

Patient and Client Council

Your voice in health and social care

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Enclosed please find the response of the Patient and Client Council to the Mental Capacity Bill consultation.

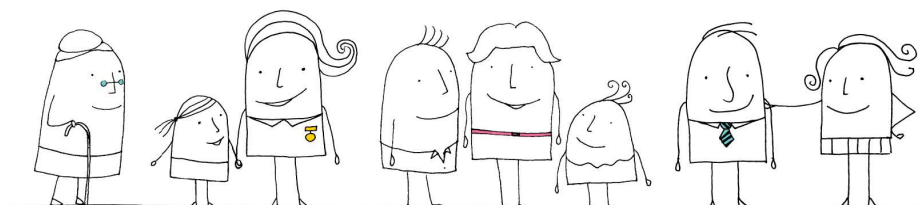
The response is the collective views of the Bamford Monitoring Group, and therefore is a response based on the views of individuals with lived experience of mental ill health or learning disability either personally or a carer for another person.

As with many organisations who have responded to this Bill, we have been limited by the unrealistic consultation window which has ran from the end of May until the beginning of September, over the summer months. This is a very substantive piece of legislation, and governs highly significant areas for service users, including detention and forced treatment and interventions. The consultation window was the first time the public have been able to see the text of the Bill, and given that this is where the detail of protection, and shortfalls in protection lie, we are disappointed that the Department chose this consultation period. Our response accordingly sets out key areas which we consider need addressed or rewritten in the Bill.

Yours sincerely



May McCann
Chair, Bamford Monitoring Group



Consultation response from the Bamford Monitoring Group on the Mental Capacity Bill

Introduction

Thank you for the opportunity to respond to the above consultation. The following response is from the Bamford Monitoring Group.

The Bamford Monitoring Group consists of individuals with lived experience of mental ill health or learning disability, either personally, or as a carer for another person.

The group has been committed to the Bill since its inception, as one of the key recommendations of the Bamford Review. As will be shown below, we consider that the Bill cannot be considered alone, but must be considered together with the current mental health and learning disability services which are available, and unavailable, in Northern Ireland. In order for the Bill to be effective, the Department must commit to providing appropriate support services (including psychological therapy), regulated independent advocacy and reform of the mental health tribunal before implementing the Bill. Additionally, in order for the protections afforded by the Bill to be genuine and effective and not theoretical and illusory, we request that the department commits to including a duty upon Health and Social Care Trusts to promote uptake of future planning mechanisms and to put in place practical, funded measures to allow individuals to make a Lasting Power of Attorney or advance statement.

Supporting People – s1 (4) and s4

We welcome the principle set out in s1(4) that a person cannot be treated as unable to make a decision for himself unless all practicable help and support to enable the person to make a decision have been given without success. People with lived experience of learning disability highlighted the need for resources to be available so that individuals had the time, support and opportunity to access information so that they could make their own decisions and that this should be provided by an independent organisation.

In order to be truly effective, we consider that s4 should include an additional sub clause s4 (4) which should state that;

'a practitioner making a decision about the capacity of P is required to record all of the steps of support which were attempted for person P, and reasons why each of these attempts were unsuccessful'.

Additionally we consider that it is essential that the Code of Practice which accompanies the Bill sets out a non-exhaustive list of appropriate supports for individuals who are subject to a capacity assessment due to mental illness or learning disability. This must include access to an advocate for the capacity assessment (particularly where an individual does not have the support of family or friends), access to his or her own community learning disability or mental health team (including in particular his or her own Consultant Psychiatrist, Psychologist, GP and CPN, Learning Disability Nurse, Social Worker or AHP.), and access to emergency psychological therapy or behaviour therapy team. Many individuals with lived experience of assessment for detention recall that their psychiatric crisis was as the result of environmental and social factors and that once an assessment had began; they felt that the team did not listen to the issues which they felt were the cause. Where these to be listened to, and assistance provided to resolve and address these issues, the crisis could be significantly deescalated. Accordingly, we consider that it is essential that this approach is provided for in the Mental Capacity Bill and supporting Code of Practice to ensure that where possible a person's crisis can be assisted to be resolved by the provision of

psychological support (which is currently unavailable) and social support that this is made available. In the situation where psychological and social support are limited resources we suggest that those affected by the bill, that is, being considered for capacity assessment should be prioritised in relation to these services.

