

**Stay Safe East Response to the  
Reforming the Mental Health Act Consultation  
April 2021**



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### **About Stay Safe East**

Stay Safe East is the only user-led ‘by and for’ organization in the UK<sup>1</sup> providing long-term advocacy and support to disabled victims/survivors of multiple forms of abuse: domestic and sexual abuse and other forms of Violence Against Women and Girls (VAWG), hate crime, harassment, cuckooing, abuse by care workers or personal assistants (which we consider to be domestic abuse), and abuse in residential and other institutions. We work with clients across London.

### **A note on accessibility**

We found the method of responding via online survey to be inaccessible and thus have opted for a less prescriptive response format.

Stay Safe East has experienced major issues in the accessibility of government consultations as of late, and we have found this process to be particularly inaccessible. We recommend that, going forward, the Department of Health and Social Care (and other government departments) obtain professional advice from Deaf and Disabled People’s organisations on how to engage and consult with Deaf and disabled people.

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<sup>1</sup> SignHealth Domestic Abuse Service supports Deaf survivors of domestic abuse, and some Deaf and Disabled People’s Organisations provide advocacy support to disabled victims of hate crime. Stay Safe East is the only specialist service for *disabled* survivors of domestic and sexual violence, and the only organization to work across all areas of abuse.

## **Background**

Our response to the Reforming the Mental Health Act Consultation will be informed by our expertise and evidence from our casework with disabled survivors of abuse. We aim to help remove the barriers to justice and resolution for disabled survivors and to ensure that the voices of disabled survivors are heard by policymakers and other providers. We work within an intersectional approach to the social model of disability, recognizing that the barriers we face are posed by discrimination and marginalization, rather than by our impairment or difference.

Our clients including a significant number of women and a small number of men with mental health diagnoses, nearly all of whom also have other impairments – around 25% have learning disabilities and a smaller number are neuro-diverse. Some clients (and some of our staff) have experienced neglect, discrimination and other abuses of their human rights within the mental health system, others have benefitted from accessing quality and appropriate therapies and support. In the past 11 years, we have supported clients in dealing with mental health professionals, been with them when they have gone to A&E after suicide attempts or a severe mental health crisis, and advocated for them when they were detained in hospital; since the Covid pandemic we have provided life-saving support to isolated clients with severe mental health issues, filling the gap left by mental health services during lockdown.

## **Liberation**

We would like to signpost to the response to the Reforming the Mental Health Act consultation by Liberation, a grass roots organization led by people with experience of mental distress/trauma. Its aim is to champion implementation of the full human rights set out in the UN Convention on the Rights of Persons with Disabilities.

Stay Safe East is in agreement with the majority of Liberation's response. However, we would like to clarify that we differ with regards to Liberation's stance on detention of people under the Mental Health Act, namely that Liberation believes in "an end to substitute decision-making, detention in psychiatric hospitals, forced treatment". We oppose forced treatment and forced medication; we believe that in most but not all circumstances, supported (not substitute) decision-making is possible but requires skill and time. We believe that, although compulsory detention should be avoided wherever possible and we are critical of the human rights implications of many decisions made in the psychiatric system, in *some* circumstances we recognise that it is necessary to temporarily apply such restrictions in the interests of preserving life. This caveat aside, we support much of the sentiment in Liberation's response.

### **Principles**

We support the fundamental principles set out in the consultation document, of choice and autonomy, least restriction, therapeutic benefit and treating the person as an individual. However, this will only become a reality if resources are substantially increased and staff well-trained and motivated, and if there is also a focus on addressing the causes of severe mental health.

We are particularly concerned that there is no pressure from services who are seeking to vacate the bed space to discharge patients who are not ready to go back to the community. Stay Safe East has had to offer informal support to clients who have been discharged too early with little support because of the pressure on beds.

Please see below some additional key principles we believe should underpin the development of a revised Mental Health Act, with references to the changes proposed in the White Paper.

