MHA White Paper Consultation – April 2021

Headlines for inclusion in Mental Health Act White Paper consultation response

Consultation link: Reforming the Mental Health Act - GOV.UK (www.gov.uk)
(deadline 21st April)

Thank you to the family carers, CB-NSG members and CBF legal panel subgroup members who have all shared their knowledge, experience and thoughts with us in response to the proposals in the White Paper.

The CBF focusses on the needs of children, young people and adults with severe learning disabilities whose behaviour challenges. Individuals with severe learning disabilities should be supported to make decisions about their own lives, and it is important that their voices are heard. The CBF is working on ways to engage with people with complex needs to seek their views (See our Seldom Heard Voices work here). However, given the short timeframe for a response and the relative complexity of the issues discussed, for this consultation we worked with family carers, family advocates, independent advocates, and people who specialise in supporting people who lack capacity. In this way the perspectives and interests of individuals with severe learning disabilities who are affected by the MHA are reflected and included.

This information has been gathered from groups of different stakeholders and collated to form a holistic and informed response to the proposals from diverse perspectives. We understand the DHSC issued funding to gather responses to this consultation - this response has not been funded by DHSC.

These are the main points that we will make throughout our consultation response. They are the fundamentals that have to be in place in order for any of the White Paper's provisions to be meaningful and effective for individuals with learning disabilities. and/ or autism.

- The Mental Health Act is currently used in order to make up for failures and deficiencies elsewhere. If other parts of the health and social care system were working effectively in the community, many individuals with learning disabilities and autistic people would not be considered for admission.
- Throughout the system it is essential that professionals and the wider workforce supporting individuals with learning disabilities and autistic people have specialist learning disability and autism knowledge – including advocates, clinicians, therapists, tribunal chairs, advocates, legal representatives,
- No changes aimed at raising threshold for detention will meaningfully reduce admissions if there isn't a significant overhaul of commissioning.

  - It is vital that there is an adequate supply of the right community support, including the right housing for people with a learning disability and/or autism. A key part of this is effective commissioning by LA and NHS. Commissioning is the identification of the support and services required to meet local needs, and the development and funding of that- it is not simply buying what is available. This involves tackling the perverse financial incentives which drive up admissions, putting early intervention and prevention of detention at the forefront of service design and ensuring people with a learning disability and/or autism and their families get the right support at the right time. Commissioners must have the right expertise around learning disability and autism and know what good support looks like (See NICE guidance here).
- There is a risk of missing the opportunity to build a progressive rights framework into Mental Health legislation. 'Principles' outlined in the White Paper are too weak. In reforming the Mental Health Act, legislators have the chance to embed clear and rigorous rights provisions to improve safeguards and quality of care in inpatient units.
- Many proposals represent piecemeal changes to mechanisms and safeguards which are fundamentally not working for people with a learning disability and/or autism, and which would need radical overhaul in order to be effective. Mechanisms such as advocacy, Tribunals, commissioning, discharge planning and more will need more than the amendments proposed.
  - We welcome that the MHA White paper aims to make it harder to detain people with a learning disability and/or autism inappropriately, to make it easier to challenge effectively, and to ensure people can only be detained if it is of therapeutic benefit. But, without addressing structural causes which lead to admissions and long inpatient stays and the lack of the effective community support, the risk is the aims will not be met and won't lead to meaningful change for people with a learning disability and autism.

The following sections are covered below:

- Detention Criteria
- Challenging detention
- Challenging treatment
- Community provision
- Interface with other laws

Detention Criteria

Section 3:

- We support the removal of learning disability and autism from the category of qualifying mental disorder under section 3
- Appropriate, sufficient, and individualised community provision of services is central to preventing unintended consequences from arising from this change.
  - Robust safeguards are needed to prevent individuals with learning disabilities and autistic people from falling into the criminal justice system and ending up under part III sections.