We consider that a capacity assessment under s1 – 4 of the Bill will form the first step of providing for detention and other forced treatment or intervention. Both detention and forced treatment involve protected substantive human rights, including right to liberty protected by Article 5 ECHR, the right to freedom from torture, inhuman and degrading treatment protected by Article 3 ECHR, and the right to private life including moral, physical and psychological integrity. Accordingly, we consider that the safeguards which the Bill proposes, including access to independent advocacy, the involvement of a nominated person and consideration of advanced planning directives are available to any person being subject to a capacity assessment, together with appropriate support. We consider that any person suffering mental illness or who has a learning disability is inherently vulnerable, and accordingly this places a positive legal obligation upon the state (the assessment team) to take positive steps to protect the individual from harm. A capacity assessment is the first stage in proceeding to assessment for detention and forced treatment or intervention, and therefore may be traumatic to a person. By providing said support from the beginning of the process, the harm caused to an individual could be reduced.

We consider that for the Bill to be rights compliant, it is essential that the other recommendations of the Bamford Review, including in particular the provision of appropriate psychological therapies to all as part of the essential supports which must be made available to a person for the purpose of s4. Furthermore, access to psychological therapy should be available in all settings, including hospital whilst a person is being treated. This is relevant for the purpose of the proposed Bill as the Bill requires frequent reassessment of an individual's capacity. Accordingly supports which would enable a person to make a decision for themselves must continue to be made available once a person is found to lack capacity for the purpose of reassessment. Currently there is an absence of provision of these services, particularly for those with moderate to severe conditions or learning disability. We consider that the provision of emergency psychological therapy can help to deescalate a psychiatric crisis and are particularly concerned that these services are yet to be commissioned over 7 years since the conclusion of the Bamford Review.

Duty upon Health and Social Care Trusts to promote future planning and to fund future planning structures and processes

We consider that as this Bill does not adopt a fully supported decision making model as required by Article 12 of the UNCRPD, but puts in place substitute decision making model, that once a finding that a person lacks capacity has been made, it is imperative that the mechanisms to protect a person's advance decisions are robust, fit for purpose, practical and effective. The Scottish Mental Health (Care and Treatment) Act 2003 provided for advance planning but did not include a duty on Health Boards (the Scottish equivalent of Health and Social Care Trusts) to promote uptake and uptake accordingly has been low. This is now one of the main subjects of reform of that legislation and has been a major focus of service user groups across Scotland who are lobbying for change to the Bill.

We recommend that the Bill includes a legal duty upon Health and Social Care Trusts to promote uptake of future planning tools. We are concerned that the lack of codification in this Bill of advance directives creates legal uncertainty which may mean that unless a person creates a formal Lasting Power of Attorney; their advance directive will not be recognised. Creation of a Lasting Power of Attorney requires for an individual to attend a solicitor, together with their nominated person. We consider that funding should be made available to cover the cost of the creation of a Lasting Power of Attorney, and appropriate support should be provided to individuals with a learning disability or pre-existing mental health diagnoses to enable them to make a Lasting Power of Attorney. For many individuals, considering future psychiatric crisis can

be incredibly difficult and re-traumatising, and accordingly appropriate social support should be given to ensure that individual rights are not weakened due to both personal and financial obstacles to the creation of a Lasting Power of Attorney. Additionally, we would recommend that solicitors hold clinics in health centres, day centres and other familiar settings (for example residential homes and supported living services) to create a suitable person sensitive space especially for particularly vulnerable individuals.

