

## **NDTi written evidence in response to the oral evidence session with the Joint Committee on the draft Mental Health Bill, 18<sup>th</sup> October 2022**

In this written submission we have tidied up and briefly expanded on our notes that were prepared in advance of the oral evidence session. At the end of the document, we have set out the projects that NDTi are involved that seek to ensure that people with a learning disability and autistic people are supported to live good lives in their communities. We also work to ensure mental health settings are able to respond appropriately to people with a learning disability and autistic people.

### **Subject 1: Changes to detention criteria**

Q1 What are your views on the draft Bill's proposal to remove learning disabilities and autism as a condition for which people can be detained under Part 2 Section 3 of the MHA?

- Will these changes help the Government achieve their goal of reducing the number of people with learning disabilities and autism in detention?
- Does the draft Bill go far enough to help people with learning disabilities or autistic people?

Some user-led groups have said the draft Bill is not compliant with the UN Convention on the Rights of Disabled People (UNCRPD) and called for a complete overhaul of Mental Health legislation. What is your view?

As we said in the oral evidence session, we are supportive of the proposal to remove learning disability and autism as conditions for which people can be detained under part 2 section 3 of the MHA. We would go further and suggest that these conditions be removed from the legislation fully. We are concerned that while they partially remain, there is potential for confusion and also misuse of the forensic sections, leading to unintended consequences. We know that currently, colleagues in health and social care become adept at finding work arounds in the legislation. We also think that good legislation is clear legislation.

We are aware of the broader unintended consequences and concerns of other panel members in relation to the removal of learning disability and autism; potential criminalisation of people, increased use of forensic pathways, people being given 'alternative diagnosis' such as emotionally unstable personality disorder, people being detained using DoLS or LPS with less robust rights to appeal and representation. We agree these are all risks that must be thought about and mitigated against. We also must note that these things are happening already.

However, we feel to leave these conditions in the MHA will continue to condone the inappropriate hospitalisation and 'containment' of people with a learning disability and autistic people, simply because we haven't adequately addressed the issues of ensuring that people are well supported in

their homes and communities, and don't reach a crisis that leads to hospitalisation. We know that a mental health hospital is rarely the right place for people with a learning disability and autistic people to be supported, even when they do have a co-occurring mental health need. For many autistic people the environment and 'approach' of hospital may increase their level of distress, cause trauma and see them trapped in a cycle of detention and use of restrictive practice. The statistics about the numbers of autistic people in long term segregation go some way to demonstrate this.

It is potentially easy to assume that mental health settings are safer places for autistic people and people with a learning disability, when the reality is that this is often not the case. The current system is failing people and we need this legislative reform to be one of the required levers for creating change.

The changes to the legislation alone, will not be enough to keep people out of hospital. They will help, but it is only part of the picture. We need to ensure that people don't get to the point of crisis and needing to be hospitalised in the first place. We need investment in appropriate community resources and ensure that nobody is admitted to hospital because of a lack of suitable community support, or because a support placement has 'broken down'. Clinicians and mental health teams as well as others must be autism informed. We could also think about what measures could be put in place to disincentivise the admission and detention of people.

People must be able to access high quality, autism informed support in the community from community mental health teams, from local authorities, from housing, from improved diagnostic services, well trained, autism aware support staff etc

We think that increased rights to independent review and scrutiny of people's care and treatment may also help.

There is also more that can be addressed within the Bill. We have set out some of these below:

- Increased rights to independent advocacy, extending opt out to informal patients and also ensuring that people are re-offered advocacy at regular intervals if they have initially declined the support of an advocate. Being explicit about the role of IMHAs in supporting people with preparing for, attending, and following up from C(E)TRs, Tribunals, ward rounds and other reviews of the care and treatment. Being explicit about when non-instructed advocacy must be provided to people who aren't able to consent to receiving advocacy support, or who lack capacity to make decisions in relation to their care and treatment. We need to ensure that there is adequate investment in independent advocacy to ensure that advocates have a regular, visible presence on the wards.
- Extending rights to advocacy for people who are on dynamic support registers or people who are identified as being at risk of admission.
- People with a learning disability and autistic people want and need access to advocacy
- Extend rights to C(E)TR to informal patients. Strengthened requirement to respond to C(E)TR recommendations and increased frequency of C(E)TR S. We should also explore the link between C(E)TR and tribunal. Additionally we need to ensure that panel membership of each have a current and positive understanding of autism and learning disability.

