



Response to the Ad Hoc Committee on the Mental Capacity Bill (NI)

Disability Action's Response July 2015

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INTRODUCTION

- 1 Disability Action is a pioneering Northern Ireland charity working with and for people with disabilities. We work with our members to provide information, training, transport awareness programmes and representation for people regardless of their disability; whether that is physical, mental, sensory, hidden or learning disability.
- 2 21% of adults and 6% of children living in private households in Northern Ireland have a disability and the incidence is one of the highest in the United Kingdom.
- 3 As a campaigning body, we work to bring about positive change to the social, economic and cultural life of people with disabilities and consequently our entire community. In pursuit of our aims we serve 45,000 people each year.
- 4 Our network of services is provided via our Headquarters in Belfast and in three regional offices in Carrickfergus, Derry and Dungannon.
- 5 Disability Action welcomes the opportunity to respond to this paper.

SPECIFIC COMMENTARY

6 **UN Convention on the Rights of Persons with Disabilities**

UNCRPD - Article 12

Disability Action welcomes the opportunity to respond to this consultation document as it refers not only to a unique piece of legislation but also to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

In relation to this legislation we are particularly concerned with its compliance with Article 12: Equal Recognition before the law.

In May 2014 the Committee on the Rights of Persons with Disabilities published General Comment on Article 12¹.

¹ Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014), Article 12: Equal Recognition before the law.

It states that "based on the initial reports of the different States parties that it has reviewed so far, the Committee observes that there is a general misunderstanding of the exact scope of the obligations of States parties under Article 12 of the Convention. Indeed, there has been a general failure to understand that the human rights-based model of disability implies a shift from the substitute decision-making to one that is based on supported decision-making".

"Supported decision-making must be available to all. A person's level of support needs (especially where these are high) should not be a barrier to obtaining support in decision-making. All forms of support in the exercise of legal capacity (including more intensive forms of support) must be based on the will and preference of the person, not on what is perceived as being in his interests."

"The right to equality before the law has long been recognised as a civil and political right, with roots in the International Covenant on Civil and Political Rights. As such, the rights provided for in Article 12 apply as at the moment of ratification. States parties have an obligation to immediately realise the rights provided for in Article 12, including the right to support in the exercise of legal capacity. Progressive realisation (art 4, para 2) does not apply to legal capacity."

There have been differing opinions on the Committee's General Comment, however, the principle of supported decision making rather than substitute decision making is key. Supported decision making is extremely important in ensuring that people with disabilities are empowered to make decisions about their lives. Without this there is a real risk that paternalistic and risk aversion cultures in society will mean that people with disabilities will continue to have their legal capacity denied.

The fact that the Committee on the Rights of Persons with Disabilities, in concluding observations, has identified specific measures to ensure the full implementation of Article 12, including development of models of supported decision making².

Disability Action welcomes that a statement on compatibility with the ECHR but is disappointed that the UNCRPD has not been included in

² CRPD/C/ARG/CO/1 Concluding Observations: Argentina, at para 20; CRPD/C/AUT/CO/1 Concluding Observations: Austria, at para 28; CRPD/C/CHN/CO/1 Concluding Observations: China, at para 22; and CRPD/C/PRY/CO/1 Concluding Observations: Paraguay, at para 30.

the explanatory notes accompanying the Bill. Disability Action would draw attention to the General Comment on Article 12, which clearly states that progressive realization does not apply to Article 12.

UNCRPD - Article 7

The Committee on the Rights of Persons with Disabilities published General Comment on Article 12³ makes particular reference to children with disabilities. It states that " While article 12 of the Convention protects equality before the law for all persons, regardless of age, article 7 of the Convention recognised the developing capacities of children and requires that "in all actions concerning children with disabilities, the best interests of the child [...] be a primary consideration" (para 2) and that "their views [be] given due weight in accordance with their age and maturity" (para 3). To comply with article 12, States must examine their laws to ensure that the will and preferences of children with disabilities are respected on an equal basis with other children".

We will address the implications of Article 12 and 7 in more detail in our comment on children later in this document.

7 General Comment

7.1 Principles - Capacity

Disability Action is concerned that the Bill states that 'all practical help and support have been given without success' will lead to substitute decision making rather than supported decision making, this will be considered later in this document.

We welcome that a person is assumed to have capacity unless it is established otherwise.

7.2 Principles - Best Interest

As outlined previously Disability Action is concerned that that the principle of best interest is not compliant with the UNCRPD or the principles set out in Bamford. Disability Action notes the Committee on the Rights of Persons with Disabilities General Comment on Article 12, paragraph 4 states that:

³ Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014), Article 12: Equal Recognition before the law.

