

Submission to the National Consent Advisory Group on the Health Service Executive's 'Draft National Consent Policy'

28 June 2012

## 1. Introduction

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 2003.

Al strongly welcomes the development of an overarching policy for consent in health and social care. Al welcomes this opportunity to submit its observations on the 'Draft National Consent Policy'. The focus of this submission focuses on the parts of the draft policy to consent in the context of mental health treatment and capacity to consent for adults and children. This submission focuses more generally on what Ireland's intention to ratify the Convention on the Rights of Persons with Disabilities (CRPD) means for law and policy. While it does not discuss many of the specifics of the national consent policy Al is available to meet the HSE to discuss the policy and Ireland's international human rights obligations in further detail.

Al would like to draw the National Consent Advisory Group's attention to the fact that the Assisted Decision-Making (Capacity) Bill 2012 will be published shortly, and will replace the antiquated Wards of Court System. The Government in its Programme for Government has committed to introducing legislation that is compliant with the UN Convention on the Rights of Persons with Disabilities and it is important that the National Consent Policy reflects the requirements of international human rights law. The Programme for Government states:

"We will review the Mental Health Act 2001 in consultation with service users, carers and other stakeholders, informed by human rights standards, and introduce a Mental Capacity Bill that is in line with the UN Convention on the Rights of Persons with Disabilities."

for Government 2011.html.

<sup>&</sup>lt;sup>1</sup> "Statement of Common Purpose" at page 8. (Dublin: Programme for Government, 2011) Available at: <a href="http://www.taoiseach.gov.ie/eng/Publications/Publications Archive/Publications 2011/Programme">http://www.taoiseach.gov.ie/eng/Publications/Publications Archive/Publications 2011/Programme</a>

# 2. International Human Rights Law

## Article 12 of the CRPD

It is important that the National Consent Advisory Group recognise that there have until recently being three main approaches to assessing capacity -the status approach, the outcome approach and the functional approach.

- The status approach is the approach of the current Wards of Court system. Under the Wards of Court system a decision of incapacity is applied to every decision and legal transaction taken by the ward. The status approach operates by assuming that a person lacks legal capacity on the basis of disability (in particular an intellectual disability). Having the status of disabled under Irish law is sufficient to strip a person of their legal capacity and provide for the imposition of substituted decision-making by a third party. Under the status approach you either have full legal capacity or you lack capacity entirely and a third party makes decisions regarding medical treatment with no requirement to seek the persons consent.
- 2 The outcome approach is rooted in the belief that in circumstances where a person makes a bad decision or a number of bad decisions that person should lose the right to continue make decisions. This approach to capacity is now out-dated, as there is recognition that "we all have the right to make our own mistakes" and that it is unjust to set the decision-making bar higher for persons with disabilities.<sup>2</sup>
- 3 The functional approach (the approach adopted in the draft policy on consent) involves a consideration of mental capacity on an issue specific basis. This approach considers that a person might not be able to make decisions of a financial nature but might be considered to have capacity to consent to an intimate relationship. This approach rejects the status approach and outcome approach. The functional approach presumes that a person has capacity unless proven otherwise and involves the provision of supports in order for people to exercise decision-making.

Article 12 requires a shift beyond the functional approach and looking at mental capacity to legal capacity and the supported decision-making model. Article 12 essentially focuses on the person and restores decision-making autonomy to them. Article 12(2) requires States Parties to recognise that persons with disabilities "enjoy legal capacity on an equal basis with others in all aspects of life". It is therefore important that the National Consent Working Group recognise that Article 12 refers only to the legal capacity of a person not their mental capacity. Mental capacity is a separate concept to legal capacity, as Ireland will shortly ratify this Convention it is important to consider this. The CRPD de-links mental capacity from a person's ability to exercise their rights. Article 12 adopts what can be referred to as a universal approach to decision-making asserting that everyone has the right to make decisions in all aspects of life including decisions relating to

-

<sup>&</sup>lt;sup>2</sup> Quinn "Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD" (HPOD Conference, Harvard Law School, 20 February, 2010). Available at: http://www.nuigalway.ie/cdlp/staff/gerard\_quinn.html.

medical treatment. That is not to say that decision-making deficits do not exist. However, the typical response of the law in the past to these deficits – all around the world and not just in Ireland – is to allow others to make decisions in the place of the individual. This is so-called 'substitute decision-making'. In the more extreme case this is done through plenary guardianship (which means the third party assumes the right to make all decisions and totally supplants the person) or partial guardianship (the right to make certain kinds of decisions).

