Written Submission from Niamh to the Ad Hoc Joint Committee on the

Mental Capacity Bill (NI)

June 2015

1. Introduction

Niamh (the Northern Ireland Association for Mental Health), is the largest and longest established independent charity focusing on mental health, learning disability and wellbeing services in Northern Ireland. Niamh is structured as a group consisting of four elements, Compass, Beacon, Inspire and Carecall.

We welcome the opportunity to make this submission to the Ad Hoc Joint Committee on the Mental Capacity Bill. Niamh made a full submission to the consultation on the Bill last year and in this submission we have focussed specifically on the legislative content and the impact it will have on vulnerable people.

Our response is contextualised by the human rights commitments made by the UK under the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and focuses on the issues arising for people with lived experience of mental ill health. Although this is legislation for the whole population, it will disproportionately impact people experiencing mental health problems.

This submission is informed by a consultation event that we organized with people with lived experience of mental ill-health and advocates, which focused on Supported Decision Making around the following themes: support to alleviate crisis before hospital admission; information and support in hospital; pre-planning for crisis: specific supports and who provides this support; thoughts on detention; independent advocacy; the Mental Health Review Tribunal; Automatic Review; and complaints.

2. Context

This will be the legislation under which the State will have powers to intervene in fundamental human rights in a way which could deprive people of their liberty or to be compulsorily treated in hospital and the community. It is also the legislation under which individuals could be fully supported to make their own decisions by: professionals in civil and criminal justice services, independent advocates and Nominated Persons; and to have their will and preferences codified through Advanced Decisions and protected through Lasting Powers of Attorney.

Given the complexity of the legislation including its inclusion of both civil and criminal justice systems, **we consider that it is imperative that there is one statutory body** with responsibility for overseeing the implementation of the legislation and Code or Practice; monitoring and reviewing its operation; and developing mitigations when issues arise. This body would have responsibility for public awareness and training around the legislation. Our position is informed by the House of Lords Select Committee on the Mental Capacity Act 2005 finding that this groundbreaking legislation's potential was not fully realized because there was no single driver and overseer of the Act.[1]

[1] 'Our principal recommendation to address the failure to embed the Act in every day practice is that responsibility for oversight of its implementation should be given to a single independent body.' (This

Central messages

We have consistently advocated for the Mental Capacity (NI) Bill to deliver the following.

- Human rights based legislation.
- A statutory duty to provide supported decision-making around both everyday issues as well as serious interventions.
- A statutory duty to provide independent advocacy at all stages of the legislation including during assessment.
- Codification of advanced decisions.
- A robust monitoring and evaluation system for the legislation.

This written submission provides the opportunity for us to expand and provide greater detail on our position by providing commentary on a number of specific provisions and where relevant made a number of suggestions.

2. Comments on the contents of the Bill

PART 1 SECTION 1 - Principles

Principles: Capacity and Best Interests

We welcome the enshrining in statute of the principle that a person is assumed to have capacity unless it is established otherwise.

We welcome the principle that a person is unable to make a decision unless all practicable help and support have been given without success.

We note that the principles referred to in the CD and Bill are not those envisaged by the Bamford Review. The Autonomy principle remains in place. However the Justice principle (applying the law fairly and equally) has been removed. The key Bamford principles of Least Harm and Benefit have been replaced with a Best Interests principle.

We recognize the Bamford Review's fundamental contribution to enhancing the lives of people with mental health problems and learning disability. However, up to now the Bamford Review has been unevenly and partially implemented. Therefore, there are significant deficits in mental health service provision, which need to be addressed if the legislation is to be successfully implemented. Further, the UNCRPD was ratified by the UK in 2009 (that is after the Bamford Review) and embodies additional human rights commitments by the UK State.

We are concerned about the use of the 'Best Interests' concept, which is considered to be outmoded; and risks a paternalistic rather than a human rights based approach to capacity for adults. We express concern that Best Interests decisions are made conditional by use of 'reasonable, practicable and appropriate' terminology.