"Where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace the "best interests" determinations. This respects the rights, will and preferences of the individual, in accordance with article 12, paragraph 4. The "best interests" principle is not a safeguard which complies with article 12 in relation to adults. The "will and preferences" paradigm must replace the "best interests" paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others."

The particular area of concern is that *"all people risk being subject to undue influence, yet this may be exacerbated for those who rely on the support of others to make decisions"*.

There needs to be amendments to the Bill so that it is the 'will and preferences' and therefore the autonomy of individual is the overriding principle.

Whilst understanding that this is primary legislation Disability Action have concerns that the wording of the Bill (Clause 3) 'unable to make a decision' does not put enough emphasis on the level of support to make a decision. Our concern is that the conditions could be open to significant mis-interpretation which will lead to substitute decision making rather than supported decision making.

7.3 Lack of Capacity

Disability Action welcomes the Bill defines the term 'lacks capacity' in way that it is clear that it is not a blanket assessment. This is of particular relevance given the wide range and scope of the areas of a person's life that the Bill will cover.

It is vitally important that the legislation does not allow for one assessment of capacity for a specific decision to then become a measure for other decisions.

7.4 Lasting Power of Attorney

Disability Action welcomes the LPA and the extension of the scope to include health and welfare matters as well as financial. The benefit of the LPA will only be realised if there is sufficient understanding of the role and it is promoted widely. In particular HSCT's should have a duty

to ensure that the LPA role has been clearly considered and explained. In particular through our existing work we know that the registration process can be difficult for individuals and families and appropriate supports need to be in place to support people through the process.

Disability Action welcomes the variant in the types of decisions that can be made by an Attorney under the LPA and that there have been appropriate mechanisms put in place for differing aspects of an individuals life. However, we would seek clarification if the legislation will allow for different Attorneys to be registered for different situations. For example, one for financial aspects and another for welfare matters?

Disability Action also welcome that an attorney must comply with the principles of the Bill, however, we would reiterate that this should be the 'will and preferences' and not 'best interest'.

7.5 Advance Decisions

The inclusion of Advance Decisions is welcome, but it is concerning that while clause 10 does require an effective advance decision to refuse treatment to be complied with, it is only applicable and valid under the common law. As the House of Lords report on the post legislative scrutiny of the Mental Capacity Act (England and Wales)⁴ found that *"advance decisions that are not recorded or shared with relevant public bodies are likely to be ineffective. Poor understanding among health and social care staff needs to be addressed to promote the benefits of advance decisions to patients, as well as to ensure that they are followed when valid and applicable"*.

This demonstrates that even with a legislative statute there is a lack of understanding of the AD and that it is not being used effectively to the benefit of people with disabilities. Without having a legislative base or at least strong regulation around AD's then it is evident that they will have little of no impact on supporting people to make decisions in advance, particularly in emergency situations.

7.6 General Safeguards

In relation to the general safeguards Disability Action would again raise concern that it states that "when doing the act, a person intervening

⁴ House of Lords Select Committee on the Mental Capacity Act 2005. Mental Capacity Act 2005: post-legislative scrutiny, March 2013

must also reasonably believe that it would be in the person's best interest". This should be replaced with 'will and preference' rather than best interest.

7.7 Additional Safeguards for Serious Interventions

Disability Action welcomes that an individual will have additional safeguards in relation to serious interventions and will provide further comment on the subsequent subordinate legislation and code of practice.

The Committee on the Rights of Persons with Disabilities in its General Comment on Article 12 make specific reference to the relationship with other articles of the convention and in particular 15,16 and 17 in relation to respect for personal integrity and freedom from torture, violence, exploitation and abuse. The comment in relation to article 14 and 25 in relation to liberty, security and consent are also applicable here.

Article 14 & 25 - "The right to enjoyment of the highest attainable standard of health (art. 25) includes the right to health care on the basis of free and informed consent. States parties have an obligation to require all health and medical professionals (including psychiatric professionals) to obtain the free and informed consent of persons with disabilities prior to any treatment. In conjunction with the right to legal capacity on an equal basis with others, States parties have an obligation not to permit substitute decision-makers to provide consent on behalf of persons with disabilities. All health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities. They should also ensure, to the best of their ability, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities."