Mental Capacity summary: The ability to make decisions for oneself

Comprises the abilities to:

- understand and retain information
- use and weigh it in reaching a decision
- communicate choice
- Psychological ability or capacity
- Functions as a threshold concept in the law

CRPD Legal Capacity summary: To have legal capacity is to:

- have the right to enter into contracts (including marriage), to sue and be sued, acquire and dispose of property
- The law's recognition of the validity of a person's choices.
- Not so much a psychological ability as a legal status or standing
- The capacity to have rights and to exercise those rights

The shift to the supported decision making model is evident in Article 12(3) where it is stated that States Parties to the Convention are required to take appropriate measures to provide access to supports in order to exercise legal capacity. All welcomes the approach within the General Principles of the draft Consent Policy that states that "efforts must be made to support individuals in making decisions for themselves where this is possible." All is concerned that the provision for supports in the guiding principles should be clearly set out under the draft national consent policy. Article 12(4) deals with the various safeguards to protect a person's legal capacity (e.g. proportionate intervention, free from conflict of interest, individually tailored).

A central aspect of Article 12 is the focus on the "will and preferences" of the person as the determining factor in decisions about their life and this requires moving away from the "best interests" approach, which brings with it the significant risk of paternalism and substitute decision-making. Al is concerned with references to the concept of "best interests", which are made a number of times in the draft National Consent policy. It is important that the National Consent Advisory Group recognises that the principle of "best interests" emerged from law and policy focused on children and it is increasingly considered inappropriate in relation to adults and is very often the underlying philosophy in the involuntary detention and treatment of persons with mental health problems.<sup>3</sup>

<sup>&</sup>lt;sup>3</sup> For a discussion in the origin of the best interests principle see "The Best Interests of the Child: Towards a Synthesis of Children's Rights and Cultural Values" [Florence: UNICEF, Innocenti Studies, 1996]. Available at: <a href="http://www.unicef-irc.org/publications/pdf/is">http://www.unicef-irc.org/publications/pdf/is</a> best interest low eng.pdf.

It is clear that the CRPD requires a move away from the "best interests" principle. Article 3 of the CRPD sets out that the principles underpinning the Convention, which include "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity...". Nowhere does the CRPD refer to the "best interests" of adults with disabilities and in fact the suggestion that the "best interests" be included in Article 12 was firmly rejected at the negotiations of the CRPD at the Ad Hoc Committee. The paradigm shift in thinking required by the CRPD and in particular in Article 12 requires a challenging of substitute decision making by third parties based on what is adjudicated to be in their "bests interests".

The UN Committee on the Rights of Persons with Disabilities has outlined the "paradigm shift" in thinking on legal capacity that is required by Article 12 to supported decision-making.<sup>5</sup> The UN Committee in its concluding observations on Tunisia's Report on its implementation of the CRPD expressed concern "that no measures have been undertaken to replace substitute decision-making by supported decision-making in the exercise of legal capacity". 6 The Committee recommended that the State Party review the laws allowing for quardianship and trusteeship in addition to taking action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making. The Committee also recommended that training be provided on this issue to all relevant public officials and other stakeholders, reflecting the need to change mindsets that sees persons with disabilities in terms of deficits.8 The Committee adopted a similar approach in its concluding comments on Spain's first Report to the Committee.9 It recommended that Spain review its laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making. According to the Committee this recommendation was necessary in order to respect 'the person's autonomy, will and preferences'. 10 In addition, the Committee again recommended the provision of training on this issue to all relevant public officials and other stakeholders. In its concluding observations to

<sup>&</sup>lt;sup>4</sup> The only references to "best interests" in the UN Convention on the Rights of Persons with Disabilities emerge in respect of children with disabilities (see Articles 7 and 23).