Section 2:

- We want to see alternative environments provided for assessment to take place in (i.e. in respite services, or other environments in the community), where it is not appropriate for this to happen in the person's usual environment.
  - The fact is that most people should not be going into an inpatient unit, and will rarely benefit from admission – this is especially true for those with severe learning disabilities.
- We need guarantees that assessment will be of high enough quality, and that reasonable adjustments will be made during the assessment period to ensure it does not lead to an escalation of challenging behaviour and worsening of wellbeing.
  - The quality of assessment needs to be judged against principles of therapeutic benefit.
- We want to see the extension of s117 aftercare to those discharged following a section 2 assessment. The proposals aim to make it harder to detain people inappropriately, which is welcome, but people must be able to get the right support in the community on discharge, otherwise the risk is there will be traumatic repeated section 2 admissions.
- Extending the challenge period from 14 to 21 days will be meaningless unless mechanisms for challenge, including the right support to challenge effectively, are drastically improved.

Part III:

- Retaining learning disability and autism in the category of qualifying mental disorder for detention under part III is an imperfect solution to the problems of a) lack of appropriate provision, including forensic support, in the community b) the inadequacy of reasonable adjustments made in mainstream facilities.
  - We see this issue as a gap for future legislation – there are pressing issues created by this differential criteria, and embedding it permanently into a 'reformed' Mental Health Act is not appropriate.

- We want an urgent action plan to address this inconsistency. This must include creating and strengthening alternative sentencing options to prison and inpatient units.
    - This ‘solution’ is propping up an inefficiency in the system elsewhere – an action plan (which already partially exists in Building The Right Support) needs to be urgent and implemented across the board.
- Address indeterminate sentencing – it has been recognised that indeterminate sentences are incompatible with human rights for public protection sentences. We want to see accountability placed on the Responsible Clinician to justify why someone continues to meet criteria for detention.

Therapeutic Benefit:

- We agree with the inclusion of ‘therapeutic benefit’ as a measure against which treatment and detention have to be justified, but there needs to be clarity of definition and measurement if it is to be an effective safeguard
    - We need a standard way to measure whether someone is therapeutically benefitting, and which informs when a person is ready for discharge. This should reflect up-to-date guidelines on supporting individuals with learning disabilities and autistic people (i.e. NICE)
    - It is recognised that it is rarely appropriate for someone with a learning disability and/or autism to be in an inpatient unit (see MHA Code of Practice and Building the Right Support service model). Any measure of therapeutic benefit should lead with this fact and acknowledge that ward environment can negate therapeutic benefit, and make a risk/benefit assessment accordingly.
- Therapeutic benefit needs extending to part III patients

Challenging Detention

Tribunals

- Proposals to increase the frequency of automatic referral will mean little without improved quality. There must be a requirement to bring in learning disability and autism specific expertise, as well as presence and input of IMHA, legal representative with that expertise, and consultation of C(E)TR.
- The Tribunal process is difficult and deeply flawed. Those working with the Tribunal often lack the necessary expertise around LD and autism and are often risk-averse.
    - We need the recording of rationale (as to why discharge doesn’t occur) to be mandated and it needs to be thorough. If discharge is not occurring due to a lack of community support, this must be recorded in the Care and

    Treatment Plan, Tribunal and elsewhere with transparency, so that it can be challenged effectively through Judicial Review if needed.
  - Tribunal needs to be clear about what is being provided in the unit that cannot be provided in the community.
- We welcome proposed Tribunal powers to direct services, but we need guarantees that this power will be strong enough to operate in the face of LA pushback/excuses and to tackle perverse incentives.
- We agree with specific timeframes for LA/CCGs to respond as they should be planning for discharge from the moment admission occurs, using information recorded in C(E)TR and at-risk register.
  - To ensure expedient arrangements are made this process will need rigorous checks to ensure accountability and follow-through
  - Delivering a package of support from scratch can be difficult – but if this community investment is made already and planning is undertaken using information already collected then LA should already know what support will eventually be needed for discharge. Plans should be set in motion ahead of admission <u>as admission should always intend to be temporary.</u>
  - Tribunal should also be able to review whether assessment and care plan and discharge plan are appropriate and if discharge is being pursued expeditiously.