## **1. Nothing about us without us**

Nothing about Us Without Us is the basic of the approach to human rights taken by disabled people's organisations. In this context we very much welcome the following:

- the replacement of next of kin with a Nominated Person
- the use of Advance Choice documents
- making care and treatment plans compulsory
- greater clarity around the right to consent to or refuse treatment

With specific reference to people with learning disabilities and autistic people, Nothing about Us Without Us encapsulates the need to involve these individuals both as patients and as Experts by Experience.

- People with learning disabilities and autistic people and their organisations, and specifically those with lived experience of mental health issues and navigating the psychiatric system, should be at the forefront of policy-related decision making
- This principle includes prioritizing and listening to responses from those with lived experience, hence our aforementioned signposting to the response from Liberation.

## **2. Right to receive accessible information on people's rights**

The ability to receive accessible information on people's rights is especially important in the case of detention and forced treatment, or indeed any act under the Mental Health Act which infringes on an individual's freedom even if only temporarily. Patients must have the right to be informed of their rights in a format which is accessible to them. This includes, but is not limited to, access to a sign language or spoken community language interpreter, information provided in Easy Read and large print, audio format etc., and rights explained fully and accessibly. This may also involve supported decision making

with the support of a third party, independent advocates. For example, if patients are given the right to challenge detention, this cannot be done unless access needs are met during the process of doing so. Our advocates have had to take on that role with clients where other professionals have failed to explain a client's rights and choices in a way that they understood.

### **3. Duty on services to take account of people's protected characteristics**

Stay Safe East very much supports the moves to address the racism within the mental health system which has blighted the lives of Black men and women, who face inconsistent diagnosis, poorer access to care, a higher rate of dying within the system and in police stations, and pathologising of their culture and beliefs. We support the introduction of a new Patient and Carer Race Equality Framework (PCREF) to embed structural and cultural change in healthcare delivery to improve how patients from diverse ethnic backgrounds access and experience mental health care

Support from BAME specialist services is essential, as survivors trust organisations within their own communities more than generic, commissioned services. These organisations must be resourced and enabled to have the same right to intervene on behalf of a patient as commissioned IMHAs and IMCAs.

We notice that, apart from one mention of 'training on LGBT issues relevant to the tribunal', there is no other mention or recognition of how Lesbian, Gay, Bisexual and Transgender (LGBT) people experience mental health issues and navigate the psychiatric system, and the discrimination and pathologising they face within it. It is especially important to recognize and be aware of LGBT relationships during the process of selecting a nominated person, where 'chosen family' may take precedence over blood, and in some cases family members may have attempted to misuse the mental system by trying to get the person labelled as having mental health issues

because they are seen as having a 'deviant' sexuality or gender identity (hence the case for a ban on conversion therapy).

We also believe that Deaf people with mental health services have the right to independent advocacy and support in their language, not in English mediated through an interpreter, and to access specialist mental health services. At present there is one specialist service for Deaf patients in the whole of London and the Southeast at Springfield Hospital, which is under-resourced. Family or others visiting Deaf patients have to travel long distances, and this increases the patient's isolation.

We welcome the recognition that autism and learning disabilities do not on their own constitute mental health conditions – several of our clients with autism have been seen as 'odd', labelled 'mad' or as having 'challenging behaviour' and given unnecessary psychiatric medication because they were different, but their impairments were not diagnosed until they were older. However, it is also important to recognize the link between mental health issues and people who are autistic or have learning disabilities, due to people's widespread experiences of abuse, marginalization and exclusion.

Similarly, other disabled people face barriers if detained – for example the mental health system has no expertise in dealing with people without speech, or with people with brain injury whose mental health issues may be dismissed as part of their physical impairment.

We have come across practice which discriminates or puts people at risk – one client who is blind and has learning disabilities was on a generic mental health ward, patients were expected to have lunch all together, but with little or no supervision; our advocate arrived to find that our client was being subject to aggressive comments from other patients about her way of eating, that she needed a 'carer'. She

had been given no mobility training within the ward when admitted, and was lost and isolated.