Article 15, 16, 17: "States parties must, instead, respect the legal capacity of persons with disabilities to make decisions at all times, including in crisis situations; must ensure that accurate and accessible information is provided about service options and that non-medical approaches are made available; and must provide access to independent support. States parties have an obligation to provide access to support for decisions regarding psychiatric and other medical treatment. Forced treatment is a particular problem for persons with psychosocial, intellectual and other cognitive disabilities. States parties must abolish policies and legislative provisions that allow or perpetrate forced treatment, as it is an ongoing violation found in mental health

laws across the globe, despite empirical evidence indicating its lack of effectiveness and the views of people using mental health systems who have experienced deep pain and trauma as a result of forced treatment. The Committee recommends that States parties ensure that decisions relating to a person's physical or mental integrity can only be taken with the free and informed consent of the person concerned."

7.8 Formal Assessment of Capacity

Disability Action welcomes that a written statement of formal assessment of capacity should be undertaken and that a written statement of capacity must be made.

The written statement should go further than what is outlined in relation to 'specify any help or support that has been given to the person, without success, to enable them to make the decision in questions'. This statement should provide further due regard to the 'will and preference' of the individual and provide evidence of supported decision making rather than substitute decision making.

The regulation power that is in the Bill in relation to designating who is a suitably 'qualified' person to undertake the formal assessment capacity is important.

7.9 Nominated persons

It is unclear from the legislation how the role of the nominated person will interact with the process as a whole. The legislation states that the duty to consult is only where '*practicable and appropriate*' and only to '*take views into account*'. All of these terms are open to significantly different interpretations and therefore there needs to be further consideration on how this would work in a practical basis.

The term 'best interest' should also be removed and replaced with 'will and preferences'.

In relation to who may act as a nominated person, the person with a disability may have capacity to nominate a person, but they may not have the capacity to make the decision in relation to the serious intervention.

It is welcome that the role of the primary carer has been recognised within the default nominated persons list.

7.10 Second opinions

The Bill seems to apply that there is no role for a second opinion on the formal assessment of capacity, only on the medical intervention. Given that the significance of the formal assessment of capacity, thought should be given as to how a person can actually obtain a second opinion in relation to the initial capacity assessment.

During the second opinion process outlined there only seems a duty to consult with 'persons principally concerned with the person's treatment' and it is not clear from this if this would include nominated persons or anyone else involved in supporting the person.

The legislation in Chapter 3 states that the second use the term 'recently enough'; this is very vague and given that many situations can change relatively.

Again consideration needs to be given to the timescales in relation to medications, 3 months is a considerably long time and could have consequences for the individual.

The narrative in the consultation document refers to the 'person's best interest', this should be changed to ensure that the autonomy of the person is respected at all times and they are supported to make as many decisions as possible about any interventions.

7.11 Deprivation of Liberty

Disability Action is concerned that the deprivation of liberty (DOL) clauses only refers to hospital and care homes. As mechanisms for independent living are expanded, it is important that there is recognition that a deprivation of liberty could occur outside of the hospital or care home situation. For example, does the definition of a care home apply to a supporting living centre? There needs to be clarification on the definition of hospital and care home but also a recognition that DOL can happen in a community based setting.

The evidence from the House of Lords Select committee report on the Mental Capacity Act in England and Wales⁵ gives weight to the considerable concerns about the application of legislation in relation to

⁵ House of Lords Select Committee on the Mental Capacity Act 2005. Mental Capacity Act 2005: post-legislative scrutiny, March 2013

deprivation of liberty. It is imperative that the learning established from other areas in the UK is used to inform the regulation and codes of practice to ensure that that DOL is only used in the most robust cases and for the shortest period possible.

7.12 Community Resident Requirements

Disability Action's concerns in relation to this are similar to those outlined in section 7.14, but we have further concerns relating to what will be designated as 'training, education, occupation or treatment'.

Currently, through our work, Disability Action support individuals who feel they do not want to attend these day activities and feel that it is being forced upon them.

Disability Action welcomes the scope legislation for regulations to ensure that such requirements are regularly monitored, this must be undertaken by an independent organisation and ensure that there is adequate scope for action to be taken against at HSCT where they have been found in breach of their requirements.

7.13 Compulsory Treatment with Serious Consequences

Disability Action welcomes that the nominated person will provide an additional safeguard for P in relation in this circumstance. It is essential that the regulations developed, clearly outline the types of treatment and the circumstances in which the above can be implemented. Learning from the House of Lords report⁶ should be considered. In one evidence session it was reported that "*several witnesses expressed concern that medical settings it appeared that an assessment was triggered in most cases only when treatment was refused*".

