

Written evidence from Mencap and The Challenging Behaviour Foundation (CBF) (MHA0020)

MHA reform is very relevant to the Government's Transforming Care agenda, which has committed to reducing the number of people with a learning disability and/or autism in inpatient units and ensuring the right community support is developed.

Currently thousands of people with LD/autism and behaviour that challenges end up inpatient units due to a lack of the right community support.

The JCHR Inquiry into the detention of young people with a learning disability and/or autism has put a spotlight on the human rights breaches happening in these settings: *'What was clear from their testimony...the detention of young people with learning disabilities and/or autism not only threatens their rights to private and family life [Article 8 European Convention on Human Rights] and their right to freedom from inhuman and degrading treatment [Article 3 ECHR] but also their right to liberty and security [Article 5 ECHR] and in some cases their right to life [Article 2 ECHR].'*

92% of people with LD and/or autism in inpatient units are detained under the MHA¹.

Once in these settings, the average length of stay is over 5 and a half years. There is a shockingly high use of restrictive interventions against people with a learning disability and/or autism in inpatient units. Within one month alone (December 2020) there were at least 3,730 incidents of restrictive interventions (the true figure is likely to be much higher due to low levels of reporting by inpatient providers).

It is well-recognised that the MHA and its 'safeguards' are not working effectively for people with LD/autism in inpatient units.

Our organisations 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.

However, careful consideration is needed to translate the aims of reform into legislation that will make a difference in practice. Ultimately, the success of the reforms depend on individuals being able to access the right support in the community when they need it.

Legislative scrutiny of MHA reform through a human rights lens

We have been consulting with family carers of people with LD/autism and relevant professionals, to inform our submission to the MHA White paper consultation. We have outlined areas identified so far where there are concerns, and where we believe JCHR scrutiny is crucial:

The right community support

New duties on local commissioners to ensure adequate supply of community services for people with LD/autism. This sounds positive but the new duties must have teeth. There is already a duty under the Care Act and it hasn't led to the right support being provided.

¹ NHS Digital Assuring Transformation data: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics>

It is important that the ‘adequate supply of community services’ reflects the full range of support set out in the Building the right support service model, including suitable housing and skilled social care providers. There needs to be a strong focus on early intervention and support to prevent needs escalating.

The reality is people can end up in inpatient units due to unwillingness to fund the community support needed, such as a bespoke package of care and housing. The proposals don’t tackle the perverse financial incentives that lead to admission, and keep people stuck in units.

Dynamic risk/support registers: We welcome the duty on commissioners to understand and monitor risk of crisis at an individual level through the creation of a Dynamic risk/ support register. It is important there is consistency over criteria used, and for it to be clear what action they should prompt. (See NAO 2017 report on local support for people with LD which highlights issues that need to be addressed to ensure effective risk registers).

Commissioners: The proposals will do nothing to hold to account commissioners who purchase services which cause harm to or abuse patients and which has been recognised as a key issue (See CQC’s out of sight report, 2020).

Removing LD/autism from detention criteria

We welcome the proposal to remove learning disability and autism as mental disorders qualifying an individual for detention under Section 3 of the Act. However, there are concerns that in practice this will not sufficiently protect against inappropriate detention under the MHA. For example, families have raised that it is likely a clinician could easily find a diagnosis of mental health problem to go alongside LD/Autism, which could enable the detention to be justified. It must also be recognised that mental health needs/trauma can be caused or exacerbated during detention, for example, during a section 2 stay for assessment.

Those who have known the individual longest (often family members) are often excluded from the assessment process in units. As always the importance of listening to the expertise of those who know the person well cannot be overstated in understanding someone’s needs and usual presentation.

The JCHR raised concerns that if it is made harder to detain people under MHA more people with LD/autism may end up stuck in inpatient units under LPS/DoLS. We agree this is a concern and must not be allowed to happen. This is where the vision/ Government commitment to stopping inappropriate detention is important and must read across all legislation.

Therapeutic benefit

That detention must be of ‘therapeutic benefit’ is welcome but will need to be clearly defined or there is a risk it will be too vague to strengthen the requirements for ongoing detention. It must be clear that for people with LD/autism admission to a unit is rarely appropriate. Being taken away from everything that is familiar and perhaps not understanding why, often far from families, is likely to be highly distressing and traumatic and in most cases will not be a therapeutic option. The definition of therapeutic benefit must include that care and treatment is in-line up-to-date LD/Autism guidance eg. NICE, it mustn’t worsen their condition/ cause

deterioration, it will be important that both assessment (section 2) & treatment (section 3) will need to be of therapeutic benefit.

Meeting physical health needs

Neglect of physical health needs in inpatient units is a recurring theme and has resulted in premature deaths. LeDeR and CQC have both published concerning data on deaths of people with LD/autism in inpatient units. For example in the LeDer 2019 annual report: Deaths of people in contact with specialist mental health services: *'Of the deaths reviewed in 2019, nine people were either a current inpatient at the time they died or had been discharged less than two months prior to their death. Issues identified in these deaths included a lack of attention to physical health issues, poor care coordination, a lack of holistic care provision, and a lack of supervision or observation.'*

The white paper says that the requirement to deliver physical health monitoring is now included in the NHS Standard Contract. However, we are concerned the requirements are too narrow and not robust enough. People with LD/autism must be able to get the right support, including management of long-term health conditions, treatment for new physical health issues eg. injuries from restrictive interventions, support for keeping healthy eg. around nutrition and oral healthcare.

