

The Draft Mental Health Bill and people with a learning disability and/or autistic people

Key points

There is an urgent need for reform of the outdated Mental Health Act.

- Mental Health Act reform is a key part of addressing the inappropriate detention of people with a learning disability and autistic people in mental health hospitals.
- There are twin issues of preventing new inappropriate admissions and enabling the discharge of people currently inappropriately detained.
- There are 2,025 autistic people and people with a learning disability in mental health hospitals in England.
- The average length of stay is nearly five years and people are often unacceptable distances away from their families.
- We continue to hear alarming reports of people being overmedicated, subjected to physical restraint and shut away in isolation in these settings, often with devastating consequences for people and their families.

Parliament's Joint Committee on Human Rights (2019) report said: "We consider that the human rights of many of those with a learning disability and/or autism are being breached in mental health hospitals."

Reforming the Mental Health Act is an essential part of ending this human rights scandal. We need this legislative reform as a matter of urgency. This must be accompanied by significant investment now in the right community support for autistic people and people with a learning disability, including the right social care, mental health care and suitable housing. In addition to legislative reform, there must be a focus on early intervention and prevention so that people with a learning disability and autistic people get the right support at the right time in the community and do not end up inappropriately detained in mental health hospitals.

Despite the previous government committing to "make to make it easier for people with a learning disability and autistic people to be discharged from hospital and improve how they are treated in law", this has not happened. Government programmes to end inappropriate detention in mental health hospitals have not included legislative change or adequate investment in community support and services, and they have not succeeded in meeting the reduction in numbers set out within the NHS Long Term Plan and DHSC's Building the Right Support Action Plan.

A key reason for this is the perverse incentives in the health and care system, which act against development of the right community support, as if a community package funded by the local authority fails and a person ends up in crisis and sectioned under the Mental Health Act, Health pick up the bill. Detention in Mental Health Hospitals continues to be used as a backstop and this is only able to happen because the Mental Health Act allows it to. We need both investment in community support and legal change.

The new Government now has the opportunity to make this happen. We are calling for the introduction of the Mental Health Bill to Parliament at the earliest opportunity, where it can then be debated and strengthened.

Background

- People with a learning disability and autistic people **can currently be sectioned under the Mental Health Act even if they don't have a mental health condition**. This leads to people being detained in a mental health hospital, not because they need inpatient mental health care, but because there is a lack of the right support in the community. **92%** of people with a learning disability and/or autistic people in mental health hospitals are detained under the Mental Health Act¹.
- People with a learning disability and/or autistic people are at **increased risk of abuse and neglect in these settings**, where there is often high use of medication and restrictive practices. NHS Digital data shows that within March 2024 alone there were 7,085 reported uses of restrictive interventions, such as physical, chemical, mechanical restraint and being kept in isolation² - due to well-recognised under-reporting, these figures are likely to be higher.
- Too often the **concerns of families of people with a learning disability and/or autistic people are not listened to and acted upon**. The Joint Committee report (2019) stated: *"Too often, the concerns raised by the families of those with learning disabilities and/or autism are considered to be hostile. The families are seen as a problem. This is unacceptable. They must be recognised as human rights defenders, and other than in exceptional circumstances, be fully involved in all relevant discussions and decisions."*
- Like anyone else, people with a learning disability and/or autistic people should be able to **live life in the community with the right support**, close to family and friends.
- Alongside investment in the right community support, **changing the Mental Health Act (MHA)** is a key part of tackling inappropriate detention of people with a learning disability and/or autistic people in mental health hospitals.
- **The government proposed changing the Mental Health Act and improving how it works for people with a learning disability and/or autistic people**. Following Prof Sir Simon Wessely's Independent Review of the Mental Health Act (MHA), the Government published a white paper on Reforming the MHA in 2021 and then a **Draft Mental Health Bill was published in June 2022, which was subject to pre-legislative scrutiny by a Joint Committee of MPs and Peers**. The Government responded to the Joint Committee's report and recommendations for the Bill in March 2024.
- It is now the **responsibility of the next Government to ensure the Mental Health Bill is brought before Parliament** where it can be debated and strengthened.

We welcomed the Draft Bill published in June 2022 and recognised the Bill's potential to implement significant changes to the interaction between the mental health system and autistic people and people with a learning disability.

Our organisations work with and support people with a learning disability and/or autistic people and their families. We have long called for both investment in community support and changes to the Mental Health Act to help tackle the inappropriate detention of autistic people and people with a learning disability in mental health hospitals.

¹ NHS Digital Assuring Transformation Data, May 2024, published June 2024.