- Strengthened role of the tribunal to direct and compel local authorities, ICBs and NHSE to create appropriate community solutions and community support that replicates the way that the Court of Protection is able to direct. They need to be able to demand action.
- We think there is scope to introduce additional independent oversight mechanisms that are triggered by longer stays in hospitals, use of long-term segregation or seclusion and/or when restrictive practices are used. This should shift decision making away from the person's current clinical team.
- Strengthening the duties on local authorities in respect to developing and commissioning appropriate community services.
- Addressing how dynamic support or dynamic risk registers can take account of people who lack the capacity to consent to being on the register. Currently people will only be included if the consent. Given that some people with a learning disability and autistic people may lack the mental capacity to provide consent, it would seem a 'best interests' solution may also be required.
- Clarify how the MCA should be used in Mental Health Settings, e.g. not to detain people because they pose a risk to self or others.
- Financial compensation for the person if they are detained inappropriately due to a lack of community support
- Require community 'crash pads', or safe spaces for when people are in crisis
- Require mental health care and treatment to be provided from home for people for whom hospital is the wrong support and recovery environment when they do have a mental health need.
- Ensuring that sensory assessment are carried out early on in someone's stay in a mental health setting to understand how the physical/sensory environment and their care and treatment needs to be adapted and reasonable adjustments made.
- Early screening for autism on admission to hospital.

In relation to wholesale reform - We need the legislative reform that is in the Bill now. That doesn't stop us moving toward wholesale reform. There is a sense of urgency, and the bill has come a long way. We would hate for us to lose momentum. Complete overhaul can happen in parallel as the implementation – which is already set to be longer than ideal.

## Subject 2: Community care

Q2 Where else in the system is more reform needed to ensure these changes are positive for people with learning disabilities or autistic people?

- Community care will be even more important after these changes. What changes would you like to see to community care provision, and how do you think they can be reflected in this Bill?
- Should changes to the MHA be paused until we are sure that people with learning disabilities or autistics people will be adequately supported in the community?

What will be the effects of people with learning disabilities or autistic people not qualifying for Section 117 aftercare?

As above we need significant reform to:

- We must ensure that high quality, autism aware support is available to people in the community. This means ensuring that people have access to appropriate housing and person led support that provides the right support, in the right place at the right time. We know that the lack of appropriate community support is one of the factors that keeps people inappropriately detained in mental health settings. We also know that decisions about who is responsible for funding housing and support can be time consuming and also lead to significant delays. Clarifying decision making processes for funding or creating clear funding streams for autistic people and people with a learning disability may make a significant difference. Schemes like '[Small Supports](#)', supported by NDTi have shown that different approaches to commissioning and delivery of support works.
- Mental Health Tribunals to ensure they are effective and also those sitting on tribunals for people with a learning disability and autistic people are aware of best practice in the support of people.
- Community diagnostics – there are often huge waiting lists and then very slow responses. This is particularly problematic for autistic women who often don't receive a diagnosis until they come into contact with mental health services and/or the criminal justice system.
- In our experience there is a significant issue in the availability and ability to access high quality autism informed Community Mental Health support. This has got worse over recent years and is potentially even more of an issues for children and young people. We have seen a significant rise in the numbers of people contacting us in distress and in hearing from people about the complete lack of mental health support in the community. People wait for incredibly long periods of time, may only be able to access a short intervention of support and then are back to being expected to manage on their own. If we are going to reduce detentions of people overall as well as people with a learning disability and autistic people, there must be investment in the provision of high quality, autism informed community support. We need robust, autism informed community mental health services alongside community learning disability services.
- At the same time, access to non-statutory advocacy has also reduced, meaning that people are less able to access independent support to navigate health and social care systems. People are less able to access support which helps them understand their rights and entitlements. Increased investment in community mental health advocacy would help.
- People's right to review and advocacy are clear under the Care Act – we need to ensure that there are rights to review and rights to advocacy support for review when people's support is fully NHS funded.
- Duties on Local Authorities/ICBs to develop and commission services.
- Duties to consider innovative use of funding – increased use of Personal Budgets, Personal Health budgets and individual service funds.
- Person led, individualised solutions that fully respond to people's sensory and communications needs.
- Rights to advocacy that extend to people 'at risk of admission' not just those who are in hospital.
- A statutory right to community C(E)TR s

We don't believe that changes to the MHA should be paused, given the significant implementation period already identified. However, there must be immediate investment in community support options and services.

