**This document provides further information and clarification to oral evidence given by Simone Aspis to the Parliamentary Committee on the Draft Mental Health Bill.**

# **About Inclusion London**

Inclusion London is an organisation led by disabled people that supports over 70 Deaf and disabled people’s organisations working across London. Through these organisations, our reach extends to over 70,000 disabled Londoners. Inclusion London supports the capacity building of national disabled people’s organisations with legislation and policy work. Consequently, Inclusion London now meets with government ministers on a regular basis.

## **Free Our People Now**

Inclusion London, a disabled people’s organisation (DPO), has received funding from the Three Guineas Trust to set up a project to support people with learning difficulties and autistic people who want to live in their own homes rather than in hospitals. Inclusion London want to work with both DPOs and disabled-led campaign groups who would like to support disabled inpatients to leave hospital and receive the support they need in the community. Inclusion London’s additional submission is the additional evidence that we were unable to provide during the oral evidence session.

### **Panel 1 Questions**

**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 (UNCRDP) and called for a complete overhaul of Mental Health legislation. What is your view?

The United Nations’ Convention on the Rights of Persons with Disabilities (UNCRPD) Monitoring Committee concluded that the UK’s existing mental health legislation violates disabled people’s human rights under Article 12 (Equal recognition before the law), Article 14 (Liberty and securityof the person), and Article 19 (Independent living). The UNCRPD Monitoring Committee made the following recommendations[[1]](#endnote-1):

* The Government should, in consultation with DPOs, ensure that both disabled people with psychiatric diagnoses and those lacking capacity have equal recognition before the law, where disabled people should not be detained by the state on the grounds of disability. This requires the abolishment of substituted decision-making concerning all spheres and areas of life by reviewing and adopting new legislation in accordance with UNCRPD to initiate new policies in both mental capacity and mental health laws.
* The Government should repeal legislation and practices that authorise non-consensual involuntary, compulsory psychiatric treatment and detention of disabled people on the basis of actual or perceived impairment.
* The Government should set up a comprehensive plan, developed in close collaboration with DPOs, aimed at the deinstitutionalisation of disabled people, and develop community-based independent living schemes through a holistic and cross-cutting approach, including education, childcare, transport, housing, employment, and social security

The draft Mental Health Bill will violate disabled people’s human rights as its provision will continue to allow for disabled people to be detained in psychiatric hospitals on the basis of psychiatric diagnoses, perceived risk, and the protection of oneself and the public at large. Inclusion London does not support any proposed mental health legislation that begins from the position of violating disabled people’s UNCRPD human rights. The proposed Draft Mental Health Bill presumes that there is a correct way of being, feeling, thinking, and relating to others in the world. In particular, many Autistic people’s sense of being, feeling, thinking, and relating to others in the world will differ from that of the neuro-typical population. Too often, Autistic people and people with learning difficulties are caught up in the psychiatric system because there is often limited-to-no understanding between themselves and neuro-typical people or acceptance of neo-divergence.

Whilst autistic people and people with learning disabilities will be removed from the psychiatric disorders to be treated under Section 3 of the Mental Health Act 1983[[2]](#endnote-2), they will nevertheless remain detained in psychiatric hospital on the grounds of having a learning disability or autism under the Mental Capacity Act and Criminal Justice provisions; both pathways are much more punitive than the current civil provisions.

Spectrum reported that 70% of people with an autism diagnosis will be accompanied by another psychiatric diagnosis.[[3]](#endnote-3) Indeed, 40% of people with an autism diagnosis will be accompanied by two or more psychiatric conditions; autistic people are at an increased risk of experiencing one or more separate psychiatric conditions as autism and psychiatric diagnoses share similar characteristics due to diagnostic overshadowing.[[4]](#endnote-4),[[5]](#endnote-5) Autistic individuals and those with learning difficulties are often admitted in distressing states and are expected to cope in an oppressive hospital environment that is not geared to meet their needs, thus having a detrimental impact upon their mental health.

Furthermore, the Prison Reform Trust identified that between 5% and 10% of adults who offend have learning disabilities or are autistic.[[6]](#endnote-6) Once detained, autistic individuals experiencing a “melt-down” or “shut-down” caused by the unsuitability of the hospital environment will unwittingly be funnelled via the criminal justice system and hospitalised indefinitely under Sections 37 and 41 of the Mental Health Act.[[7]](#endnote-7) Inclusion London are concerned given the potential for autistic individuals’ behaviour to be punished and criminalised as a result of being funnelled through the criminal justice pathway. Autistic people have highlighted the damage that the criminal justice system, including prison and hospital detentions, can inflict on people with learning difficulties and autistic people.[[8]](#endnote-8)