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is discussed in Chapter 4 Addressing Poor Implementation of the Act, paragraphs 113-117) (13 March 2014)

We note that the four part meaning of an individual being 'unable to make a decision', which relates to their capacity to: understand, retain, appreciate and communicate.

We recommend

1. The adoption of a human rights based approach to (i) ensure equal recognition before the law (in line with Article 12 of UNCRPD) and (ii) secure knowledge of and acting on the 'will and preference' of the individual.
2. Explicit definitions of what is meant by 'reasonable, practicable and appropriate'; and a duty to record personnel's decision making and actions regarding such limitations on ensuring that the individual's 'will and preference' are respected.
3. The human rights compatibility of the four part assessment of an individual's capacity is addressed in the statement of human rights compliance in the Bill's Explanatory Notes.

PART 1 SECTION 3 - Capacity

We welcome the issue and time specific character of the definition of 'lacks capacity'.

PART 1 SECTION 5 - Supporting Person to Make Decision

We consider that 'Supporting person to make decision' is a critical component within the Bill.

Providing person-centred support to individuals, their families and carers in the community has been the preferred model of mental health care for several decades. Whilst hospitalization can provide the most appropriate care for certain individuals in specific circumstances, it can be both distressing and disruptive both of the individual's lives and their recovery. Detention can be a traumatic experience for individuals and their families and carers.

We recommend

1. The Bill should clearly set out a duty to demonstrate that a record is kept on each of the measures detailing the actions taken in order to (i) de-escalate the situation, (ii) ensure adequate support was offered, (iii) check whether an Advanced Plan and / or Lasting Power of Attorney was in place, and (iv) provide that every measure was exhausted. This includes recording the reasons why the support was ineffective and why it is considered that no alternatives of support were available.
2. Ensure that these records are made available to an individual post-crisis / emergency in order that they can understand what has happened (as this can be difficult for individuals to recollect or comprehend). Issues of carer confidentiality will need to be considered regarding provision of these records.
3. Set out detailed codified safeguards for people who are visibly distressed and / or have mental health problems.

PART 2 SECTION 9 - Protection from Liability

We have a number of concerns regarding the scope of the Protection from Liability due to its relationship with other parts of the legislation. We have made recommendations around these clauses. The protection against civil and criminal liability provided actions "will be in P's best interests' raises concerns given our view that this provides scope for staff to act paternalistically rather than on the basis of P's will and preference (PT2 C1 9(1)(d)(ii)).

PART 2 SECTION 11 – Advance Decisions

We note: (i) the centrality of advanced decisions in mental health care and the recovery ethos; (ii) that the Mental Capacity Act in England and Wales codified advance decisions; and (iii) the NI legislation has been presented as a once in a generation opportunity to deliver ground breaking legislation.

We consider to be inadequate the Department's explanation for the decision not to codify advance decisions: 'the law…is still evolving and that it would therefore be premature to fix it in statute at this point'.

In the context of recovery, Advanced Decisions are a positive, therapeutic and empowering resource for people with mental health problems, their families and carers, and the services that support them. The draft Bill's requirement of 'an effective advance decision to refuse treatment to be complied with, if it is valid and applicable under the common law (clause 10, CD para 2.17 p12) is insufficient to address the wider purpose of Advanced Directives. Without codified Advanced Decisions, there is a high risk that the recorded will and preference of individuals will be (i) unavailable in crises or emergencies (because it is not centrally lodged) or (ii) partially or completely disregarded. We consider codified Advanced Decisions to be a fundamental safeguard.

We recommend

1. Codification of Advanced Decisions.
2. Duty on statutory services to promote and facilitate Advanced Decisions (whether they are codified or not).
3. Review of Advanced Decisions on a 6 month basis in order to ensure that they are current.
4. Clarification of the Department's decision not to codify the common law rules in relation to Advance Decisions.
5. If the Department continues with its decision not to codify Advance Decisions, clarification of what systems will be put in place in order to ensure that professionals and services are up-to-date with common law.
6. If the Department continues with its decision not to codify Advance Decisions, commitment to a public awareness raising programme regarding the common law on Advance Decisions.