"Nurses and other staff working with adults with learning disabilities interviewed by Dr Julie McVey admitted that "if a service user implied consent by not resisting care, treatment or interventions then the MCA was not used". Others expressed concern about this "since it ran the risk of allowing a vulnerable adult to undergo treatment without any of the relevant safeguards provided by a best interests test, as long as they were acquiescent."

⁶ Ibid

Disability Action would seek clarity on the safeguards which will be put in place with regard to individuals with fluctuating capacity and would express concern that this group of individuals would not have additional safeguards included.

7.14 Independence Advocacy

Disability Action welcomes that the right to independent advocacy has been included within the Bill and that further regulations will be developed. However, it is our strong belief that the provision of independent advocacy should not only relate to the 'serious compulsory interventions' but should be available at all stages of the processes, including prior to the capacity assessment.

The House of Lords report recommended that:

"Extending the range of circumstances in which IMCAs are appointed, and involving them earlier in the decision-making process, would be beneficial" and;

"We recommend that local authorities use their discretionary powers to appoint IMCAs more widely than is currently the case. To support this, we recommend the Government issue guidance to local authorities and health service commissioners about the benefits of wider and earlier use of IMCA services. We believe the costs of greater IMCA involvement should be balanced against the resources required in lengthy disputes or ultimately in litigation."

Disability Action recommends that the individual should have a right to an advocate of their choosing and that the HSCT should be obligated to provide this. If the individual has an established relationship with an advocate or advocacy provider which they wish to retain this should be allowed. We support the functions of an independent advocate. We welcome the inclusion of Clause 84.

We believe that the right to advocacy should extend to under 16's We also believe that the right to advocacy should be extended from higher tier interventions and include a right to request an advocate should the individual so desire.

We agree that the individual should be given information regarding the advocacy service but that this should be done through engaging with an

advocate, rather than allowing a professional with a different area of expertise to explain this role.

As it stands the person who is potentially most challenged by the presence of advocacy is also the gateway to the service. We feel the advocate is best placed to explain their role and offer the service and meeting an advocate in person is reasonable support to the decision making process of whether to use an advocate.

There should be clear guidance on 'self-referral' to independent advocacy services in either the Bill or subsequent regulations. This would mean that it is not just when a trigger point is established by the Trust but that a person or their nominated person could act to obtain the services of an independent advocate when they see appropriate.

The term 'best interest' should also be removed and replaced with 'will and preferences'.

7.15 Review Tribunal

Disability Action welcomes the change of name from The Mental Health Review Tribunal to the Review Tribunal so that it reflects the scope of the legislation and to whom it may apply.

We welcome that others, apart from the HSC Trust may make an application for Tribunal, especially in relation to those that have no family or capacity to identify a nominated person.

Disability Action would suggest that the duty of the HSC to refer P's case to the Tribunal within two years should be reduced to a period of one year.

We have had opportunity to support people under detention, wherein it was not expressly stated in an appropriate way to P when an extension was applied for or the reasons for such an extension.

We would also welcome clarity around the HSCT informing authorities such as RQIA around its intention to refer the individual for Tribunal, to ensure the application was done in a timely manner and was wholly appropriate for the needs and within the rights of the individual.

Disability Action has supported someone through such an instance who clearly asked 'Am I detained or am I not'. If a person is not seen as

meeting the requirements for detention it should be lifted with immediate effect rather than allowing the person to be treated in a way which clearly is in breach of their rights. This can also lead a person to believe that they have a 'fear of consequence' hanging over their head whilst they wait for the said date and this in itself is a deprivation of liberty

In relation to clause 55, Disability Action has some specific concerns.

An advocacy role is to support someone in a decision making process, help them voice their opinions and represent their opinions. It is therefore a misunderstanding and misrepresentation of the role of the advocate to say the views of the independent advocate should be taken into account. To do so would signify a substituted decision making approach rather than a supported decision making approach and is a matter of serious concern.

We again express reservations about the declaration processes and safe guards.

The term 'best interest' should also be removed and replaced with 'will and preferences'.

7.16 Power to make Regulations about Dealing with Money and Valuables

Whilst the legislation is prescriptive there needs to be further guidance as to how a person can be supported to make decisions about different aspects of their finances. There needs to be due regard given to improving the capacity of an individual so that they can increase the control they have over their expenditure and payment. Guidance will also need to be available as to what is meant by a 'reasonable price'.

7.17 Transfers between Jurisdictions

If a decision is made in relation to transfer of jurisdiction there must be evidence provided on what measures have been put in place to ensure that, before the individual is considered for transfer, that all other reasonable and practicable solutions were tried and given a suitable timeframe in which to work.