² NHS Digital MHSDS Data, March 2024, published June 2024.

The Mental Health Bill must remain a priority for Government. This means including the Bill in the upcoming King's Speech and ensuring there are no further delays.

We supported a number of the recommendations in the Joint Committee's report on the Draft Mental Health Bill, including that a detailed plan for resourcing and implementing the Bill should be published alongside it, with the requirement to report annually on progress during the implementation period.

The urgent need for the Government to review, revise and strengthen the Building the Right Support Action Plan

The Joint Committee's report has a strong focus on the need for robust community support for people with a learning disability and/or autistic people. We welcomed their recommendation for the Government to review the Building the Right Support Action Plan, including the milestones, funding and monitoring to ensure the right community support is developed.

NHS Digital data shows there is a pressing need for this. There are currently 2,025 people with a learning disability and/or autistic people in inpatient units³.

The Government and NHS England did not meet their target of a 50% reduction in numbers of inpatients with a learning disability and/or autistic inpatients by March 2024, with the overall reduction plateauing at around 30%. Progress across Integrated Care Systems (ICSs) has been varied with some areas having met targets to reduce in-patient numbers, and others making no progress or going backwards.

The unacceptably slow pace of reduction in the total number of people with a learning disability and/or autistic people detained in mental health hospitals since 2015 shows that there is still much more to do to tackle inappropriate detention and the disproportionately long lengths of stay that many experience (with almost half of people with a learning disability in inpatients units having been detained for over 5 years). The shocking increase in the number of autistic people without a learning disability in mental health units (a 115% increase since 2015) also demands urgent focus.

Since the target was missed, the Building the Right Support Action Plan has not been revised or strengthened even though the targets and much of the plan are now out of date.

NHSE operational guidance for 2024/25 has confirmed the 50% inpatient reduction target continues for this year, however this has not been reflected in the cross-government Building the Right Support Action Plan, which was published in Summer 2022. This is further evidence that the plan needs to be updated and strengthened as a matter of urgency.

It is essential that the new plan includes actions to address the important recommendations from the DHSC commissioned Red Quadrant funding flows report. More must be done to remove the well-known perverse financial incentives in the health and social care system which work against a preventative approach and the transformation of care for children and adults with a learning disability and/or autistic people.

³ NHS Digital Assuring Transformation Data, May 2024, published June 2024

In the absence of an effective government Action Plan, the Challenging Behaviour Foundation has led on the development of a co-produced plan with people with lived experience, the voluntary sector and those working in the field; much of this could be used to inform the Government's Action Plan going forward.

What we want to see in the Mental Health Bill

- **The removal of learning disability and autism from the definition of mental disorder under Section 3, Part 2**
- **Strengthened duties for community provision**
- **Ensuring recommendations from Care, Education and Treatment Reviews (CETRs) are followed and the reviews are of high quality**
- **Granting the Mental Health Tribunal power to direct services in the community**
- **Preventing alternative routes to detention via the Mental Capacity Act, criminal justice system and inappropriate additional mental health diagnoses being made**
- **Access to independent advocates with specialist knowledge of learning disability and autism**
- **Processes and treatment plans are accessible for people with a learning disability and autistic people**
- **An independent and rapid pathway for families to raise concerns if they are being excluded or their concerns about their loved one's care are not being addressed.**

The removal of learning disability and autism from the definition of mental disorder under Section 3, Part 2

Autism and learning disability are not mental health conditions, and they should not be treated as such in law.

People with a learning disability and autistic people can currently be sectioned under the Mental Health Act and detained for an indefinite period even if they don't have a co-occurring mental health condition. This is wrong as people can end up detained in a mental health hospital just because there is a lack of the right support in the community (for example, suitable housing and adequate care packages which properly meet their care and support needs), not because they need inpatient mental health care.

We remain supportive of the approach in the draft Bill to remove learning disability and autism from the definition of mental disorder under Section 3, Part 2.

Whilst the definition change must happen from the start of implementation, it must sit alongside implementation of the new duties on commissioners for community support. Past failures provide evidence of the need for legislation to act as a spur to drive the investment in community support for autistic people and people with a learning disability that has been long promised but not adequately delivered.

We recognise that there are concerns about sequencing of these provisions due to fear of unintended consequences if there is a lack of sufficient support in the community for autistic people and people with a learning disability. It is essential there is robust monitoring to ensure these unintended consequences don't happen/ can be urgently addressed.