PART 2 SECTION 12 - Restraint

We welcome the use of a broad definition of restraint; requirement of proportionality; and the clear statement that a person who is involved in a disproportionate act of restraint that will not be protected under Section 9(2) -Protection from Liability. We consider that matters relating to restraint in the Bill, Regulations and Code of Practice must be evidenced based and co-produced with people directly impacted by the use of restraint and the voluntary organisations that work with them. The use of scenario building methodology would be particularly useful.

We recommend

1. Research into the use of restraint in Northern Ireland and other UK jurisdictions should inform the Bill, Regulations and Code of Practice.
2. The Regulations and the Code of Practice should be co-produced with people directly impacted by the use of restraint and the voluntary organisations that work with them.

PART 2 CHAPTER 2 - Additional Safeguards for Serious Interventions
SECTION13 Formal assessment of capacity

We have commented already on:

- the need for compatibility with UK human rights commitments and
- the general safeguards of the person intervening (i) must take reasonable steps to establish whether P lacks capacity in relation to the matter, and when doing the act, must reasonably believe that P lacks capacity in relation to the matter; and (ii) must reasonably believe it would be in P's best interest.

PART 2 CHAPTER 2 SECTION 15 - Nominated person

We consider that it is essential that the Nominated Person is in place, consulted and have her/his views taken into account with regard to the person's will and preference (rather than best interests). We are concerned that the approach of 'where practicable and appropriate' weakens this safeguard. If our recommendations regarding the codification of Advanced Decisions are accepted, we intend that this will be the primary basis on which decisions are taken regarding serious interventions.

As the legislation creates a number of new roles, it is essential that the Departments work with those directly impacted by the legislation (individuals, families and carers), professional bodies and services to agree how these roles will work together, and how any incidents of conflict will be mediated. Primary carers have raised concerns about how they will be involved in assessment of capacity and ongoing operation of the legislation, how their expertise will be taken into account, and how their confidentiality will be protected with regard to information and opinions that they contribute.

We recommend

1. A duty on the HSCT to ensure that the NP must be in place, consulted and have his /her views taken into account with the regard to P's will and preference.
2. The Code of Practice should include detail the operation of the NP role and how these must be recorded.
3. The NP role should be a recognized responsibility and adequately resourced.
4. Measures should be put in place so that the NP can fulfill this role including at short notice.
5. The default list should include social as well as familial relationships.
6. Additional measures should be put in place for individuals who are isolated from family and social relationships.
7. The Department clarifies with individuals who will be impacted by the legislation, professional bodies and services how the new roles created by the legislation including the NP will work together with the individual and the primary carer(s).

PART 2 CHAPTER 2 SECTION 16 - Second Opinions

Comments regarding 'best interests' apply to this section. It is important that all second opinions are independent of the service in which the serious intervention is to take place.

We recommend

Second Opinions should be secured from professionals who do not work or have not worked in the same HSCT area in which the serious intervention is to take place; and take place in a timely manner.

PART 2 CHAPTER 4 SECTIONS 19-28 Authorisations etc

We note that serious interventions includes Deprivation of Liberty, Compulsory Attendance, Compulsory Residence, and Compulsory Treatment. We note that mental health organisations in England and Wales are so concerned about the operation of Community Treatment Orders that they have called for them to be ceased until there is a robust evidence base about their therapeutic value. We will be interested in how these serious interventions are dealt with in the statement of human rights compatibility.

We express significant concern that the legislation proposes a HSCT constituted panel as the authorisation mechanism for serious interventions. It would be helpful if the Department would clarify the panels composition, independence, accountability, and transparency (deliberations and decision making). The operating protocols and procedures for the panels will be particularly important for example information sharing, notice periods, attendance, resourced participation and duration (in order to ensure adequate time for substantial consideration).