In relation to 117 aftercare. We know that people are already being kept in hospital informally and or on a DoLS as a way of avoiding people accessing 117 funding. If people have been in hospital because they have a mental health need, they should still be eligible for 117. If people don't have a co-occurring mental health need, then 117 funding shouldn't be being used.

However, access to funding and clear decision making in relation to funding does remain an issue. There must be clarity about funding responsibilities, so people aren't pushed from pillar to post or left in limbo while funding decisions are made. Given the significant cost of keeping people in hospital (into the millions per annum), we should consider ways of that resource being freed to develop appropriate, high-quality community supports. Use of Personal Health Budgets, integrated person budgets and ISFs should be being considered.

Currently competence of staff is an issue. Many staff don't understand risk mitigation or how to get there for individuals. Change for people who are neurodivergent is likely to be challenging, it may be rocky. We need staff to better tolerate uncertainty, risk and challenge and to be able to support people through those rocky transitions with less fear of what could go wrong. Staff need more experience of it going well and getting out the other side of a transition to people being more settled.

There must be clear leadership to achieve the change needed.

### **Subject 3: Alternative routes to detention**

**Q3** We have heard concerns that the proposed changes to the MHA may mean more people with learning disabilities or autism are detained under the Mental Capacity Act. How concerned should we be about this possibility?

- If there is a basis for these concerns, what will be the real effects on the people you represent, and how could these effects be mitigated?
- Would better community care solve this issue?

This may well be a possibility, and we think that it should be clear that the MHA isn't used to detain people in mental health settings. The MCA isn't designed for use in these settings. We need to ensure that there is no loss of rights independent review and/or access to appeal as well as no loss of rights to independent advocacy.

We know that it may also lead to people being held under a DoLS/LPS and subject to restrictive practice in the community. Again, we need to ensure that there is no loss of right to review, appeal and advocacy.

It is also worth considering how independent monitoring, oversight and scrutiny and/or regulators are involved whenever and wherever there is use of restrictive practices, such as restraint and seclusion.

As before, we know that health and social care professionals become adept at finding ways around the legislation, whatever that is. This makes it even more important that people have

access to the appropriate community supports that keeps them out of crisis and hospital in the first place.

People are already being held under a DoLS in Mental health settings and we know people being in hospital 'informally'. This impacts people rights to access advocacy, review and appeal.

It is worth noting that some advocacy colleagues will say that when they find someone who is in hospital informally but being defacto detained as they are in hospital informally but not actually free to leave, they often push for people to be under a DoLS (the MCA) than a section of the MHA, as they are more likely to have success getting people discharged with appropriate support and accommodation, via the Court of Protection. This brings us back to the powers of the mental health tribunal needing to be strengthened and ensuring that mental health tribunals are always autism aware and have a clear understanding of the needs of people with a learning disability.

We are already hearing that people are being given alternative diagnosis – eg. EUPD in order for clinicians to justify detention. Health and social care professionals get good at finding ways round the legislation. Legislation needs to ensure the rights of people with a learning disability and autistic people are protected regardless of the reason for or mechanism of detention.

**Q4** What is your perspective on the Bill's proposal to apply different provisions to people with learning disabilities or autism who are civil patients as opposed to those who come through the criminal justice pathway?

- We have heard concerns that more people with learning disabilities or autism are at risk of coming into contact with the Criminal Justice System as a result. Do you agree? If so, what can we do about it?
- If so, could this further disadvantage people with learning disabilities or autism who are also from minority ethnic groups?