<sup>&</sup>lt;sup>5</sup> The Committee on the Rights of Persons with Disabilities (CRPD) is the body of independent experts, which monitors implementation of the Convention by the States Parties.

<sup>&</sup>lt;sup>6</sup> "Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations of the Committee on the Rights of Persons with Disabilities" [Committee on the Rights of Persons with Disabilities: Fifth session, 11-15 April 2011] p 4. Available at: <a href="http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session5.aspx">http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session5.aspx</a>.

<sup>&</sup>lt;sup>7</sup> Ibid.

<sup>&</sup>lt;sup>8</sup> Ibid.

<sup>&</sup>lt;sup>9</sup> "Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations of the Committee on the Rights of Persons with Disabilities" [Committee on the Rights of Persons with Disabilities: Sixth session, 19-23 September 2011] p 6. Available at: <a href="http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session6.aspx">http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session6.aspx</a>

<sup>&</sup>lt;sup>10</sup> Ibid.

Peru the Committee similarly recommended that it "abolish ... laws allowing for guardianship and trusteeship to ensure their full conformity with Article 12 of the Convention and take action to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will, and preferences". The recently published Interim Report on the review of the Mental Health Act 2001 recognises the inappropriateness of "best interests" principle as a guiding principle in the 2001 Act. 12

In the draft national consent policy there is a reference to a "trigger" when the presumption of capacity is called into question. All considers that this approach is not consistent with the CRPD and that the focus has to be on acting in accordance with the "will and preference" of the person.

# Supported decision-making in practice

Al in partnership with a number of civil society organisations developed a document that set out a number of principles to underpin legal capacity legislation. The document entitled Essential Principles: Irish Legal Capacity Law is a useful guide for the National Consent Advisory Group in adopting a human rights compliant approach to the national consent policy.<sup>13</sup> These principles aim to reflect the spirit and values of the CRPD. In line with the HSE consent policy the principles recommend that everyone should be presumed to have the capability to make decisions. The main focus of the new law and any policy must be to support people to make their own decisions. The Essential Principles recommend three different levels of support:

- (i) The first level is where a person has the ability to make decisions with only minimal support e.g. easy to read information.
- (ii) The second level is 'supported decision-making', where a person is supported by someone they trust to make a decision, and
- (iii) the third level is 'facilitated decision-making', this is used as a last resort where the person's will and preferences are not known. Here, a representative has to determine what the person would want, based on what they know about that person and on their best understanding of their wishes.

Principle 4 provides that people who need support to make decisions have a right to be provided with that support by the State. For example, advocate supports should be recognised and assist the person in understanding options and expressing their will and preferences. It is important that the national consent policy acknowledges that there is a need for different levels of support should be provided depending on what the person needs to be able to make decisions. For example, it is important for health professionals to provide

<sup>&</sup>lt;sup>11</sup> "Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations of the Committee on the Rights of Persons with Disabilities" [Committee on the Rights of Persons with Disabilities: Seventh session, 16-20 April 2012] p 5. Available at: <a href="http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session7.aspx">http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session7.aspx</a>.

<sup>&</sup>lt;sup>12</sup> Department of Health, Interim report from the Steering Group on the review of the Mental Health Act 2001. Available on: http://www.dohc.ie/publications/pdf/int\_report\_sq\_reviewMHA\_new.pdf?direct=1

<sup>&</sup>lt;sup>13</sup> Essential Principles: Irish Legal Capacity Law. Available on: http://amnesty.ie/sites/default/files/report/2012/04/PRINCIPLES WEB.pdf

reasonable accommodation to help the person understand the decision. Different ways of providing information must be explored (including sign language, alternative communication, flexibility with regard to time and location for delivering information, pacing, repetition, and a trusted source for information, etc.). The policy should also recognise the role of advocacy and there should be a range of advocacy supports, as well as other forms of individual advocacy (e.g. citizen advocacy, peer advocacy, self-advocacy support). Principle 7 is also worth considering as it provides that strict safeguards must be in place to protect the human rights of people who are supported in making decisions, or who have someone making a decision for them. These safeguards should include; awareness-raising about supported decision-making, and education and training for all involved including health professionals. Principle 8 provides that decisions made by someone else for a person is a last resort when all supports have been considered (facilitated decision making). It should only apply for specific decisions and for the length of time necessary for that purpose.