We would ask that the safeguarding mechanism for serious interventions would include membership of individuals with lived experience of mental ill-health and carers, as well as professionals trained in mental health.

We recommend

1. The Bill, Regulations and Code of Practice are informed by the HOC and HOL Select Committee reports and that particular attention is given to the actions on the Deprivation of Liberty Standards to be updated on within 12 months of the reports.
2. The Department clarify whether the panels will have members who are service users or carers.
2. An independent and regional safeguarding (that is one not organized in each HSCT) mechanism should be included in the legislation, which benefits from enhanced Part 2 safeguards.

PART 2 CHAPTER 5 SECTION 35 - Independent Advocate

Access to an independent advocate is viewed as an essential support and safeguard by people with mental health problems.

We welcome the work undertaken on advocacy to date by the DHSSPS and the Advocacy Network Northern Ireland (ANNI). We note that both the HOC and HOL Select Committees reported serious issues in relation to: provision of and access to independent advocacy.

Therefore, we express significant concern that access to an Independent Advocate is restricted to after the assessment is made that P lacks capacity, and only in very restricted circumstances. Independent advocacy should be consistently available to all persons who are impacted by the legislation including those assessed under its provisions.

We recommend

1. Invest in independent advocacy provision to all those who come into contact with the legislation, including access to independent advocacy as one of the supported decision making measures under Principles Clause 4: 'It cannot be concluded that a person is unable to make a decision unless all practicable help and support have been given without support'. 2. A duty for RQIA to publish an annual activity report detailing by HSCT the level, type, quality, activity and impact of independent advocacy provision; with data disaggregated by the individual's capacity status.
3. A robust quality assurance system including standards and complaints procedures.

PART 2 CHAPTER 7 - Rights of Review

SECTION 45 - Review Tribunal

We have concerns about the operation of the Mental Health Review Tribunal including the issue of an individual's status being changed 48 hours or less before their hearing. This has been raised through our services and our consultation. Individuals and advocates report that the preparation process, access and quality of legal representation and format of the review hearing require reform.

We recommend

1. A review of the Mental Health Review Tribunal is undertaken and the findings of this inform the development of the legislation and Code of Practice.
2. A duty requiring HSCTs to appropriately and adequately inform individuals about the MHRT; and facilitate individual's access to the MHRT.

3. A regional panel of solicitors for the Review Tribunal including the requirement for a proportion of these to have expertise in mental health and the mental health system.

PART 2 CHAPTER 7 - Rights of Review
SECTION 48 – Duty of HSC Trust to refer case to Tribunal (Automatic Right of Review)
We express significant concern that the period of ARR remains at 2 years. We do not consider that this is compatible with human rights.
We recommend
1. The Department clarifies why the ARR period remains at 2 years.
2. The Department clarifies how the proposed 1 year for 16 and 17 year olds, and 2 years for those aged 18 years and over is to be calculated particularly for individuals moving from child to adult services.
3. Reduction of the ARR period to 6 months (as a minimum). Our preference is that it is reduced to 3 months.
4. Data is collected on the operation of the ARR provision in order to inform the legislation's monitoring and review.

PART 2 CHAPTER 8 - Supplementary
SECTIONS 52-54 Emergency Interventions
We welcome the explicit definition of 'Emergency' in the Bill.

PART 2 CHAPTER 8 SECTION 55 - Information
We welcome the focus on information and consider that accessible, appropriate and timely information in a range of formats is a general safeguard. Services and staff need to understand the ways in which mental ill-health can impact an individual's ability to take in and process information. The information at first contact with the legislation is particularly important: through assessment and initial interventions (including signposting and referral to community services, and hospital admission).