Restrictive interventions

Though the White Paper proposes that 'Least restriction' is one of its key principles, there are limited proposals around tackling the shocking levels of restrictive interventions used against people with LD/autism in inpatient units. This is an opportunity to take steps, in addition to the requirements brought in by the Use of Force Act 2018, for example to put good practice guidance (which often isn't followed) into legislation, such as there must be no planned prone restraint, restraint should only ever be used as a last resort after less restrictive options have been tried. The white paper says: *'There may also be a need to strengthen the existing text on restrictions within the Code of Practice and the CQC's role in monitoring its implementation.'* This does not seem ambitious enough or specific enough to tackle this deeply shocking issue.

Challenging detention

Care (Education) and Treatment Reviews (CETRs)

The white paper is proposing a duty on the Responsible Clinician to consider the findings and recommendations from CETRs. This does not go far enough. Firstly, this duty must be on ALL relevant professionals (eg. Local Authority, CCG and NHSE commissioners who have a key role in taking actions forward to enable discharge).

Secondly, as the JCHR proposed, CETRs should be made statutory so they actually happen. They are a key safeguard in an MHA system where other safeguards like tribunals do not work well for people with LD/autism.

This needs to be the case for both pre- admission C(E)TRs & C(E)TRS in the unit.

Tribunals

The white paper's proposals focus on increasing the frequency with which tribunals can be accessed. The families we support don't think this will improve outcomes for their relatives as the Tribunals lack the relevant expertise in LD/autism.

There should be a **requirement for the Tribunal to bring relevant expertise in**. Where a CTR hasn't happened then the tribunal should be able to require this happens and/or a relevant expert report obtained – recognising that particular expertise is needed around decisions about care and treatment for people with LD/autism.

There are proposals for new powers for the tribunal to be able to direct services in the community. This is a welcome step, but we are not clear how effective this new power will be in practice, and we believe this needs to be accompanied by specific proposals to tackle the perverse financial incentives in the system which keep people stuck.

We would want to see tribunals given the power to review whether the assessment and care plan and discharge plan contain appropriate provision and whether the discharge plan is being pursued expeditiously, with a power to revise all aspects of the plans.

Challenging care, treatment and conditions in the unit

C(E)TRs often make important recommendations about improving care and treatment and reducing restrictive interventions, but too often these are not followed. As said above, it is important that these are statutory.

We know that currently it can be hard to challenge care, treatment and conditions. Safeguarding referrals can be ineffective as safeguarding teams can view it as a 'care/clinical issue' and say it is a specialist unit that is clinician-led.

We are concerned that the proposals in the white paper do not appear to offer an effective way to challenge care, treatment and conditions. The white paper focuses on the route of a SOAD and appeal to the Tribunal to challenge specific treatment. This sounds very much like it is only for 'medication' challenges. It is vital there is an effective route to challenge misuse of restrictive interventions as well as other aspects of the person's care.

In relation to medication challenges, unfortunately we know that SOADs are often not effective for people with LD/autism (See CQC's Survey of medication for detained patients with a learning disability, 2016²). There is currently no requirement for a SOAD to have the necessary LD/autism expertise and there are no proposals to address this. This is of concern as we know many people with LD/autism are overmedicated (see NHSE STOMP programme).

Independent advocacy and representation

Most people with LD/autism in inpatient units are under the MHA, and yet less than half of people with LD/autism in units have an IMHA³.

² https://www.cqc.org.uk/sites/default/files/20160209-Survey_of_medication_for_detained_patients_with_a_learning_disability.pdf

³ NHS Digital Assuring Transformation data: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics>

The Wessely independent review recommendation to make IMHAs ‘opt-out’, which we welcomed, has not been accepted. This is of concern as many people with LD/autism will find it difficult to understand the benefits of advocacy and take up the offer of an IMHA.

For people with LD/autism who don’t have an IMHA - the increased IMHA powers proposed will be irrelevant.

There are well-recognised issues relating to independent advocacy for people with LD/autism eg. around quality, knowledge of LD/Autism, access, true independence. These are not addressed in the white paper and instead there is a statement that there will be another review into advocacy for people with LD/autism.

People under the MHA have a right to representation from a mental health solicitor and yet we see people with LD/autism stuck in units for many years despite this safeguard. There are no proposals in the white paper around ensuring effective legal representation from mental health solicitors for people with LD/autism.

People under Part 3/ Forensic sections

Under the white paper proposals, people with LD/autism **will still be able to be detained on basis of LD/Autism (without a mental health problem) under Part 3** of the MHA. The white paper says *‘this is to ensure that accused people and offenders...are not forced into the criminal justice system which is not able, or indeed intended, to cater for their needs.’*

However, there is no urgent plan set out to address the inconsistency between what they are proposing for people with LD/autism under civil sections and those under forensic sections. This is deeply worrying. There must be much more focus in the reforms on making community alternatives to admission or custody a reality (see paper by Alison Giraud-Saunders, Independent consultant, Jenny Talbot from the Prison Reform Trust and Harm Boer, consultant psychiatrist⁴).

There are many people with LD/autism who could easily fall into being detained under part 3 if they are not given the right support in the community. It is crucial there are robust safeguards for this group. Concerns for those under Part 3 include indeterminate lengths of sentence (whereas indeterminate prison sentences for public protection were abolished as incompatible with human rights).

23/03/2021

⁴Facilitating Discharge 2: Discussion paper from a second roundtable, held 5 Nov 2019, on enabling discharge of detained people with intellectual (learning) disabilities and/or autism.