These concerns include:

- More people with a learning disability and/or autistic people ending up in prison
- More people ending up detained under Part 3 of the MHA (forensic)
- Deprivation of Liberty Safeguards/Mental Capacity legislation used instead to detain people in mental health hospitals
- People being given unnecessary mental health diagnoses to try to justify detention
- People ending up homeless or in crisis due to a lack of appropriate community support

This is why we need legislative change and investment in community support at the same time. They are mutually dependent and need to be simultaneous.

Autistic people and people with a learning disability being locked away in mental health hospitals is fundamentally a human rights issue. We believe that current legislation is acting as disincentive to invest in the adequate community support options and a backstop for system failure. Change can only come from removing this legal backstop and galvanising a shift away from a reliance on inappropriate detentions and to provision of care in the community.

Much-needed reforms should not be delayed, and wrongful, untherapeutic detentions and human rights breaches must end. Without addressing both the lack of community support and the inappropriate use of the Mental Health Act, we will continue to see human rights violations and indefinite delay in an area that has seen insufficient progress since the Winterbourne View Hospital scandal in 2011.

We understand the compromise of limiting the change to Part 2 (civil sections) of the Mental Health Act due to needing an ongoing ability to divert people from the criminal justice system.

Strengthened duties for community support

We welcome proposed new duties in the Draft Mental Health Bill on local authorities and CCG (now Integrated Care Board (ICB)) commissioners to ensure an adequate supply of community services for people with a learning disability and/or autistic people. However, the proposed duties are too weak.

We welcome the Joint Committee's recommendation for the duties on LAs and ICBs in the Draft Bill to be strengthened. There must also be a firm duty on LAs and ICBs to work together to meet the needs of people with a learning disability and/or autistic people.

It is important that the 'adequate supply of community services' reflects the full range of support set out in the NHSE Building the Right Support service model (2015). There must be a strong focus on early intervention, support to prevent needs escalating and preventative planning to avoid inpatient admission.

We welcome a new duty in the Draft Bill for local areas to develop and maintain a Dynamic Support Register. It will be important that the policy underpinning Dynamic Support Registers is reviewed and regulations are introduced where needed to ensure Dynamic support registers are consistently effective across all local areas. The link between the new commissioning duties and the duty around establishing and maintaining a Dynamic Support Register is essential, and there must be a clear focus on social care and health working together to provide support at the right time for individuals. This should include pooled budgets and other mechanisms to remove perverse incentives and promote a

joined-up approach, such as being able to access additional funding from a national pot where people have more complex needs and need a more bespoke package of care in the community.

Ensuring recommendations from C(E)TRs are followed and the reviews are of high quality

We welcome the Draft Bill's proposal to put Care (Education) and Treatment Reviews (C(E)TRs) on a statutory footing. It is important this includes community C(E)TRs as there must be a strong focus on avoiding inappropriate admissions.

There are three key issues with C(E)TRs that the Bill must address: that C(E)TRs are of varying quality, their recommendations are not always followed, and that they are too infrequent.

1. Ensuring C(E)TRs are of high quality

It is also essential that the C(E)TRs are of high quality, with a C(E)TR panel with the right skills, an emphasis on involving the person and their family, and ensuring that where appropriate C(E)TRs are chaired by an independent person.

2. Ensuring recommendations from C(E)TRs are followed

We support the Joint Committee's recommendation to strengthen the duty for relevant professionals to act on the recommendations. This will drive positive change in people's treatment and discharge into the community.

3. Ensuring C(E)TRs are offered at appropriate intervals

We are concerned that a 12-month maximum interval between C(E)TRs will be too long in many cases. We suggested that this should be reduced to 6 months, which was adopted by the Joint Committee. In its response the Government stated it would look into reducing the maximum interval. We would like to see this made a legislative requirement.

Mental Health Tribunals

Power to direct services

Alongside the strengthened duties on public bodies for community support, the Government should strengthen the powers of Mental Health Tribunals to direct the provision of services in the community as recommended by Sir Simon Wessely's Independent Review. The proposed new power in the draft Bill for the Tribunal to make recommendations on section 117 after-care⁴ is too weak.

The Tribunal, like the Court of Protection through its powers under s.49 of the Mental Capacity Act, must have the ability to be a more active case manager and apply pressure on public bodies to work collaboratively to facilitate discharge. These powers should apply equally to 'restricted' patients under Part 3 of the Mental Health Act where they are on a pathway to discharge.