Not only does the Draft Mental Health Bill not go far enough, it also starts from the wrong position. Inclusion London has not found any evidence that supports the notion that hospital settings involving non-consensual treatment can be humane environments that promote disabled people’s human rights. However, investigative reporting in recent years has consistently highlighted the inhumane and abusive practices disabled people endure in such institutions on a daily basis.[[9]](#endnote-9),[[10]](#endnote-10),[[11]](#endnote-11),[[12]](#endnote-12),[[13]](#endnote-13) What these reports highlight is that psychiatric institutions that control disabled people and their contact with the outside world will also be at risk of epidemic abusive practices, and as such institutions must be closed down. If the Draft Mental Health Bill begins from a place of promoting disabled people’s rights to good mental health, then its emphasis would be on promoting disabled people’s well-being, where community and mental health care would sit alongside the social-economic levellers (i.e., good quality housing and employment). Social opportunities, support, and sufficient financial income would therefore be central to reducing unnecessary hospital detentions.[[14]](#endnote-14)

#### **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 autistic 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?

The Draft Mental Health Bill provides a statutory right to care and treatment if sectioned. However, there is no corresponding statutory right to community care to prevent the need for detention in first place. The Draft Mental Health Bill must shift its focus from regulating hospital detention to providing (1) care and treatment for disabled people facing a mental health crisis and (2) provisions that promote their good mental health and positive well-being within their local communities. The Draft Mental Health Bill fails to provide autistic people and people with learning difficulties a statutory right to community care, or more broadly the right to independent living under the UNCRPD Article 19. The 12 Pillars of Independent Living identifies what disabled people require to have a good quality of life[[15]](#endnote-15); this is associated with good mental health and well-being and access to education, employment, leisure, and public transport. A good quality of life also recognises disabled people’s participation in opportunities and activities outside health and social care services.

Inclusion London concludes that the Draft Mental Health Bill needs to strengthen its Care Act[[16]](#endnote-16) provisions to ensure they are compliant with disabled people’s right to independent living under UNCRPD Article 19[[17]](#endnote-17), in addition to incorporating the 12 Pillars of Independent Living. Reclaiming Our Futures Alliance (ROFA) have developed a National Independent Living Service that should be legislated for.[[18]](#endnote-18),[[19]](#endnote-19)

##### **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?

Inclusion London are against the Mental Capacity Act provisions being utilised to detain people with learning difficulties and autistic people who are not resisting detention or who lack the capacity to give consent. We are concerned that the Mental Capacity Act’s provisions are weaker than those of the Mental Health Act with regards to the judicial oversight of hospital detentions. There is no evidence to suggest that people who lack the capacity to consent should be placed within a psychiatric hospital setting rather than living in the community.

As we have highlighted in answering the first question, the Draft Mental Health Bill needs to be framed around disabled people’s right to independent living, which will support their positive well-being. Disabled people must have an absolute right to independent living support. The Draft Mental Health Bill must thus include legal duties placed upon Integrated Care Boards (ICBs) including:

* Strategic plans to close psychiatric hospitals and create community mental health services in combination with people with learning difficulties and autistic people with lived experience of hospital detention and mental health challenges.
* Strategic plans to develop homes and the support that promotes people with learning difficulties and autistic people’s well-being.
* The commissioning of individual support packages that promote disabled people’s well-being.

Inclusion London wants a statutory duty placed on Integrated Care Boards to develop strategic plans that actually move autistic people and people with learning difficulties out of psychiatric settings and into their own homes.

**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?

There has been extensive research into both people with learning difficulties and autistic people’s experiences of the court process itself and the areas of improvement required by the criminal justice system to ensure a fair trial.[[20]](#endnote-20),[[21]](#endnote-21),[[22]](#endnote-22) However, there is limited research exploring the interactions between criminal law, the criminal justice system, and the mental health system. It’s rare that a single factor exists for why people with learning difficulties and autistic people offend. In 2018, Professor David Murphy highlighted that cognitive, sensory, social difficulties and differences, coping strategies, psychopathy, mental capacity, suggestibility, and case management all have a part to play in why autistic individuals offend under existing criminal legislation, such as the Offences against the Persons Act.[[23]](#endnote-23)

The National Autistic Societyprovides some concrete examples of how autistic people’s behaviour can be criminalised[[24]](#endnote-24):

*“A young autistic man in his “day-setting” wanted to shake everybody’s hand whenever he saw them. This was potentially a slight issue, but generally manageable. The problem stemmed from the fact that he would constantly have his hand down his trousers too! Combine the two and suddenly there are numerous issues that arise.”*

*“A child in a public place smelling a person's hair or touching a particular type of clothing because they like the material may be seen as “odd” or “strange”, but a 6ft adult male behaving in the same way is going to be interpreted very differently. It might lead to outsider intervention, possibly to police involvement and even criminal proceedings.”*

*“An autistic gentleman who would seek out sensory stimulation in terms of smell found himself attracted to women’s public toilets. Lots of complaints were received, the police became involved and he was detained in a special hospital.”*

Inclusion London wants further research to investigate positive options that should be in place such as community care solutions that will help autistic people and people with learning difficulties who are at risk or have experienced the criminal justice system.