Principle 10 provides that when somebody else is being appointed as a decision-maker for a person ('facilitated decision-making'), the person should have the opportunity to take part in the process and be fully represented, keeping in mind that a facilitated decision-maker should only be appointed where the will and preference of the individual is not known. This should be reflected strongly in the national policy. Those making decision for someone else (facilitated decision makers) should be independently appointed and monitored on a regular basis, this is particularly important in relation to decision-making in the health context.

# Article 17 of the CRPD

It is important that the HSE consent policy reflects the requirements of Article 17 of the CRPD, which requires that the "physical and mental integrity" of a person with a disability should be respected "on an equal basis with others". The UNCRPD Committee in their commentary to date on Article 17 have expressed concern around consent within health and mental health services. In its concluding observations to Tunisia the Committee expressed concern around the lack of legal clarity with the legislation protecting "persons with disabilities from being subjected to treatment without their free and informed consent, including forced treatment in mental health services." On the basis of this concern the Committee recommended that Tunisia incorporate into its domestic law the abolition of surgery and treatment where there the patient does not give their full and informed consent. The Committee also recommended that Tunisia should ensure its domestic law in particular respects women's rights under Articles 23 and 25 of the Convention. In its concluding observations on Spain's compliance with Article 17 the Committee expressed concern that persons with disabilities "whose legal capacity is not recognized may be subjected to sterilization without their free and informed consent." The Committee therefore urged Spain "to abolish the administration of medical treatment, in particular sterilization, without the full and informed consent of the patient; and ensure that national law especially respects women's rights under Articles 23 and 25 of the Convention." <sup>14</sup> Medical law has generally required that in order for consent

\_

 $<sup>^{14}</sup>$  The issue of sterilisation of persons is a very topical issue in Europe with the case of Gauer and Others v France (Application no 61521/08) currently being litigated before the European Court of

to be present it is necessary for the patient to have informed consent, give the consent voluntarily and that the patient had the capacity to give consent. It is interesting that the Committee in their analysis did not refer to the capacity of patients to consent, rather their comments referred to full and informed consent and the vulnerability of persons with disabilities to violations of their human rights when their legal capacity is not recognised. The Committee will likely develop its jurisprudence on Article 17 to reflect the shift in thinking on capacity to make decisions as required by Article 12 (see above) and it is important that this approach is reflected in the national consent policy.

## Recommendation:

- All recommends that when there is a question raised as to the decision making capacity of a person to consent to or refuse treatment there should be an assessment of the supports that a person needs to enable them to exercise their legal capacity and to make the necessary decision. The role of supported decision makers must be recognised and a broad range of supports provided, including for example advocacy and advance directives.
- All recommends that "best interests" should not feature as a principle in the national policy on consent. In line with international human rights law the "will and preference" of the person should be the guiding principle in the national policy on consent.
- All recommends that "mental capacity" should not be used as a term or concept in assessing whether a person has the capability to make decisions.
   All recommends that there should be a requirement for health professionals to assess the supports needed to make decisions or appoint a supported decision maker and where the persons "will and preferences" are not known, a facilitated decision-maker.
- All recommends that the national policy on consent adopt the principles set out in the document Essential Principles: Irish Legal Capacity Law.
- The HSE consent policy should reflect the requirements of Article 17 of the CRPD, which requires that the "physical and mental integrity" of a person with a disability should be respected "on an equal basis with others".