The physical environment of most mental health wards presents considerable access barriers for disabled patients which may exacerbate their mental and physical health: inadequate physical access to toilets, showers, bedrooms and shared facilities; intense lighting which may trigger sensory overload in neuro-diverse people, high levels of noise etc.

The new law should seek to address the above intersectional issues and to place a duty on services to meet access, support and communication needs of patients prior to, during and after they are detained under the Mental Health act.

The three principles above should be written into the new law,

#### **4. Introduction of a right to a Nominated Person**

We very much welcome the introduction of a legal right to nominate someone of their choice who is not their relative to look after their interests under the Act. This is particularly important for people who have been victims of abuse at the hands of family members, including Deaf and disabled individuals who are more likely to be experiencing abuse by family members who are also their 'carers'. To further mitigate this circumstance, the support the person receives to choose a nominated individual must be received independently, away from their family, which may also facilitate a first disclosure of abuse.

#### **5. IMHAs and IMCAs**

We support the expansion of the role of IMHAs. IN the current context we are concerned that IMHAs and IMCAs may be seen as 'part of the system' by survivors, because they are contracted by mental health services, and that many have a role which is restricted to informing the patient of their choices, but not working for their

rights to be upheld. Their role must carry a duty to work for the right of the patient.

We support better training for both IMHA and IMCAs, and can see the benefits of accreditation. This must be open to other specialist advocates such as domestic abuse advisers (IDVAs) or sexual violence advocates (ISVAs), disability rights advocates etc. We do not support greater regulation as this may deter organisations which speak out on behalf of the most marginalized and disempowered mental health system survivors, including BAME people and people with learning disabilities. Sometimes the most informal advocacy which is grounded in the community and life experience of the patient is the most effective.

We believe the patient should have the right to choose to have an independent advocate of their choice, which may not be an Independent Mental Health Advocate (IMHA) or IMCA. In practice, we have acted as informal IMHAs and IMCAs for our clients who have been detained, because they know us and trust us. Patients should also have the right to access and select an informal advocate from specialist BME, LGBT and disability organisations. For this reason, we support greater training on the rights of mental health service users, and the right to choose one's advocate (and for services to recognise that advocate), but not greater formalisation of the role.

## **6. At risk register**

Stay Safe East is concerned by the proposal to introduce a local 'at risk' or 'support' register of people with learning disabilities and autistic people in the local population. How will this register be used? What is the potential for error here? Will the people concerned be informed they are on the register, and will they be able to refuse to be on the register? And how do we address the

significant challenges of obtaining an autism diagnosis as an adult, for example, alongside the potential for misdiagnosis. We would argue that such a register will at best be incomplete (as now happens with registers of people who are visually impaired, where most people do not opt to be 'registered' because it brings them no benefits), at worst an abuse of GDPR and people's rights.

## **7. Rights of people with Learning disabilities and autism**

We support the change to the law to clarify that autism or a learning disability are not considered to be mental disorders, but would like further clarification of what is meant by "for the purposes of most powers under the Act". As mentioned elsewhere in this document, our clients and staff with autism have been pathologised for being different.

We support the provision that "where the driver of this behaviour is not considered to be a mental health condition, for example it is due to an unmet support need, an unmet social or emotional need, or an unmet physical health need (including untreated pain), grounds for a detention under the MHA would no longer be justified and the detention should cease." This may help prevent serious human rights abuses of people with learning disabilities and autism. However, in our experience, the quality of assessment by social workers for people with learning disabilities is often poor, and the above needs not identified. There is a need for training and scrutiny of such assessments. we have found that many of our clients with learning disabilities have profound trauma due to their experience of growing up in institutional settings where their rights were denied; this may express as what some may see as 'challenging behaviour' – when our clients get to know and trust us, this behaviour may become moderated.

We would like clarification of what is meant by 'people with learning disabilities and autism'- many people with autism including some of our staff do not have learning disabilities and would not come with

the remit of the Mental Capacity Act, though we are aware of this happening to other neuro diverse people who behave or express themselves differently.

