity and understanding to appreciate the nature and consequences of the specific health care treatment decision<sup>103</sup>;
- The Bill should clarify that the recommendations concerning healthcare decision-making by persons under 16 years of age should also be applied in the context of mental health, including decisions in respect of admission and treatment under the Mental Health Act 2001; and
- In the context of refusal of life sustaining treatment by a person under the age of 18, an application may be made to the High Court to determine the validity of the refusal. The High Court may order treatment that is necessary to save life and where this is in the best interests of the person under 18 years of age. In any such application the person under 18 shall be separately represented.

<sup>&</sup>lt;sup>102</sup> LRC 103-2011, *Report on Children and the Law: Medical Treatment, at 4.08.* 

<sup>&</sup>lt;sup>103</sup> LRC 103-2011 Recommendation 4.09. The factors recommended by the LRC in determining whether a person under 16 has the maturity and capacity to consent to and to refuse health care treatment are: (a) whether he or she has sufficient maturity to understand the information relevant to making the specific decision and to appreciate its potential consequences; (b) whether his or her views are stable and a true reflection of his or her core values and beliefs, taking into account his or her physical and mental health and any other factors that affect his or her ability to exercise independent judgement; (c) the nature, purpose and utility of the treatment; (d) the risks and benefits involved in the treatment, and(e) any other specific welfare, protection or public health considerations, in respect of which relevant guidance and protocols such as the 2011 Children First: National Guidelines for the Protection and Welfare of Children (or any equivalent replacement document) must be applied.[para 2.175 and recommendation at para 4.10]

## Wards of Court

If the wards of court system is to be effectively abolished and replaced by the guardianship system set out in the Bill, then, in addition to having any detentions of existing wards of court automatically reviewed under the Bill, all existing wards of court should automatically have their capacity reviewed under the Bill and should have personal guardians appointed to manage their property and/or personal affairs, where appropriate.

**RECOMMENDATION:** The Bill should provide that all wards of court should have their cases automatically reviewed within a reasonable transitional time period. Where appropriate personal guardians should be appointed to manage the property and affairs of wards of court.

#### Other steps to strengthen the Guiding Principles and Best Interests provisions

#### Where lack of capacity is temporary

A number of participants in the research referred to the often temporary nature of incapacity experienced by persons with mental health problems. As currently drafted Head 1(b) of the Scheme states 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'.

The UN Special Rapporteur on the Right to Health Mr Anand Grover stated in his most recent report that "[i]n the absence of a proxy, if a person is authoritatively judged not to have legal capacity due to a transitory physical or mental state such as unconsciousness, a health-care provider may resort only to a life-saving emergency procedure, and only in the absence of a clear prior or immediate indication of refusal".<sup>104</sup> This suggests that in order to comply with international law, if a person is likely to regain capacity, treatment should not be administered without consent unless it is necessary and cannot be postponed until the person is expected to regain capacity. Head 1(b) of the Scheme could be strengthened to expressly state that no intervention should take place if it can be postponed until the person in question is expected to regain capacity.

**RECOMMENDATIONS:** 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.

#### **Codes of Practice**

Al notes that Head 39 of the Scheme provides for the preparation of Codes of Practice by the Public Guardian to provide guidance to relevant persons in applying the provisions of the legislation. Given the importance of such Codes of Practice, it is imperative that they be drafted well in advance of the Bill being brought into force, so

<sup>&</sup>lt;sup>104</sup> Report of the Special Rapporteur on the right to the highest attainable standard of physical and mental health UN Doc. A/64/272 (10 August 2009) para 29.

that the Codes of Practice can be subject to the necessary scrutiny and discussion by all relevant stakeholders.<sup>105</sup> It is crucial that the Public Guardian consults widely with all relevant stakeholders in preparing such Codes of Practice, including in particular, people with direct experience of mental health problems, their representative organisations and other groups most likely to be affected by their provisions.

**RECOMMENDATION:** Codes of Practice must be drafted as soon as possible and before the Bill is brought into force, in consultation with all relevant stakeholders, including in particular people with direct experience of mental health problems, their representative organisations and other groups most likely to be affected by their provisions.

## **Specialist Board / Tribunal**

#### Structure, composition, sitting arrangements and location

Recommendation 99(4) of the Committee of Ministers of the Council of Europe to Member States on Principles concerning the Legal Protection of Incapable Adults requires that there should be "fair and efficient procedures for the taking of measures for the protection of capable adults".<sup>106</sup>

Al strongly urges that the Bill be drafted so as to provide for the establishment of a multi-disciplinary specialist Board in accordance with the recommendations of the Law Reform Commission in their report on *Vulnerable Adults and the Law*.<sup>107</sup> The Court system is already overburdened and inaccessible and is an inappropriate setting for decisions in relation to capacity under the legislation. It is our understanding that specialist court systems used in other jurisdictions, such as the Court of Protection system in the UK, are more akin to specialist tribunal systems, which in practice is very different from the ordinary Courts contemplated by the Scheme. The establishment of a multi-disciplinary Guardianship Board would provide the flexibility required to give effect to the time-specific and issue-specific functional approach to capacity adopted by the Scheme; it is difficult to envisage how this will be achieved if the ordinary Courts are given primary jurisdiction under the legislation.