Human Rights. Gauer and Others v France is a case involving five women with intellectual disabilities who were forcibly sterilised. The decision of the European Court of Human Rights will be an important statement on the reproductive rights of persons with disabilities and the positive obligations on the States in safeguarding persons with disabilities against abuse. The European Court of Human Rights has used the UN Convention on the Rights of Persons with Disabilities (CRPD) as an interpretive aid to the European Convention on Human Rights and this decision may further demonstrate that the ECtHR is edging closer to the philosophy of legal capacity as set out in Article 12 of the CRPD.

#### 3. Consent to mental health treatment

While AI welcomes the inclusion of the presumption of capacity to consent in the draft national consent policy AI considers that the functional approach to capacity adopted in the policy is not fully consistent with the requirements of international human rights law. Article 12 requires States to move towards supporting people to make their own decisions as much as possible.

Informed and voluntary consent and mental health treatment

The provisions of the 2001 Act on consent to treatment are significantly out of step with international human rights law and standards. In particular, the need to respect patient autonomy is given insufficient weight. The national consent policy should address this imbalance. As the law currently stands there is no significance attached to the "will and preferences" of a person detained as an involuntary under the Mental Health Act 2001 in the provisions relating to ECT or the administration of medication for more than three months. No formal weight is given to advance directives. The 2001 Act can be seen as encouraging a culture of exclusion of service users in treatment decisions, which is firmly at odds with the recovery ethos advocated by A Vision for Change, as well as international human rights law, including the CRPD. In as far as possible the national consent policy should seek to resolve this inconsistency in respecting the autonomy of persons subject to the 2001 Act.

Al welcomes the recognition in the draft national consent policy of the need for consent to be voluntarily given and be informed. Informed consent in healthcare is a key component of the right to the highest attainable standard of physical and mental health. It invokes several human rights that are interdependent and interrelated, such as the right to autonomy, freedom from discrimination, freedom from inhuman or degrading treatment and the right to privacy and bodily integrity. There are three elements to informed consent. Firstly, consent must be given freely, without force, undue influence (advantage taken from a position of power over someone) or misrepresentation (a false statement of fact that guides someone to a particular conclusion). Secondly, associated benefits, risks and alternatives to a medical procedure must be provided before the patient makes a decision. Thirdly, the person must have capacity to consent. The right to consent to treatment also includes the right to refuse treatment, regardless of the outcome for the patient of that decision or how wise that decision appears to others.

Al has undertaken extensive consultation with service users on the Mental Health Act 2001. There was a sense among service users and carers that there was a significant power imbalance in the relationship between the psychiatrist and the individual patient. Al considers that the new national policy on consent should seek to address this power imbalance. The European Court of Human Rights has stated that there is a need for "increased vigilance" in light of the power imbalance. <sup>15</sup> It is essential that the national consent policy acknowledges

<sup>&</sup>lt;sup>15</sup> See the Herczegfalvy v Austria Application no. 10533/83, judgment 24 September 1992, paragraph 82.

that the presence of a mental health problem does not mean that a person lacks capacity to consent to treatment or refuse treatment. As is clear from the discussion of Article 12 of the CRPD requires a universal approach to the recognition of legal capacity.

Under the 2001 Act, the treating consultant psychiatrist is effectively tasked with determining whether a patient has capacity to consent to treatment and acting as substitute decision-maker where the patient lacks capacity. This approach is not consistent with Article 12 of the CRPD. The Act does not provide for clear guidance on this resulting in affording a broad discretion to the psychiatrist to deny recognition of the legal capacity and human rights of a person subject to involuntary detention under the 2001 Act.

#### Recommendations:

- All recommends that the National Consent Advisory Group give further consideration to the UN CRPD as it moves towards finalising their work on the national consent policy.
- All recommends that the functional approach to "capacity" be moved towards the supported decision-making model as required by Article 12(3) of the CRPD.
- Al recommends that the national consent policy be more explicit on the issue of consent to mental health treatment reflecting international human rights law. There should be an obligation to ensure the person gives free and informed consent. There should be an obligation by health service providers to provide information on an ongoing basis. There should be an express obligation to that all communications are in a form and language that can be understood and that a member of staff explains the information.
- The national consent policy should seek to address the power imbalance in the relationship between the psychiatrist and the individual patient when it comes to decision-making around mental health treatment. In so far as possible, a multi-disciplinary approach should be adopted to supporting people to make decisions, particularly in relation to treatment decisions.
- The national consent policy should explicitly acknowledge that the presence of a mental health problem does not mean that a person lacks capacity to consent to treatment or refuse treatment.
- The national consent policy should recognise the right of persons subject to involuntary detention to consent to or refuse treatment.