Default nominated person list

We consider that in the absence of a lasting power of attorney or other advance directive which puts in place a nominated person, it is imperative that the default nominated person list set out in s74 of the Bill recognises that when a person is in psychiatric crisis, their wishes may conflict with those of their family and carers, and that tensions within families in times of crisis may leave a person without the assistance of the default nominated person. We consider that the Bill should be reflective of this, and that it should include a role for a close personal friend who can advocate for them. For many people with a learning disability, family carers play an important role in ensuring that decision makers understand and take account of the needs of the person they care for and they are likely to be identified as the default nominated person. The Bill must ensure that the decision maker is required to demonstrate how they have taken account of the views of the nominated person and how they have ensured that these views reflect the views and wishes of the person assessed as lacking capacity. Recognition should also be given to the fact that there may be more than one family carer who could be considered to be the nominated person and that they may not always share the care and support in the one household, such as parents who are separated or divorced or siblings.

'Emergency' clause

We are concerned that the inclusion of the 'emergency' clause in ss12 (6) (Additional Safeguards for Serious Interventions), ss13 (4) (nominated person: need to have in place and consult), ss14 (5) (Second opinion needed for electro-convulsive therapy, and other interventions with serious consequences), s17 (5) (objection from nominated person) is vague and could be used to override the protections which the Bill should afford. Additionally we are concerned that the definition of emergency in ss65 is not fit for purpose.

We do not condone its inclusion in respect of ss14 (1) (a) – electro-convulsive therapy, as we consider that this form of treatment which can have irreversible effects requires the most stringent regulation, and the highest safeguards.

We would recommend the following definition;

'An emergency is a situation where a person is unconscious, or at risk of becoming unconscious due to self-harm or overdose or another medical cause'.

We strongly recommend that if the emergency cause is invoked, that there is a legal duty to conduct a capacity assessment as soon as possible after the emergency, and accordingly involve an independent advocate and an individual's nominated person as soon as possible.

Reform of the Mental Health Review Tribunal

The Mental Health Tribunal at present and under this proposed Bill is the primary legal remedy to challenge detention. We do not however consider that at present the Mental Health Review Tribunal is an effective remedy for the purpose of Article 5(4) of the ECHR which states; Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful' (emphasis added).

Currently, there are delays of between 8 – 10 weeks for a hearing before the Mental Health Review Tribunal which is in direct violation of the requirements of Article 5(4). In England, delay before the equivalent tribunal of 4 weeks was found to be in violation of Article 5.

We are also concerned that individuals, nor their family members or carers are not made aware of the right to review before the Tribunal and do not have the knowledge of how to make an application to the Tribunal. Additionally, there is little knowledge about the right to instruct a solicitor to take the case before the tribunal, and there is no information on wards about how to do this, or the contact details of suitably qualified solicitors who could be contacted to do this. We are also concerned that there is a lack of specialisation amongst legal practitioners in this area, and would encourage the Department to invest in training of solicitors on mental health and disability law in advance of the implementation of the Bill, in order to ensure the right to an effective remedy protected by Article 13 ECHR is realised.

Independent Advocacy

We consider that independent advocacy should be available to anyone using mental health and learning disability services, at all points of treatment or intervention, whether in the community or in an inpatient hospital environment.

Advocacy plays a key role in ensuring the wishes of an individual are heard throughout treatment or another intervention, and to ensure equality of arms before any assessor. Many service users report that the lack of continuity of care between their community treatment team and their hospital team is very difficult in a crisis situation, as they lose contact with the Psychiatrist, Social Worker and Psychiatric Nurse who know them and have a relationship of trust. We consider that the same principle should extend to engagement with advocates, and that a person should be offered to have access to the same advocacy team in all settings and in the community both prior to and after their hospital treatment.

Given the key role advocacy will play in protecting individual rights under the Bill, we consider it essential that there is independent regulation of advocacy services. We welcome the Code of Practice adopted by ANNI, but note however that at this point this is a voluntary code. In order to ensure high standards and consistency of service across all Health and Social Care Trusts, we recommend that advocacy services are subject to a Statutory Code of Practice which is developed and put into place at the same time as the Bill, and are independently regulated.