Challenging Treatment

Care and Treatment Plans (CTPs):

- There are too many opportunities to exclude families from their development. Plans are hospital-centred not person-centred.
- Most people should have a care and support plan prior to admission- this needs to be built on and adapted for the temporary inpatient admission.
- A CTP needs to cover:
  - how care *could* be provided in the community, what circumstances make detention appropriate/necessary, and why they don't see community package as suitable
  - crisis planning
  - details on what the person was like prior to admission – what is known about the person prior to admission can then be adapted upon admission to cover how their previous needs and preferences will be provided in the community
  - other aspects of care – family, friends etc
  - a Behaviour Support plan with proactive strategies
  - environment, restraint, medication

        - All uses of restraint should be recorded to a) minimise their use and b) provide accountability

C(E)TRs:

- Need to be made statutory so that they actually take place (as has been recommended by JCHR) and recommendations considered by all relevant professionals, including community professionals from the person's home area, not just RC. We also want the RC to face more oversight than simply having to 'explain if recommendations aren't taken forward'.
    - What is this explanation process – Who to? How strongly? What opportunity for pushback?
    - There should be a duty to record rationale so it can be challenged
- C(E)TRs are variable in quality and conducted by people who don't know the individual well – need to have requirements to collect information about the person and to be co-produced with family, friends – especially if the person lacks capacity. Families often aren't aware of how to get a C(E)TR.
- Tribunals can simply disregard C(E)TRs
    - Often, C(E)TRs are not a part of Tribunal paperwork.
    - Where the C(E)TR and RC differ in views, the Tribunal should have to bring in expertise rather than automatically siding with RC.
- We don't want this to simply be process for process' sake. C(E)TRs need to be robust, high quality and carry weight and being made statutory is the way to do this, with an escalation process triggered when recommendations aren't followed.

Refusing treatment

- People should be supported to make their own informed decisions in units – danger of creating a differential rights framework for those with and without capacity. The MCA should be used properly in order to avoid this.
- It is also important to note that there are wider considerations to care than medical treatment alone.

Nominated Person

- Additional powers of Nominated Person (NP) – the role will need strengthening beyond what is outlined if it is to be an improvement on Nearest Relative.
    - NP should be able to participate in MDT and Tribunal (as in MCA)
    - We want to see requirements that the Interim NP will have learning disability and/or autism expertise
    - We want guarantees that the 'duty to consult' an NP on certain decisions will *actually* take their view into account – with rationale recorded if NP position is not adopted, so that challenging decisions is possible.
    - Nominated Person may need support to fulfil responsibilities of the role and to act on the person's rights. If taking on the role of NP, Family Carers

should be offered independent support and information, particularly around accessing IMHAs, Mental Health Solicitor.

Advocacy

- Needs to be made 'opt-out', rather than the duty proposed which states hospitals need to make patients aware that advocacy services are available. For those who don't have an IMHA (>50% of patients), proposals to increase powers are irrelevant
- The quality and availability of advocacy is variable. Advocacy can be improved by:
  - Providing specialist advocacy for non-verbal individuals.
  - Formalisation of family advocacy
  - Mandated extension of advocacy to informal patients (*not* subject to future funding decisions)
  - Improved standards, qualifications, including clarity on their role e.g. where necessary to support the person to challenge/ challenge on the person's behalf - and training on working with families.
  - Advocacy often lacks independence and expertise, often being provided through care providers 'in-house'.
    - Advocacy should always be centrally provided rather than locally – avoids perverse incentives (and makes regulation easier)
  - Offering combined/cross-over advocacy – advocacy is fragmented and advocates will not have a view of whole system – individuals may require support from advocates who have combined IMCA, IMHA and General expertise.
  - Being long-term and in the community, with cooperation between IMHAs and general/'outside' advocates – rather than being issue based, short term and fragmented.
  - If the system was functioning well a person should already have an independent advocate who knows them well.
    - In the current system in-crisis provision means advocacy will begin from scratch
  - Fixing advocacy starts with how advocates are commissioned, not simply changes to mental health legislation.
    - We want to see a clear, outlined plan for a review of advocacy to ensure that it is working as needed.

Advanced Choice Documents:

- Advance Choice Documents need to have been made during a time when a person has capacity.
  - What about people without capacity, will there be a best interests equivalent?

  - If someone has been admitted once, this knowledge should be captured and can be used again as long as it has been recently reviewed.

Community Provision

Robust community support and services are crucial but are currently lacking.