We've covered this to some extent above. We do think there is scope for confusion, miss-use and unintended criminalisation of people with a learning disability and autistic people and therefore we believe the conditions should be removed from the act entirely. It doesn't make sense that autism and learning disability are recognised conditions in one part of the act and not the other.

We see three issues that need to be considered:

- 1) The use of criminal sections over standard sentencing for people with a learning disability and autistic people which can see people effectively serving indefinite sentences and trapped in they system
- 2) How the criminal justice system can and should be making reasonable adjustments for people a learning disability and autistic people who have committed a crime and need to serve a sentence
- 3) The potential criminalisation of autistic people in mental health settings (Alexis Quinn set this out brilliantly in her evidence) because they are being subject to an inappropriate physical and sensory environment, staff who aren't autism aware and therefore a lack of reasonable adjustments

We need to ensure that the criminal justice system can appropriately respond to the needs of people with a learning disability and autistic people. This means learning disability and autism aware staff/police. (Including police that are able to recognise and de-escalate when people are experiencing a 'melt down' and not in a position to self-regulate).

We know that review process for people on criminal sections also aren't working currently; with often risk averse decision making in place. We hear that learning disability and autism are seen as reasons to be cautious in relation to discharge. Conditional discharge process must have clear criteria. We're also concerned that decision re discharge or often down to one individual; Ministry of Justice representatives have to agree a person's discharge process and sign it off. Our experience is that people are often required to meet impossible criteria, leaving them trapped and other services powerless.

We need to ensure the criminal justice system is also able to make appropriate reasonable adjustments for people with a learning disability and autistic people and are encourage by the introduction of Autism Liaison Officers by the Prison Probation Service. We've also heard interesting work happening in this area at Pentonville Prison.

It may be easy to consider that hospitals are better than prisons because prisons aren't responding to the needs of people with a learning disability and autistic people and not making the reasonable adjustments required of them. And we wouldn't want to see people with a learning disability in prison. However, we also know that hospitals are often not making the reasonable adjustments they need to. Or are not the appropriate physical and sensory environment in which people can be assessed and recover. Whether you're in touch with the CJS or MH services – those services must make reasonable adjustments and be learning disability and autism aware.

#### **Subject 4: Assessment and treatment**

Q5 Is the 28-day assessment period under Section 2 appropriate for mental health professionals to assess people with learning disabilities and autism?

- How much of a problem do you anticipate diagnostic overshadowing to be during this assessment period? How might the draft Bill address this?
- Do you have any alternative suggestions for how the Government could make this provision more appropriate for people with learning disabilities or autism?

In terms of 28 days. It is difficult to answer. For some people it will be too long and others not long enough. However, if there is a suspect co-occurring mental health condition people will be able to detained on a section 3. If there isn't a co-occurring mental health need then it would seem prudent to support people to access the right support, care and treatment in a more appropriate environment as soon as possible.

Inpatient services can be harmful for autistic people causing a deterioration in mental health, resulting in longer detention, increased use of seclusion and long term segregation (very high numbers of autistic people in seclusion). So, in that instance it's about ensuring people are being supported in an appropriate environment for them. Busy, noisy mental health settings may not be right for any length of time.

Other people may need longer than 28 for staff to get to know them and to understand their learning disability/autism and mental health needs. But we think that assessment and treatment at home or in a community setting designed with the needs of autistic people and people with a learning disability in mind would be far more appropriate than hospitalisation.



Diagnostic overshadowing has potential to be a significant issue. We need to ensure early screening for autism on admittance to hospital, we need autism informed teams who understand the sensory and social processing differences of autistic people and will adjust how they work to accommodate people's needs.

In terms of other suggestions, we think increasing the role of autistic peer workers in mental health settings can be extremely helpful. They are likely to understand the sensory needs of the person and how the environment does and doesn't support someone. They are able to flag challenges, and champion change from within. It may also help remove issues with double empathy.

As before:

- Think about how the act can respond to the needs of individuals rather than making blanket approaches try to fit
- Rights to review, oversight and independent scrutiny.
- Think about environments and their impact ([It's Not Rocket Science Report may help](#))
- Ensure people aren't in hospital in the first place.
- Hospital at home, where there is the same clinician, same team
- Alternatives to hospital. Crisis beds, community crash pads,
- Recognition that additional sensory needs are further impacted and challenged by changes. This makes it even more important to support approaches which provides continuity for the person.
- Easy access to additional support for people who have changing needs.