Learning disability and autism expertise on Tribunals

The Draft Bill did not include proposals to ensure learning disability and autism expertise on Tribunals, and we share the Committee's concerns over this major gap. All Tribunal hearings for people with a learning disability and/or autistic people (whichever section they are under), must

⁴ <https://www.nhs.uk/conditions/social-care-and-support-guide/care-after-a-hospital-stay/mental-health-aftercare/>

have input from specialist members with learning disability and/ or autism expertise and/or a clear route and requirement for involving appropriate experts.

Guarding against additional unnecessary mental health diagnoses

The Committee recognised the risk that people with a learning disability and/or autistic people could be given additional unnecessary mental health diagnoses to try to justify detention when they can no longer be detained under Section 3, Part 2, without a co-occurring mental health condition. There must be a commitment from Government to transparently manage and mitigate this risk, to carefully monitor this, and to analyse data and act on concerns.

This links to the need for Mental Health Tribunals and C(E)TR panels to have the right expertise around learning disability and autism. It is important that all staff are trained appropriately, including those conducting Section 2 assessments, who must be aware of behaviours associated with autism and learning disability to prevent these from being mislabelled as a symptom of a mental health condition.

Ensuring the Mental Capacity Act Deprivation of Liberty Safeguards are not used instead

We welcome the Draft Bill's aim to reduce the inappropriate detention of people with a learning disability and/or autistic people in mental health hospitals.

We support the Joint Committee's recommendation for "the Government to urgently review the operation of the Mental Capacity Act in this context (inpatient units) with a view to amending the Deprivation of Liberty Safeguards (or in future the Liberty Protection Safeguards) so they cannot be used as an alternative route to the Mental Health Act to deprive people with learning disabilities or autistic people of their liberty in inpatient mental health units for lengthy periods of time and thereby undermine the intention of this Bill".

It will be important to ensure there is extensive data reporting once the definition change comes into effect to ensure that there has been no displacement from the Mental Health Act into the Mental Capacity Act.

People with a learning disability and/or autistic people under Part 3 of the MHA

It is essential there is an ongoing focus on those under Part 3 of the Mental Health Act (a forensic section) to ensure that more autistic people and people with a learning disability aren't being criminalised and detained under Part 3 of the Mental Health Act following changes to the MHA. A specific programme under the Government's Building the Right Support Delivery Board should be established to monitor this and establish any necessary changes to mitigate the risk.

Independent Advocacy

We welcome that the Draft Bill introduces opt-out independent advocacy for people detained under the Mental Health Act.

We welcome the Committee's recognition that there are shortages of advocates with the specialist knowledge of learning disability and autism, relevant language skills or cultural knowledge to support people with specific needs. We also welcome their conclusion that for advocacy to be truly effective for people with a learning disability and autistic people then specialist services are required. We need a national approach led by DHSC or NHSE to the commissioning and oversight of

specialist advocacy service(s) for people with a learning disability and autistic people in mental health hospitals as part of the strategic approach to advocacy recommended in the national advocacy review 'A review of advocacy', NDTI⁵. It is essential that Independent Advocates for people with a learning disability and/or autistic people detained in mental health hospitals have the right skills and knowledge, including understanding the Care Act, as this legislation is key to getting the right support in the community to enable timely discharge. The Whorlton Hall SAR concluded that currently "There is an illusion of advocacy"⁶.

Processes and treatment plans are accessible for people with a learning disability and autistic people

Care and Treatment Plans must be accessible for people with a learning disability and autistic people. People's communication needs must be understood and met, and people get the formats and/or support needed to engage with and understand processes and treatment plans. If it is not possible for people to understand their treatment plan and they are not supported to engage with it in an informed way then this can be a huge barrier to hospital discharge. A second important point is that treatment plans must be relevant. Currently autistic people and people with a learning disability can be detained without a co-occurring mental health condition so a big question is what is in the inpatient treatment plan and is it even relevant.

An independent and rapid pathway for families to raise concerns if they are being excluded or their concerns about their loved one's care are not being addressed.

There has been widespread outrage over the treatment of people with a learning disability and autistic people in mental health hospitals, exposed in reports and media. However, families continue to be shut out, criticised and ignored where they raise concerns, including where legal obligations are not being met and national policy and guidance is not being followed. Current routes for raising these concerns and getting them addressed are not working. An independent, rapid and effective pathway needs to be introduced through the Bill or other routes.

We would like to see the Mental Health Bill introduced to Parliament at the earliest opportunity, where it can then be debated and strengthened.

⁵ <https://www.ndti.org.uk/resources/research-project/a-review-of-advocacy-october-2023>

⁶ [SCIE LT SAR Whorlton Hall \(safeguardingdurhamadults.info\)](#)