Inclusion London wants an extensive review on the interaction between criminal and mental health law so that the behaviour of autistic people and people with learning difficulties will not be stigmatised and criminalised after being funnelled through the criminal justice system. Without a comprehensive review of the criminal legislation, we fear that people with learning difficulties and autistic people being detained under the criminal justice provisions of the Mental Health Act 1983 will substantially rise if autism and learning disabilities are removed from Section 3.2

###### **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?

Female inpatients have reported to Inclusion London that their autism is either left undiagnosed or that their existing autism diagnosis is ignored. Women inpatients are often diagnosed with borderline personality disorder, bipolar, schizophrenia, or another psychiatric diagnosis. Additionally, 70% of autistic people will have an accompanying psychiatric diagnosis, with 40% having two or more additional psychiatric diagnoses during a psychiatric hospital assessment.2,3 Having a dual diagnosis of a psychiatric diagnosis means that hospital staff can justify medicating inpatients without their consent under Section 3 of the Mental Health Act 1983.2

Inclusion London are aware people from the BAME communities are far less likely to have formal learning disabilities, learning difficulties, and autistic diagnoses.[[25]](#endnote-25)

*“There may be various reasons for the disparity, from communication or cultural barriers between minority parents and physicians to anxiety about the complicated diagnostic process and fear of stigma."**[[26]](#endnote-26)*

Inclusion London wants everyone to be screened for autism and learning difficulties, particularly those coming from BAME communities and women.

**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-patient care?

The treatment criteria is focused on fixing the individual as though the mental distress is located as a chemical in-balance deep within the brain requiring medication or mindsets needing to be altered by psychological treatments. Treatment of therapeutic benefit does not include the changes in external environments and social determinants such as housing in safe neighbourhoods, support, sufficient income, and strong social networks which are associated with promoting positive well-being.[[27]](#endnote-27)

Inclusion London does not believe the Draft Mental Health Bill provisions will reduce or prevent the abuse and inhumane treatment that people with learning difficulties and autistic people experience in psychiatric hospital environments.[[28]](#endnote-28) As psychiatric hospitals are closed institutions where every aspect of inpatients’ lives can be controlled, including prohibiting outside contact, we do not believe anything can be done to stop the ongoing inhumane treatment that autistic inpatients and inpatients with learning difficulties experience. As long as psychiatric hospitals remain closed institutions, the abuse and inhumane treatment of individuals with learning difficulties and autistic inpatients will always be a real possibility.

**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 this process could be improved?

Inclusion London does not believe that there will ever be sufficient safeguards for inpatients detained under the Mental Health Act. Institutional settings with closed cultures hold unlimited power to do whatever management and staff like under the guise of therapeutic treatment. Staff not only have the power to administer any form of treatment but also to prevent or restrict contact with families, friends, advocates, and the like; this culture allows abuse to flourish within such settings. A decade of unending psychiatric hospital scandals[[29]](#endnote-29),[[30]](#endnote-30),[[31]](#endnote-31),[[32]](#endnote-32),[[33]](#endnote-33),[[34]](#endnote-34),[[35]](#endnote-35),[[36]](#endnote-36),[[37]](#endnote-37),[[38]](#endnote-38),[[39]](#endnote-39) affirm that care and treatment reviews, care programme approaches, and other inpatient review processes provide insufficient safeguards for inpatients.

**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?

The at-risk registers require the consent of autistic people and people with learning difficulties before being added to the list. Put simply, we are asking whether autistic people and people with learning difficulties would voluntarily want to be added to the register. Unless there is a statutory provision in place that would keep autistic people and people with learning difficulties out of psychiatric hospital, we do not see what purpose the registers will serve.

**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?

Inpatients value independent mental health advocacy support. The Social Care Institute for Excellence outlines the benefits from advocacy[[40]](#endnote-40):

* individuals feel empowered
* their quality of life is improved
* their access to support options is improved
* communication between service users and professionals is improved
* there are wider changes in services

Aside from the pending NHS England (NHSE) research into inpatient advocacy, there has been limited research to draw upon how effective independent mental health advocate (IMHA) services have been for autistic inpatients and those with learning difficulties. We are looking forward to reading the findings and recommendations from the NHSE research as People First groups have been involved in holding focus groups with inpatients with learning difficulties and autistic inpatients. Subsequently, they will be able to ascertain what needs to be changed so that IMHA and other forms of advocacy services are informed by the social model of disability and human rights principles.