Duties on Local Authorities:

- The duty to ensure adequate supply will need strengthening in order to differ from Care Act duties, and to reflect the full range of support set out in The Service Model – the duties set out in the Care Act aren't working, so how will this differ? Community provision aimed at reducing detentions will need a focus on early intervention, prevention, and tackling perverse incentives.
  - Duties set out in White Paper are too loosely defined and permit too much responsibility-shifting between agencies.

At-risk Register:

- We endorse the creation of a duty on Local Authorities to maintain such a register, but it is important that this is not just 'names on a table'. To be effective, it must carry the weight of ensuring immediate, targeted, and specialised support when the person needs it in order to prevent admission. Needs to be well-funded, start early and carry practical weight.
  - Questions over eligibility – what will ensure this also prevents admission for individuals with mild/moderate learning disabilities, 'borderline cases', children, and those who are not regular service users.
  - In areas where these registers are in use, families have expressed hesitation over being on the register. In order to ensure high take-up, information needs to be widely shared, informing families that registration fast-tracks you to community support to prevent crisis as well as immediate support in case of crisis.
    - There is possibility to link up with the examples of risk registers set out by NHSE and in NICE guidelines, wherein 'risk of admission' is only one element of the meanings of 'risk'
    - The registers could be used to move away from a crisis management approach- identifying individuals for whom risk factors are known should enable access to early intervention and prevention support- and not wait until a crisis is developing.

Budgetary Issues:

- To resolve budgetary issues (surrounding pooled budgets and reporting on spend), we need to see joined up working between Health, Education, Social Care, including between children's and adult's services

  - We want to see an actual cross government Transforming Care strategy – that sets out the range of actions being taken in different parts of the system in a co-ordinated and sustained approach, with measurement of outcomes based on robust community support and quality of life.
  - Pooled budgets have been discussed for years as a way to help Transform Care being outlined in the original Transforming Care strategy. The PAC recommended making pooled budgets mandatory and DHSC and NHSE have done work to encourage the use of pooled budgets for services for people with a learning disability and/or autism. There should be a lot of information from the Transforming Care programme about any barriers and how these should be addressed.
    - The model of integration also needs to be correct, with shared outcomes between agencies and commissioners being held accountable.

CQC monitoring role:

- How could the CQC support the quality of care by extending its monitoring powers?
  - We want to see better monitoring of Mental Health Act safeguards at individual level (advocacy etc).
  - CQC inspectors often will not know what to look for or what good care in an inpatient unit looks like. They may not be able to identify problematic practices, conditions, and may not be prepared to challenge clinicians.
  - Could better support quality of care by scrutinising how the service is run - what expertise, qualifications etc the managers/staff have.
    - In the ward they should assess planning of care and treatments and have expertise to ensure that what is written down is of sufficient quality and meaningful and what is being provided is appropriate

Interface with other laws

With Mental Capacity Act:

- The interface between MHA and MCA is not working, and a solution to the broken interface will require significant overhaul. This may be in the form of binary legislation, wherein it is agreed that the Mental Capacity Act should not be used to detain individuals in mental health wards (as suggested by the Law Commission), or in the form of fusion legislation as has been instituted in Northern Ireland.
  - The Mental Health Act White Paper does not give sufficient scope for a total discussion of the legislative solutions, further consultation is needed

    - before Liberty Protection Safeguards are brought in. This is a gap for future legislation.
    - There needs to be equal safeguards and equal access to equivalent and effective challenge mechanisms. The Court of Protection is slow and backlogged, meanwhile the Tribunal is often a weak mechanism for challenge.
    - Each framework is often used inappropriately due to limited knowledge of the interface by those using them in hospitals (Kings Fund).
        - Need to have a total review of this interface to prevent reforms to the MHA resulting in increased use of MCA/LPS inappropriately.

New Principles:

- In reforming the MHA, there is an opportunity to embed a progressive rights framework into legislation, outlining prohibited practices (such as outlawing prone restraint) and entitlements (such as embedding human rights and right to independent living). The White Paper misses this opportunity - its ‘new principles’ need greater clarity and direction and therefore will be a weak safeguard
- Families told us that these principles ‘just sound like buzzwords’
- Reforms *should* focus on the potential to restructure care around these rights and entitlements – such as with obligations to monitor physical and mental health and meet health needs, and alignment with STOMP and attempts to limit the inappropriate use of medication.
    - Creating requirements to record and publish the above will also create much needed accountability.