Al notes that the Government has cited additional costs as one of the main reasons for choosing not to establish a specialised tribunal. All urges the Department to take note of the opinions expressed by the Law Reform Commission and the Law Society of Ireland that the use of the ordinary Courts would lead to greater delay and expenditure in the long run than the establishment of an efficient specialist Board.

Al also echoes the recommendation of the Law Society of Ireland that the Bill should provide that the specialist court or tribunal may sit at any place, on any day and at any time.<sup>108</sup> Such flexibility is essential if a functional approach to capacity is to become a reality.

<sup>108</sup> Submission by the Law Society of Ireland to the Department of Justice, Equality and Law Reform on the Scheme of the Mental Capacity Bill 2008, available at

<sup>&</sup>lt;sup>105</sup> See M Donnelly 'Legislating for Incapacity: Developing a Human Rights-Based Framework' (2008) 30 Dublin University Law Journal 395 (2008) 437. <sup>106</sup> Principle 7(1). <sup>107</sup> Law Reform Commission *Report: Vulnerable Adults and the Law* LRC 83-2006, 8.51.

http://www.lawsociety.ie/documents/committees/lawreform/Submission Mental Capacity Bill 260109.p df, accessed on 20 February 2009.

**RECOMMENDATION:** The Bill should provide for the establishment of a specialist Guardianship Board as recommended by the Law Reform Commission.

#### **Procedural safeguards**

Recommendation 99(4) of the Committee of Ministers on Principles concerning the Legal Protection of incapable Adults calls for "adequate procedural safeguards to protect the human rights of the persons concerned and to prevent possible abuses".<sup>109</sup>

As has been highlighted in a number of other submissions already made to the Department, some of the provisions of the Scheme relating to procedures for hearings are a cause of concern.<sup>110</sup> In particular, AI calls on the Department to amend Head 9(5), 9(6) and Head 13 to provide for the following in the Bill:

- All persons whose capacity is contested should be given an express right to legal representation, both at the initial proceedings where the presence or absence of capacity is determined and at all subsequent applications, including applications for review of capacity decisions. This is necessary to comply with the requirements of Article 6(1) ECHR.
- The person whose capacity is in question should be entitled to attend the hearing save in the most exceptional circumstances, which should be clearly stated in the Bill. Moreover, the specialist court/tribunal should not be empowered to dispense with a full hearing save in limited circumstances to be specified in the Bill. These protections are essential safeguards required by the jurisprudence of the European Court of Human Rights and other international human rights law and standards, including Principle 13 of the Principles of the Committee of Ministers of the Council of Europe Concerning the Legal Protection of Incapable Adults.<sup>111</sup>

The person whose capacity is in question should also be given the opportunity to challenge any expert reports or other evidence brought before the hearing and to present their own evidence whether medical or otherwise.

**RECOMMENDATION:** The Bill should include necessary procedural safeguards in all hearings to adequately protect the rights of persons whose capacity is in question.

#### Exclusion of certain areas such as marriage, sexual relations etc

Al notes that certain areas where consent is required are excluded from the Scheme pursuant to Head 20. Al emphasises that the CRPD is applicable 'in all aspects of life' and that exclusion of certain aspects of life in law is likely to be incompatible with

<sup>&</sup>lt;sup>109</sup> Recommendation No. R(99) 4, adopted by the Committee of Ministers on 23 February 1999, Principle 7(2).

<sup>&</sup>lt;sup>110</sup> See: Irish Human Rights Commission Observations on the Scheme of the Mental Capacity Bill 2008, November 2008, available at <u>http://www.ihrc.ie/documents/article.asp?NID=272&NCID=6&T=N&Print</u>, accessed on 23 February 2009 and Submission by the Law Society of Ireland referred to at note 15 above.

<sup>&</sup>lt;sup>11</sup> Recommendation No. R(99) 4, adopted by the Committee of Ministers on 23 February 1999.

the CRPD. AI asks that consideration is given to bringing Irish law, in particular section 5 of the Criminal Law (Sexual Offences) Act 1993, into compliance with the CRPD. What steps are being taken to ensure that the existing law is appropriately amended to comply with the CRPD? In particular AI would ask the Department of Justice to clarify what steps are being taken to ensure that the necessary changes will be made to section 5 of the Criminal Law (Sexual Offences) Act 1993 in order to bring Irish law into compliance with the CRPD.

**RECOMMENDATION:** Consideration should be given to bringing the law on marriage and sexual relations in line with the CRPD.

## **Review of the Act**

The Bill should include a provision requiring periodic reviews of the Act including not only the operation or functioning of the Act but also a broader review of whether the Act has succeeded in fulfilling the objectives and aims sought to be achieved by its passing into law.

**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 passing into law.

#### Conclusion

While AI welcomes the publication of the 2008 Scheme of the Mental Capacity Bill there are a number of serious concerns about how its provisions fulfil Ireland's obligations under international human rights law, as set out in detail in this submission. We are keen to meet with relevant stakeholders to discuss in more detail our comments. Progressive legislation in this area will allow Ireland to move a step closer to the effective protection and realisation of the equal rights of persons who experience mental health problems in accordance with international human rights laws. This Bill is an important opportunity and we would strongly welcome a Bill that fully recognises the supports people need in order to enjoy legal capacity.

#### ENDS//

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