PART 5 CHAPTER 1 -Lasting Powers of Attorney
We welcome the provision for a new system of Lasting Powers of Attorney that will replace the existing Enduring Powers of Attorney system; and through this the extension of decisions to include health (mental and physical) and welfare matters.

In order to maximize awareness and uptake of LPA, it is essential that the LPA system should be promoted by HSCTs. This will be particularly important if Advanced Planning is not codified in the legislation.

LPA should be available to as many people as possible, in as straightforward a manner as possible. Therefore the system needs to be accessible, designed to keep

legal costs down and suitable for assistance with applications to be possible through advice services.
We further welcome the introduction of a duty on HSCTs to promote the use of the LPA.
It is important that the application forms and process for registration be simple and clear and that the introduction of the LPA is adequately resourced through: public and targeted information campaigns; and training and service resource for both voluntary organisations working with groups who may avail of this provision and also advice services.

PART 8 Research

We note that the UK Research Governance Framework is to be updated during the passage of the Bill. This work will be led through England's Health Research Authority.

We recommend

The Bill Teams engage with this process in order to inform the Research Governance Framework for research undertaken with people who lack capacity.

PART 11 Transfers between Jurisdictions

Our advocacy service has raised a number of concerns about the current system of transfers between jurisdictions including the following.
(i) Under the current system once an individual is transferred from Northern Ireland to Britain the responsibility for care and treatment is devolved, and there appears to be little or no routes to appeal or revoke the decision should the individual or their family be unhappy with their ongoing treatment.
(ii) When an ECR is made to Britain and there is a cost to the HSCT there is an inherent incentive for the sending HSCT to return the individual to NI as promptly as possible in order to save costs. However, this is not the case when an individual is sent to Carstairs in Scotland because individuals are accepted by Carstairs at no cost to the HSCT. This appears to be an historic arrangement. In such cases it has proven difficult to get the HSCT to consider returning a patient to NI or to be pro-active in monitoring any developments within their care and treatment.

We recommend

1. The Departments undertake a review of issues regarding people being transferred to England, Scotland and Wales; and also being returned to Northern Ireland in order to identify whether the legislation, subordinate legislation and Code of Practice provide opportunities to resolve difficulties within the system.
2. A duty is placed on the discharging/transferring Consultant to continue to review and monitor ongoing treatment while an individual is outside of Northern Ireland; and for periodic multidisciplinary review meetings to be held involving the individual and his / her family, if appropriate.
3. The Department clarifies which jurisdiction's legislation a person is being treated under; and how the care planning will be seamlessly managed between jurisdictions on both transferring from and returning to Northern Ireland.

2.13 Other Decision Making Mechanisms

We welcome the provision of the other decision making mechanisms of the High Court, Court Appointed Deputies and Office of the Public Guardian.

We recommend

1. These mechanisms are fully costed and adequately resourced.
2. Simple and straightforward public information about and access to these mechanisms is provided for.

Part 12 Children

We consider that it is essential that the legislation and Code of Practice are compliant with UK human rights obligations. We await the statement on human rights compliance to be published in the Explanatory Notes.

We express concern at the, albeit temporary, retention of the Mental Health Order for children who are detained for assessment / treatment of mental disorder. The Bamford Review called for capacity-based legislation, which removed discrimination against people with 'mental disorder'. Whilst the new legislation will progress this call for adults; children under 16 years will continue to be subject to the discriminatory Mental Health Order. Given the time that has passed since the Bamford Review reported, it is deeply disappointing and frustrating to be in this situation.

We welcome the provision of access to an appropriate independent advocate.

We recommend

1. A review of the use of restraint on children is undertaken urgently; and safeguards regarding the use of restraint enhanced on the basis of the outcome of this review.
2. Children who are hospitalised are provided with education at the same level as is available to them in the community; and, if their mental health permits, their continued attendance at their own school is resourced in order to promote continuity in learning and relationships with teachers and students.
3. The Department clarifies how the proposed 1 year for 16 and 17 year olds, and 2 years for those aged 18 years and over is to be calculated, particularly for individuals moving from child to adult services.