Mental health services for people with learning disabilities with acute mental health issues are currently problematic and subject to little or no oversight – Covid has of course made this worse; in extreme cases, abuse happens, much of it gender based; this happens particularly but not exclusively in privately run, poorly supervised ‘assessment units’ (Whorlton Hall, Winterbourne Court and others) where people whose behaviour is seen as challenging are assigned, often hundreds of miles from their home and families. None of the recommendations of the inquiry into the abuse at Winterbourne Court have been implemented.

There is no implementation of the right to be on a single sex ward in these specialist segregated facilities. This puts disabled women at risk not only from male staff (e.g. Whorlton Hall) but from male patients.

Psychiatric facilities for people with learning disabilities or autism should be subject to more intense oversight and scrutiny than other services, because the people held there have the least ability to speak out for themselves. Experts by experience have a critical role to play in this, including those ExE schemes run by people with learning disabilities themselves. This should be built into the legislation.

At local level, we have noted that unlike counselling services for people who don't have learning disabilities, there appears to be no duty of confidentiality on the learning disability psychology service who provide counselling – notes of often intimate disclosures, including of past sexual abuse are shared with social workers, housing support workers and others. Whilst there are duties of safeguarding, we believe that people with learning disabilities must have the same rights in law to privacy and confidentiality as others.

We support the proposal to place a new duty on local commissioner to ensure that adequate community mental health services should be provided for people with a learning disability or autism. These services must be local, confidential and culturally appropriate, and offer tailored support that is suitable for the client group. given the history of many people in this group, it is also essential that such services are trauma informed and have the funding to commission access to organisations such as Respond or Beverly Lewis House.

## **8. Equal understanding of the impact of trauma on people's mental health**

We believe that there is a structural lack of consideration for – or proper treatment of – trauma in how it engenders and exacerbates mental health issues. In our experience, individuals who have experienced extreme trauma, including but not limited to domestic abuse, rape and other forms of sexual abuse and institutional abuse are often being provided with treatment such as Cognitive Behavioural Therapy (CBT) or other therapies more suited to short-term intervention. Waiting lists for trauma therapy are around 2 years, during which the survivor is left with minimal support, often precipitating suicide attempts and hospitalization. We are proposing a shift in both attitudes and practice, constituting a wider choice of therapeutic interventions **with specific focus on trauma-informed care.**

We note the barriers to access to mental health support for people with no recourse funds who are asylum seekers who may have experienced severe trauma; at present this is mainly provided by voluntary services such as Freedom from Torture. There is an urgent need for access to more specialist services, both independent and within the NHS to help prevent people's mental health becoming acute.

Stay Safe East is especially concerned by the current understanding of and treatment of those diagnosed with Borderline Personality Disorder (BPD), also known as Emotionally Unstable Personality Disorder (EUPD). 75% of those in receipt of this diagnosis are women<sup>2</sup>, the majority of whom have experienced childhood trauma<sup>3</sup>. We posit that such a heavily gendered diagnosis, the overwhelming majority of its recipients being women, requires our interrogation. This gender bias brings into question the extent to which the BPD diagnosis individualizes and pathologises women's responses to the trauma that is so pervasive across their sex. This gendered trauma is exemplified in areas such as domestic abuse, where the latest ONS data reports 92% of defendants in domestic abuse cases were men and 77% of victims were women<sup>4</sup>, and incidents of rape, where the latest figures show that women are statistically more than fifteen times more likely to experience rape than men<sup>5</sup>. As outlined above, we recommend a structural and attitudinal shift in how we understand patients meeting the criteria for a BPD diagnosis, involving trauma-informed care which validates and acknowledges the fact that these are typically survivors presenting with a natural response to trauma. This acknowledgement should serve to identify and locate the source of distress *outside* the individual who has experienced it.