The Interim Review of the Mental Health Act 2001 identified that issues regarding voluntary patients generated significant comment in its consultation process and it was identified as a major area of concern. The report also acknowledged that in reality many of the voluntary patients in approved centres "lack the capacity to consent to admission and treatment" or rather they lack the support to consent to admission and treatment. As such these persons are voluntary patients, not because they have consented to admission. Rather they are voluntary as they have not objected to detention or treatment. This group of patients are often referred to as "incapacitated but compliant" and are "de facto detained yet do not enjoy the protections provided to involuntary patients in the Act". This means that there are many persons who have legal capacity or who with support could exercise their legal capacity who stay for lengthy periods in approved centres without external review of their admission, detention or capacity and similar treatment decisions for voluntary patients are made without external oversight. 18

#### Recommendation:

- The national consent policy should seek to ensure that the legal capacity
  of this category of persons is respected. Voluntary patients should
  include only those persons who have genuinely consented to their
  admission to an approved centre and consent to treatment.
- A person requiring support in order to exercise their legal capacity should be provided with it.
- Provisions and safeguards in relation to the administration of treatment should apply equally to voluntary and involuntary patients.

## Involuntary treatment in an emergency situation

In emergency situations, such as if a person is actively suicidal; it may not be possible to comply with the procedures for involuntary treatment. The World Health Organisation (WHO) recognises that laws should provide for emergency treatment, provided there are sufficient safeguards and emergency treatment is within a specified short time frame. The WHO states that emergency treatment should not include electro-convulsive therapy (ECT), depot neuroleptics or irreversible treatments such as psycho-surgery. <sup>19</sup>

Specific safeguards for the administration of ECT and administration of medication

<sup>&</sup>lt;sup>16</sup> Interim review at page 19.

<sup>&</sup>lt;sup>17</sup> Ibid.

<sup>&</sup>lt;sup>18</sup> *Ibid*.

<sup>&</sup>lt;sup>19</sup> WHO Resource Book on Mental Health, Human Rights and Legislation (2005) page 60. Available at: http://www.who.int/mental\_health/policy/legislation/Resource% 20Book\_Eng2\_WEB\_07% 20(2).pdf

Sections 59 and 60 of the 2001 Act allow a programme of ECT or medication for a period in excess of three months to be administered to an involuntary patient where the patient is "unable or unwilling to give consent", thereby overriding refusals of treatment. While these provisions require that a second consultant psychiatrist approve of the course of treatment, there is no requirement that he or she be independent of the treating psychiatrist, rendering the practical value of this "safequard" questionable. The European Committee for the Prevention of Torture has recommended that Sections 59 and 60 be amended to provide that the second consultant psychiatrist is independent. <sup>20</sup> The MI Principles <sup>21</sup> state that intrusive and irreversible treatments for mental health problems may be administered only where "the patient has given informed consent and an independent external body has satisfied itself that there is genuine informed consent and that the treatment best serves the health needs of the patient". 22 The law should require written consent by all patients and a series of protective safeguards where a person requires support to exercise their legal capacity. There should be a tribunal review of every decision to carry out a programme of ECT. There should be a right to appeal to the Circuit Court against any decision by the tribunal to allow a programme of ECT to be administered to a person.