**Q6** Are further changes necessary to ensure that people with learning disabilities or autism and a mental disorder that might warrant detention are given treatment that is suitable to their specific needs?

- Does the draft Bill need to go further in defining "therapeutic benefit", and how that relates to people with learning disabilities or autism?
- Is there anything more that the draft Bill can do to address the mistreatment of people with learning difficulties in inpatient care?

The draft Bill must define therapeutic benefit. We would also suggest that there should be a therapeutic benefit threshold to criminal sections.

We've covered some of the areas that the bill could be strengthened. We could also consider:

- Have a clear point of contact for families; somewhere that's easy for parents to access. Families often understand process. We think a role akin to IMCA 39d could be helpful, where by families are able to access advocacy support in the role of nearest relative/nominated person.
- A clear and central point to go to with issues and concerns re care and treatment for people, families and advocates?
- Independent scrutiny of care and treatment when people experience delays in discharge, restrictive practice and long term seclusion. Introduce strengthened independent oversight



when people are 'stuck'. Beyond CTR – enhanced tribunal – tribunals with autism informed panel when there is use of restricted practice/LTS

- Recourse to damages when people aren't discharged in a timely fashion.
- Prosecuting appropriately when people with a learning disability and autistic people have been assaulted in mental health settings.
- Support for families. Many of whom give up work in order to spend their time seeking to support their relative and see them discharged to appropriate support settings. The costs, emotional and financial of having a loved in detention, especially if placed far from home are huge.
- More transparent and open safeguarding processes
- Requirements around training and qualifications of staff supporting people with a learning disability and autistic people.

## Subject 5: Safeguards

Q7 Will making Care (education) and Treatment Reviews a statutory requirement be enough to ensure they are effective?

- Are there other ways that that this process could be improved?

In short, no. There needs to be clarity about the role and function of C(E)TR s. Currently they will frequently start looking at and doing care planning which is not their function. We think this is well intended as people often don't have appropriate care plans in place.

Care plans do need to be appropriate and the C(E)TR s may have a place in proposing solutions, however they don't always have the expertise needed to get it right.

C(E)TR recommendations are rarely followed and as it stands the bill could be strengthened to further require that recommendations are followed. And to introduce sanctions or other consequences if action is not taken in a timely way. Currently relevant parties don't include Local Authorities and only require parties to 'have regard to the recommendations'. Local authorities must have responsibilities to commission and develop community solutions and be accountable.

We need robust C(E)TR policy, clarity of purpose and enforceability of recommendations.

We also think:

- The right to a C(E)TR should be extended to informal patients and to people at risk of admission in the community (sometimes called a blue light C(E)TR or a community C(E)TR )
- The bill or code of practice could be specific about right to independent advocacy support for C(E)TR .
- It would be beneficial to increase frequency of C(E)TR s, particularly 2 weeks and then 3 monthly for children and young people. A year is a very long time for young people.
- There are many undiagnosed autistic people in hospital and multiple barriers to diagnosis (even in hospital). If you don't have a diagnosis, you won't get a C(E)TR . We suggest screening needs to be implemented on admission, and those who self-identify or who meet a threshold on screening are eligible for C(E)TR and also included in any additional support offer and reasonable adjustments.
- Duties to provide information in a variety of formats

Q8 The draft Bill places a duty on 'Integrated Care Boards' (ICBs) to monitor individuals 'at risk' of detention. Will this help care services to intervene before detention?

- Disability Rights UK told us that the planned risk registers appear "somewhat double-edged" as they might lead to further stereotyping of people with learning disabilities or autistic people. Is this a risk?

What information do you think should be included or omitted from the registry?

We support the creation of local dynamic risk registers. To be effective they must go beyond those at immediate risk of admission to hospital and drive proactive responses from public bodies rather than be a passive record. They must also be actively used to understand population needs and feed into immediate, medium-and long-term plans to enhance community-based capability and capacity.