Considering the wider context within which women enter and navigate the psychiatric system, i.e. one where they may have experienced male-perpetrated trauma, they should be granted the right to deal only with female staff. We believe this would not only

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<sup>2</sup> Skodol, A. E., & Bender, D. S. (2003). Why are women diagnosed borderline more than men?. *The Psychiatric quarterly*, 74(4), pp.349–360.

<sup>3</sup> Zanarini, MC, Frankenburg, FR, Hennen, J, Reich, DB, Silk, KR. (2006). Prediction of the 10-year course of Borderline Personality Disorder, *American Journal of Psychiatry*, 163(5), pp.827-832.

<sup>4</sup> Office for National Statistics (ONS). (2020) *Domestic abuse and the criminal justice system, England and Wales: November 2020*. Published online: ONS.

<sup>5</sup> Office for National Statistics (ONS). (2020) *Nature of sexual assault by rape or penetration, England and Wales: year ending March 2020*. Published online: ONS.

reduce the levels of distress experienced by the woman in question, but ultimately be more conducive to long-term recovery.

## **9. Detention of people who may be a risk to themselves or others**

We have found that our clients feel caught between wanting to get help and the threat of being sectioned and conversely some clients wanting to be in hospital but being turned down because they are not seen as being at 'enough' risk. We have found that some people are denied a hospital bed even though they are in severe crisis which cannot be managed at home; this may be because they have multiple substance misuse issues, or because they have access or support needs which standard mental health wards find difficult to meet.

Stay Safe East agrees with the proposal that people can only be detained if there is a substantial likelihood of significant harm to the individual or another person.

The same criteria must apply to patients with learning disabilities and/or autism detained under the Mental Capacity Act as to other patients in terms of reviews, appeals etc. This should be open to being done by the patient's family, their advocate or their nominated representative.

we support the proposal that health and local authorities be given no more than 5 weeks to deliver on directions made by a mental health tribunal.

## **10. Advance choice documents, care and treatment plans**

We support the use of advance choice document to set out treatment options. This will allow people with fluctuating mental health to make provision for their needs and wishes to be respected when they are hospitalized, just like any other patient in the NHS.

Care and treatment plans must include a clear plan on how the patient's access and communication needs, cultural needs, safety needs, fears/trauma etc. will be addressed.

We support the proposal that if someone has prepared an advance document, this must be used if they are admitted as a voluntary patient – there is a stigma associated with being 'sectioned' which most people would prefer to avoid. We are however concerned that should someone be a voluntary patient and then decide to leave, they will in most cases be detained 'in their best interest'.

## **11. DOLs**

Stay Safe East is extremely concerned about the proposal that where a patient is seen as not having capacity, only DOLs should be used. Whatever its flaws, the Mental Health Act offers greater protection of people's human rights than legislation on mental capacity, and is subject to more thorough scrutiny.

The timescales for appeal should be the same whatever regime a patient has been detained under – not to do so would lay the NHS open to a claim of discrimination. We would argue that there should be greater opportunities for review for patients without capacity detained under DOLS as these are the people who are most at risk of abuse within the system.

## **12. Mental Health Safety Improvement programme**

Stay Safe East supports the development of such a programme, which must be developed in co-production with survivors, with a specific focus on the safety of women in the mental health system. Changes have been made but there is a considerable amount of work to be done to address the safety of women who are detained, and for example what happens when they are back in the community, where supported living arrangements may be unsafe.

under diagnosis of mental issues in disabled people, or ascribing mental health issues to our impairments

### 13. Police stations as places of safety

Stay Safe East very much welcomes the ending of the use of police cells as 'places of safety' this acts as a major deterrent, in particular for BAME people with mental health issues, and will help reduce deaths in custody. we would like to see this happen as soon as the new Act becomes law.

We are however concerned that staff in hospital A&E departments will be left to deal with people in severe crisis – and may then call the police or have to use poorly trained security guards who don't have the skills to talk people down, or in extreme situations to restrain someone safely.

**Stay Safe East. April 2021**