#### Recommendations:

- Emergency situations should be narrowly defined in line with the common law doctrine of necessity. This should provide for the administration of treatment (with the exception of psychosurgery, ECT and depot neuroleptics) for a short period of time. Such emergency treatment should be restricted to a maximum period after after which it may only be continued after the provisions of section 60 of the Mental Health Act have been complied with. The Department of Health and HSE should consult with service users and healthcare professionals to ascertain what would be a reasonable maximum time period for the administration of emergency treatment. In any event this should be no longer than the 72 hours recommended by the WHO.
- Mental health tribunals should be given a role in reviewing treatment decisions.
- Where a person consents in writing to a programme of ECT, the mental health tribunal should review:
  - o whether the treatment decision reflects the "will and preferences" of the person;
  - o whether the treatment is necessary as a last resort and constitutes the least restrictive treatment or therapy appropriate to the patient's needs;
  - o whether the person has given free and informed consent to the programme of ECT;
- Medication should only be administered with the free and informed consent of the patient and is in accordance with the persons "will and preferences". In AI's review of the Mental Health Act

<sup>20</sup> 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. page 65. Available at: <a href="http://www.cpt.coe.int/documents/irl/2011-03-inf-eng.pdf">http://www.cpt.coe.int/documents/irl/2011-03-inf-eng.pdf</a>

<sup>&</sup>lt;sup>21</sup> The Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (MI Principles) were adopted by the UN in 1991. The MI Principles established standards and procedural guarantees and provided protection against the most serious human rights abuses that might occur in hospitals. The Principles are now outdated in many ways. The CRPD goes much further in protecting the autonomy of the individual.

<sup>&</sup>lt;sup>22</sup> MI Principle 11(14).

2001 from 2011 we made a number of recommendations for safeguards in relation to the administration of medication to people who have been "deemed to lack capacity." See pages 231 to 235

http://www.amnesty.ie/sites/default/files/MENTAL% 20HEALTH% 20ACT% 20REVIEW.pdf. In light of the evolving understanding of the CRPD we will be further developing these recommendations to look at compliance with the requirements of Article 12. Recognising that Ireland has not yet ratified the CRPD and that much current thinking is based in the functional approach AI draws the HSE's attention to these recommendations. AI will be further responding to the Interim Review of the Steering Group for the review of the 2001 Mental Health Act and will develop these recommendations further then.

#### 4. Children and consent to mental health treatment

Minors Aged 16-18

The Mental Health Act 2001 amended the definition of child to bring it in line with the Child Care Act 1991, defining a child as a person under the age of 18 years, other than a person who is or has been married. This definition has been problematical, as acknowledged by the Department of Health's Interim Report of the Mental Health Act 2001. The definition has given rise to difficulties in the recognition of the capacity to consent. The National Consent Advisory Group should be aware that section 57 of the Mental Health Act 2001 requires as a general principle, the consent of the patient to treatment. Unfortunately the definition of patient does not include children so it appears that children are not recognised as having the capacity to consent to or refuse admission or treatment. This means that decisions around consent and refusal of treatment are to be decided by parents. It is well recognised that there is a lack of clarity in relation to the interface between the Mental Health Act 2001 and the NonFatal Offences against the Persons Act 1997. The 1997 Act provides that a 16 or 17 year old can consent to treatment and where consent is given, it is not necessary to obtain the consent of person's parent or guardian. There is much uncertainty as to whether section 23 of the 1997 Act has any application with respect to admission to and provision of treatment for a mental health problem. The National Consent Advisory Group has an opportunity to address this lack of clarity. The Interim Report on the Review of the Mental Health Act recommended that children aged 16 or 17 should be presumed to have capacity to consent and refuse mental healthcare and treatment.<sup>24</sup> While the Interim Report also recommended that the admission and treatment of children under 16 requires the consent of the parent, it expressly stated that the views of the child should be heard and given due weight in accordance with the child's age and maturity. Al welcomes that statement in the draft national consent policy regarding children and mental health that the "general principles of consent apply where any other treatment or intervention in health and social care is required to be provided to the child or young person". Al welcomes the recommendation of the

 $<sup>^{23}</sup>$  Ibid 12, at pages 16 – 17.

<sup>&</sup>lt;sup>24</sup> Ibid 12, at page 17.