Inclusion London are pleased to hear that speaking up groups with experience of empowering autistic people and those with learning difficulties are starting to receive funding; this will allow them to work with inpatients directly within the ICBs to undertake specific areas of work that will start to empower inpatients using group facilitators, peer advocates, befrienders, and undertaking one-to-one work, all of which should be placed on a statutory footing with IMHA. Unlike IMHA, People 1st organisations will support their members on a range of issues, such as housing, community care support, and social security benefits; all of these other issues alongside challenging hospital detentions are usually considered by Mental Health Tribunals when considering hospital discharge. In the Care Quality Commission’s review across England, 60% of discharges were delayed*31*:

*“A lack of suitable care in the community prevented discharge for 60% of people we met. Most people in long-term segregation needed bespoke packages of care in the community, but this was difficult to achieve.”*

What is needed is an integrated advocacy service that allows advocates to support autistic people and those with learning difficulties across a range of issues such as mental health, community care, and housing, among others. Too often, MHRTs will refuse to discharge inpatients from their section until the panel is satisfied with the community care and housing arrangements; the area falls under the Care Act rather than IMHA provisions.

Further, the availability and provision of legal advice services is needed to supplement the advocacy work being undertaken on the ground. Inclusion London believes that people who are detained under the Mental Health Act 1983 must always have access to legal aid regardless of savings particularly when they are at high risk of abuse and inhumane and non-consensual treatment. And the scope of non-means-tested legal aid should include community care, housing, human rights and discrimination,

We very much hope that the ICB will fund speaking up groups to undertake further strategic work that includes working together to develop strategic plans that will allow people with learning difficulties and autistic people to move out of hospitals and into their own homes.

Inclusion London wants autistic people and those with learning difficulties to have a holistic and well-funded range of advocacy support (traditional advocacy, peer advocacy, and collective advocacy) covering all aspects of life. Additionally, Inclusion London wants DPOs working on advocacy for disabled people to be funded and supported to facilitate their work with ICBs. This will lead to the formulation and implementation of strategic plans that will move people with learning difficulties and autistic people out of hospitals and into their own homes.

Yes, voluntary and detained inpatients’ who are Autistic and/or learning difficulties must have the right to independent mental health advocacy services. Inclusion London believe that anyone living in the community who is at risk of being detained under the Mental Health Act must have a statutory right to independent mental health advocacy services.

**Subject 7: Minority groups and women**

**Q10 The Independent review found that women and people from minority groups 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?

The Draft Mental Health Bill does not take an intersectional approach to deal with disabled people’s experience of mental distress, multiple protected characteristics (including people belonging to the BAME community, gender identification, and social-economic factors), and the psychiatric system. The Draft Mental Health Bill focuses on an individual’s ability to function in a world where inequality exists. For instance, minorities, disabled people, and women are more likely to experience disadvantages that will raise the pressure on their mental health. Education, housing, employment, health, and the criminal justice system are social determinants of mental health that are rarely taken into account.[[41]](#endnote-41) Instead, when there are discussions about racial differences in mental health services, narratives are often blame victims and link to race/ethnicity alone.[[42]](#endnote-42)

Further, the Draft Mental Health Bill joint committee should also reflect the impact that this draft bill will have on LGBTQAI+ communities. Autistic adults and adolescents are approximately eight times more likely to identify as asexual or ‘other’ (not heterosexual) than their non-autistic peers.[[43]](#endnote-43)

Gender identity and sexual orientation are reported to be more varied among autistic people than in the general population, and autism is more common among people who do not identify as their assigned sex than it is in the population at large. Indeed, autistic people are three to six times more likely than neo-typical people to identify as not heterosexual.[[44]](#endnote-44),[[45]](#endnote-45) Studies highlight that having multiple identities can have an impact upon mental health and this can create minority stress.[[46]](#endnote-46)

The mental health system must holistically work with individuals around their race, religion, beliefs, sexual orientation, and gender. Moreover, mental stress does not come from one single experience, but a range of intersectional experiences that individuals with learning difficulties and autistic people experience when engaging in society. Accordingly, community support and housing arrangements must support disabled people to be their authentic selves.

There is an awareness that race and LGBT+ related mental stress stems from the social-economic inequalities that exist in the Western economic system.[[47]](#endnote-47) Increasingly, there is also an awareness that the social-economic inequalities between the marginalised and non-marginalised groups need to diminish to reduce the mental health distress experienced by individuals. Consequently, to improve the well-being of society there is a need to put a mechanism in place to ensure that everyone has access to what is needed to create a happy society; this includes socio-economic security, social cohesion, social inclusion, and social empowerment. At a more practical level, it involves implementing the UNCRPD and the 12 Pillars of Independent Living.

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