We believe that any dynamic support register or monitoring of individuals needs to be linked to local Safeguarding Teams/Boards and to quality community supports. We also need to think about how to include people who haven't yet got a diagnosis / are on waiting lists. There may also be benefits in linking with schools and education systems. We need to include those Children and young people who are unable to get into school (emotionally based school refusal).

We understand the risks highlighted by Disability Rights UK and agree the risk exists. However, if the monitoring and registers lead to appropriate high-quality services and support for people then the potential benefit outweighs the potential risk. We note that autistic girls are often not listed on Dynamic Support Registers as they're not known to services until in crisis / at point of admission.

As before we think there needs to be exploration of how people who are unable to consent due to mental capacity or due to perceived competence for children and young people is managed. There is a higher detention rate for autistic children, many of whom may not be able to consent to being on the DSR, but who may benefit from being included.

## Subject 6: Advocacy

Q9 Are the draft Bill's proposals for expanded advocacy services enough to ensure that people with learning disabilities or autism are able to get their voices heard?

- Are people with learning disabilities or autism at risk of being disadvantaged by the 'opt-out' advocacy system not being extended to informal patients?
- Are improvements to advocacy services deliverable to the timescales the Government envisages?

NDTi welcome the changes to rights to advocacy in the draft bill and we believe that there are some easy additions that could be made to ensure appropriate advocacy support is available to people with a learning disability and autistic people:

- People want and need more holistic and longer-term support than others without a learning disability. Continuity of support is crucial, and we need to consider pre,

admission, inpatient and post admission support when we think about continuity. The Bill needs to reflect the requirements for reasonable adjustments to be made in the commissioning, delivery, and facilitation of independent advocacy for people with a learning disability and autistic people.

- The current bill makes clear how advocacy should be commissioned, but we know this isn't followed. Commissioning responsibilities and arrangements must be clarified to strengthen independence and ensure provision is based on the needs of the local population. There are current confusing arrangements when the Mental Health Act isn't followed which leads to multiple advocacy providers in one setting. Our view is that this is mostly problematic rather than helpful.
- We also know that it is problematic when NHS and independent hospitals commission their own advocacy services. Currently many hospitals commission their own advocacy and sometimes limit access to statutory, local authority commissioned services. The bill needs to make clear the commissioning and delivery of advocacy must sit apart from any hospital setting.
- We know that people need time to build relationships with advocates and that advocates need to be visible and present on the ward in order to maximise take up of advocacy. Advocacy services needed to be resources adequately to provide this level of contact and support. We must ensure advocacy services are adequately resourced to ensure availability and visibility of advocates, funding for training and support of independent advocates.
- Statutory IMHA isn't enough, and people need to be able to access broader advocacy support including group advocacy and peer advocacy support
- We think the bill could introduce increased responsibilities on hospitals and commissioners to involve advocates. We know that advocacy support is often forgotten or seen as an inconvenience rather than a key part of the participation and involvement of the person in their care and treatment.
- We also know that many clinicians and staff across health and social care misunderstand the role of advocacy as well as people's right to access advocacy. We think staff need to be able to demonstrate a minimum understanding of advocacy rights in order to appropriate support people's access to advocacy and to then facilitate that access on an ongoing basis. When there are misunderstandings people mis out – especially when people may lack capacity to decide to access advocacy.
- Be specific about a right to advocacy at C(E)TR
- The bill and associated code of practice needs to make clear approaches that should be taken when people decline advocacy, especially when they may lack the mental capacity to make that decision. This is to ensure that appropriate non-instructed advocacy is provided.
- Ensure that impact assessments properly plan for the appropriate level of advocacy support required by people with a learning disability and autistic people.

- Statutory rights to advocacy are limited and set out in a piecemeal fashion in separate pieces of legislation (Care Act, MCA, MHA) – we believe that ultimately a review and bringing together of the advocacy legislation would benefit people with a learning disability and autistic people.