PART 13 - Offences

We welcome the creation of a new offence of ill treatment or willful neglect.

We welcome the offence of the unlawful detention of a person who lacks capacity

We are concerned that sec 259 and sec 260 may result in criminalizing family, carers and friends who may be ill-advised but acting with good intention.

PART 14 – SECTION 268 Expenditure and Payment for Necessary Goods and Services

We accept this provision on the basis that all applicable safeguards are met; and that the Part 2 safeguards are strengthened.

PART 14 – SECTION 271 Direct Payments

We note Lord Justice Girvan's Judicial Review determination in 2011 that individuals lacking capacity cannot enter into contracts with HSC Trusts and therefore cannot provide the requisite consent demanded by Section 8 of the Carers and Direct Payments Act (Northern Ireland) 2002. We note the interim arrangements that have been put through the Office of Care and Protection.

We welcome this provision and the intention to develop Regulations, noting the importance of criteria and scrutiny of the 'suitable person' particularly with regard to financial abuse.

NOTES

Equality and Human Rights

We note that the CD (para5.6, p67) commits to a statement of compatibility with the European Convention on Human Rights and relevant international agreements, such as the UNCRPD, in the Explanatory Notes accompanying the Bill when it is introduced to the Assembly. As we have particular concerns about the human rights compatibility of the Bill, we look forward to reviewing this statement.

Co-production of Regulations and the Code of Practice

It is essential that those people who will be impacted by the legislation should co-produce the Regulations and Code of Practice; and the monitoring and review system and consequent mitigations that are required. Although the legislation will cover the whole population, people who experience mental health problems will be disproportionately impacted; and must be fully engaged in its development and operation. They are well placed to provide advice on how the legislation will (i) integrate with existing civil and criminal justice systems of support, care and treatment; and (ii) contribute to achieving the primary goal of mental health recovery.

The term 'co-production' is increasingly used in policy and service provision, with specific work in Northern Ireland being taken around Recovery Colleges as part of IMROC in each HSCT. We note the availability of valuable resources such as the Mind commissioned literature review produced by the New Economics Foundation (Slay and Stephens 2013), the Social Care Institute for Excellence's guide (October 2013) and best practice examples from the UK and internationally.

We recommend

1. People directly impacted by the legislation, including people with lived experience of mental ill-health, family members and carers, co-produce the Regulations, Code of Practice, monitoring and review systems, and the mitigations developed in response to their findings.
2. All co-production partners agree the meaning of and approach to be taken to this work.

3. The Executive invests in peer led networks of people with lived experience of mental ill-health and carers in order to make this work possible.
4. This co-production initiative is evaluated and learning is shared.
Additionally, with regard to the Code of Practice:
We recommend that the Code of Practice be published and commenced at the same time as the legislation.

Investment in provision, service re-orientation and culture change
In order for the legislation and Code of Practice to be successfully implemented there is an urgent need for parity of investment in mental health services; as well as service re-orientation and culture change in the civil and criminal justice systems.
We recommend
1. The Ministers of HSSPS and Justice address the need for parity of investment between mental health and physical health and social care within Budget rounds during this mandate.
2. An anti-stigma initiative is developed for staff in the civil and criminal justice systems in order to (i) address negative attitudes towards people who experience mental health problems, and (ii) enhance understanding of supported decision making and recovery.
3. The Executive invests in peer led networks of people with lived experience of mental ill-health and carers in order to make this work possible.

Conclusion

We welcome the opportunity to provide this written submission and look forward to future opportunities for Niamh and people with experience of mental ill-health to engage in the development, implementation, monitoring and review of the primary and secondary legislation and the Code of Practice; as well as the broader public policy agenda of securing parity of investment in mental health services and culture change around mental health within the civil and criminal justice systems.

Niamh would welcome the opportunity to brief the Committee on the content of this submission.