There should be a right to independent advocacy to ensure the individual has had involvement around all care planning around their transfer and why such a transfer is required, especially in the case of

individuals who are transferring to a setting which has greater security/restrictions in place.

Disability Action would ask for clarification on how an individual's right to a private and family life will be upheld when an individual is transferred out of the jurisdiction in which they live and what duty will be placed on the HSC to ensure that they can still access family life.

It is essential that the individual knows about their rights in relation to application to the Review Tribunal and the timeframes for applications within their new jurisdiction.

The individual or their nominated person should be made aware of any changes of legislation that will have an effect on them that they were not subject to in Northern Ireland and when this will take effect. The placement should be under regular review and independent scrutiny. The individual should not remain indefinitely in another jurisdiction on the basis of a lack of resources or placements, which in itself would be a deprivation of their liberty.

The term 'best interest' should also be removed and replaced with 'will and preferences'.

7.18 Excluded Decisions

Disability Action would advise that before making comment on the exclusion of family relations from the Bill that there needs to be a rationale provided by the Department as to why it hasn't been included. Further discussion is needed, in particular with reference to the CRPD Committee General Comment on Article 12⁷ which states in relation to women with disabilities (Article 6); "*The Convention on the Rights of Persons with Disabilities recognizes that women with disabilities may be subject to multiple and intersectional forms of discrimination based on gender and disability. For example, women with disabilities are subjected to high rates of forced sterilization, and are often denied control of their reproductive health and decision-making, the assumption being that they are not capable of consenting to sex. Certain jurisdictions also have higher rates of imposing substitute decision-makers on women than on men. Therefore, it is particularly important to reaffirm*

⁷ Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014), Article 12: Equal Recognition before the law.

that the legal capacity of women with disabilities should be recognized on an equal basis with others".

7.19 Direct Payments

With regard to the references to Direct Payment in the Mental Capacity Bill, we welcome the proposed changes, particularly as since the outcome of the judicial review in 2011, there have been significant bureaucratic barriers to individuals and their families in accessing direct payments.

7.20 Children and Young People

In their General Comments on Article 12, the CRPD stated that " While article 12 of the Convention protects equality before the law for all persons, regardless of age, article 7 of the Convention recognised the developing capacities of children and requires that "in all actions concerning children with disabilities, the best interests of the child [...] be a primary consideration" (para 2) and that "their views [be] given due weight in accordance with their age and maturity" (para 3). To comply with article 12, States must examine their laws to ensure that the will and preferences of children with disabilities are respected on an equal basis with other children".

7.21 Police and Place of Safety

Individuals we have supported have indicated how they would like to have had an opportunity to use some type of advance statements when it comes to detention or being removed from a place by the police. They have explained how they can't communicate it at the time of their interface with the police/ASW but how they would like to indicate the place of safety that they feel safest in. Some would prefer a police station whilst others are vastly opposed to it and others find going to an acute hospital's A&E department to be highly unsuitable due to the lack of time staff have, feeling judged by other members of the public or having greater access to things they can use to harm themselves. Whilst we recognise the role of the police to protect both the individual and the public we would ask consideration be given to this honest appraisal by those who have been through the process.

We would also like to see clarification on who would be involved in decision making when both health and criminal justice are involved. Due to the short timeframes available for some decisions to be made, we

would still expect due process to occur and that the model of supported decision making be in place.

7.22 Courts, Remand and Sentencing

The role of independent advocacy is essential to the individual for court and its subsequent outcomes - especially to try and appropriately explain processes such as remand and sentencing. It is very important that as with the Tribunal, an individual can apply to the court for a termination of remand based on a medical report from a medical practitioner of their choosing. It is also important to ensure that the medical examinations are carried out within the timeframe required before compulsory treatment can occur.

We welcome the community residence order in place of the Guardianship Order; although whilst it stipulates the particular place may include a hospital, we would prefer that this would be looked at as a last option if this is not what the individual wanted. We would also refer again to our disapproval of anyone being forced to attend training, education or occupation.

7.23 Unfitness to Plead

During consultation the Law Commission hoped any new unfitness to plead tests would modernise the language. It is disappointing that the language in the Bill is stigmatising, we would ask that this is amended.

7.24 Community Based Disposals in Unfitness to Plead

We do not agree with the use of the community residence order to require people to attend training, education or occupation in unfitness cases. These should be seen as personal choices and do not sit alongside the clear requirement and necessity for treatment or residence in a particular location.

8 CONCLUDING COMMENTS

Disability Action will provide a detailed clause by clause response by 31 July 2015.