There is a risk to people with a learning disability and autistic people being disadvantaged by opt out. This could be addressed through:

- Extending opt out to informal patients.
- Ensuring hospitals have a duty to inform people and their families about rights to advocacy
- Ensuring that information about advocacy is available in a variety of formats
- Ensuring that multiple opportunities are made to people to explain the advocacy role and the benefits of accessing advocacy.
- Ensuring that advocates and advocacy is visible – we know that people need to see advocacy in action to understand the benefits and draw on advocacy support.
- Ensuring advocates are fully trained in the delivery of non-instructed advocacy, when people lack the mental capacity to instruct their advocate or consent to advocacy
- Ensure staff in mental health settings have clearly defined roles and responsibilities in facilitating access to advocacy.

We're unclear about what improvements to advocacy the Joint Committee think are required, however we believe that clear commissioning and resourcing of advocacy along with robust training and support of advocates is achievable with the right investment.

NDTi have been leading an NHSE commissioned review of inpatient advocacy to people with a learning disability and autistic people who are inpatients in mental health, learning disability and autistic people. The Advocacy Review was commissioned by NHSE utilising one off Spending Review Funding (2021/22) committed by the Department of Health and Social Care.

NDTi working with partners were commissioned to carry out a comprehensive review of advocacy provision for people with a learning disability and autistic people who are inpatients in mental health, learning disability and/or autism specialist hospitals.

The report from the review is not yet published so we can only share high level details until publication. We expect the report to be published before the end of the year.

### **Some of the Key findings:**

The review explored independent and statutory advocacy, as well as peer, self and group advocacy, and families' experiences as advocates.

Findings and main themes are complex, multi-faceted and systemic. The review has found that people with a learning disability and autistic people face additional barriers to independent advocacy whilst in mental health hospitals.

This includes, for example, how people are supported to understand and access advocacy, how advocacy is usually offered and the impact of commissioning arrangements on this, current constraints on the advocacy that is available, some of which is addressed in this Draft Bill, the culture around how people are enabled to benefit from advocacy, and how supported families are when they also advocate for their family members.

We hope that there will be time to consider the full findings of the review in due course.

### **Subject 7: Minority groups and women**

Q10 The Independent review found that people from minority groups and women experience higher levels of detention. Is enough consideration given in the draft Bill to specific issues facing patients from these groups who also have learning disabilities or autism?

- Women and girls with learning disabilities and autism also experience higher detention rates. Why is this, and is there enough recognition of this problem in the draft Bill?
- Do you have any suggestions for how the draft Bill could go further to improve inequalities for these groups, especially where individuals have multiple protected characteristics?

There is a need for improved access to diagnostic services (including pre and post diagnostic support), particularly for autistic women. Where people remain undiagnosed, they also remain off dynamic risk registers. There needs to be increased opportunities for people to be included.

Too often the first time the support needs of a person with mild/borderline learning disability are recognised is when they come into contact with the criminal justice system. It would be worth exploring the potential for joining up 'register' activity with Multi Agency Safeguarding Hubs to avoid both duplication and gaps.

It's hard being a teenager, and it's even harder being an autistic teenager. Many autistic girls are diagnosed later (there are some stats on that in the rocket science report linked earlier). Women and girls are known to mask, so support needs are not identified or understood. Many manage until they hit crisis and then can't manage anymore.

Part of the answer sits outside the bill and in community services and schools. We need better support for autistic people before admission is necessary.

When people are well understood and well supported in the community they are less likely to offend/be unwell or experience placement breakdowns that shouldn't but, do currently lead to admission to mental health settings. As before mental health hospital is rarely the right place for people with a learning disability and autistic people in crisis.

High quality, autism informed community support is essential if we are going to achieve reduction in hospital admissions.

### **About NDTi**

The [National Development Team for Inclusion \(NDTi\)](#) is a social change organisation working to enable people at risk of exclusion, due to age or disability, to live the life they choose. We inspire and support policymakers, services and communities to make change happen - change that leads to better lives.

NDTi support People to live good lives in their communities through a number of relevant programmes: Small Supports, C(E)TR s across the South of England, Supporting advocacy providers through the advocacy quality performance mark, reviewing advocacy to people with a learning disability and autistic people who are inpatients in mental health settings, assessing the sensory

environments of hospitals and CAMHS units. NDTi has a skilled team of experts by experience who are autistic, have a learning disability or are family members of people with a learning disability and autistic people.