The Scottish Government published in 2013 'Independent Advocacy – A Guide for Commissioners'¹. We endorse the principles and standards set out in this Guide and recommend that the Department puts in place equivalent principles and standards for independent advocacy in Northern Ireland prior to the implementation of the Bill.

In particular, we draw attention to the definition of independent advocacy set out in the Mental Health (Care and Treatment) Act 2003 Code of Practice, Chapter 6 which governs Patient Representation. Para's 108, 109 and 110 of the Code of Practice state;

'108 Independence is key in the patient's right to advocacy, because it is vital that the role of independent advocacy is not compromised in any way. Independence ensures that the advocacy services provided are divorced from the interests of those persons concerned with the patient's care and welfare. **Conflict might occur for example, if a person providing advocacy services was also a care provider and a patient wanted to raise issues about their care. It is clear that in those circumstances, the advocate's ability**

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Available here: <http://www.scotland.gov.uk/Publications/2013/12/7000/downloads>

to support that patient would be severely compromised.

109 The Act, therefore, makes specific provision that to be "independent", the advocacy services must be provided by persons other than a local authority or a Health Board responsible for providing services in the area where the patient is to receive care or treatment, or a member of those bodies or any other person involved in their care treatment or in providing services to them. Any independent advocacy organisation should have policies in place to identify and manage/minimise the risk of any conflict of interest.

110 Independent advocacies should be provided by an organisation whose sole role is independent advocacy or whose other tasks either complements, or do not conflict with, the provision of independent advocacy. If the independent advocacy service or advocate has a conflict of interest, they should inform all relevant parties of this, and should withdraw from acting for the patient.'

We recommend that the development of the Code of Practice for the Mental Capacity Bill considers the aforementioned Guide for Commissioners and puts in place similar safeguards to ensure independence of advocacy and to identify potential conflicts of interest, for example, where an advocate is attached to an organisation providing care to an individual.

Some perspectives particular to carers

Role of carers and family

Whilst the Bill goes some way to acknowledging the important role of carers, the Code of Practice needs to clarify further the differences between: nominated person; advocate, carer, D and Lasting Power of Attorney.

More information and greater clarity required regarding the Power of Attorney, including the process, rights and costs.

Privacy and confidentiality in relation to carers

It is important the privacy of carers is recognised in the bill, carers are anxious about how the information they provide in assessment of capacity will be used and the how carer confidentiality will be safeguarded in information sharing.

The Code needs to tackle the ongoing issue of confidentiality and information sharing which mental health carers currently find one of the biggest barriers in supporting the recovery of a loved one.

Advance Directives

More widespread use of advance directives would need to be supported by a public promotion / education initiative accompanied by training for organisations who could be involved in giving advice and guidance on advance directives (e.g. from statutory services through to community advice centres). Access to advice on drawing up and the whole process of making an advance directive needs to be easy and clear for people to understand.

Support to make decisions

Carers of people with a learning disability recognised that their family member may be able to make everyday decisions but would need support when making serious or really serious decisions. They said that resources must be put in place to provide people with a learning disability with the support, time and opportunity to access appropriate information so that they can make their own decisions and that this should be provided by an independent organisation. Carers said that they,

too, needed adequate information about the options so that they could provide the right support to their loved one.

Carers asked what would happen if there was a conflict between what the carer needed to happen and the person's wishes, such as if the carer needed the break from caring but the person did not wish to go into respite.

Carers recognised that, if their family member no longer lived with them, the person or people who know them best should be consulted and listened to when a decision was being made.

Carers were concerned about who would help their son or daughter make decisions after they were gone.

Definitions

Family carers of people with a learning disability said that greater clarity was required regarding the definitions around a serious and really serious decision. They said that the law needed to be clear and they needed to know what was expected of them.