Law Reform Commission to introduce a Health (Children and Consent to Health Care Treatment) Bill.<sup>25</sup>

# Children under 16 years old

The position in relation to children below the age of 16 years is less clear than those ages 16 and 17. Competence 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 a "sliding scale test" in determining whether a minor under 16 has maturity and capacity to consent, including decisions in respect of admission and treatment, as put forward by the Law Reform Commission. The Law Reform Commission has stated that its recommendations regarding healthcare decisionmaking by persons under 16 should also be applied in the context of mental health. Their recommendations state that there should not be a presumption of capacity for those under 16, but that a person under 16 may consent to, and refuse treatment where it is established that he or she has the maturity and understanding to appreciate the nature and consequences of the specific treatment. The Commission also recommend that the usual situation should be that the parents or guardians are involved in the decision-making process and that the child should be encouraged to involve his or her parents and that it is therefore only in exceptional circumstances, and having regard to an objective assessment of both the rights and the best interests of the child, that treatment would be provided to those under 16 without the knowledge or consent of parents or quardians. It is of the utmost importance that the concept of the best interests of the child or young person be interpreted and applied in light of the need to respect the evolving capacities of the child. The UN Committee on the Rights of the Child has stressed that there is no tension between the Article 3 (best interests) and Article 12 (right to be heard). 26

It must be stressed, however that all children who are capable of forming their own views must be allowed to express their views freely. 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 has capacity. Accordingly, thought needs to be given as to who should be tasked with determining whether the child has capacity and whether a multi-disciplinary team might be more suitable to perform this assessment.

# Recommendations:

- The National Consent Policy should expressly provide for recognition of 16 and 17 year olds to consent or refuse mental health treatment.
- Any reference to "best interests" as it pertains to children in either the Mental Health Act Review or the draft Health (Children and Consent to

<sup>&</sup>lt;sup>25</sup> See "Report Children and the Law: Medical Treatment" (Dublin: Law Reform Commission, LRC 103-2011) at page 150.

<sup>&</sup>lt;sup>26</sup> See UN Committee on the Rights of the Child *General Comment No 12* (the right of the child to be heard) *UN Doc* CRC/C/GC/12 (20 July 2009) para 74.

Health Care Treatment) Bill should make reference to the UN Convention on the Rights of the Child and be drafted in a manner that considers both Article 12 of the UN CRC (right to be heard), Article 5 of the UN CRC (evolving capacity of the child) and Article 3 of the CRPD, which requires "respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities".

- A person under 16 may consent to, and refuse treatment or admission where it is established that he or she has the maturity and understanding to appreciate the nature and consequences of the specific treatment. Specific factors to be taken into account in determining such capacity should be outlined, as recommended by the LRC. It is only in exceptional circumstances that treatment would be provided to those under 16 without the knowledge or consent of their parents or guardians.
- it shall be lawful for a healthcare professional to provide healthcare and medical treatment to a person who is 12 years of age but less than 14 years of age, provided that the healthcare professional has complied with certain requirements.<sup>28</sup>

#### 5. Conclusion

Al welcomes the work of the National Consent Advisory Group. Al is concerned that the functional approach to capacity, as set out in the draft policy, is inconsistent with the requirements of Article 12 of the CRPD. It is essential that the functional approach be moved towards the supported decision-making model required by Article 12(3) of the CRPD. Al urges the Advisory Group to further consider the requirements of Article 12 of the CRPD with respect to legal capacity. Al recommends that the national policy adopt the "will and preferences" as the guiding principle in accordance with Article 12(4) of the CRPD and examine the issues around consent of persons receiving mental health treatment as both voluntary and involuntary patients.

Any reference to "best interests" as it pertains to children in either the Mental Health Act Review or the draft Health (Children and Consent to Health Care Treatment) Bill should make reference to the UN Convention on the Rights of the Child and be drafted in a manner that considers both Article 12 of the UN CRC (right to be heard), Article 5 of the UN CRC (evolving capacity of the child) and Article 3 of the CRPD, which requires "respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities".

<sup>28</sup> LRC CP59-2009 Recommendation 7.21.

<sup>&</sup>lt;sup>27</sup> LRC 103-2011Recommendation 2.174.