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| **Submission to the Human Rights Committee for the List of Issues Prior to Reporting: United Kingdom**  **National Survivor User Network**  13th January 2020 |

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**Introduction**

**What the National Survivor User Network is**

The National Survivor User Network (NSUN)[[1]](#footnote-1) is an organisation led by people with lived experience of using mental health services/mental distress. NSUN is an umbrella agency with membership from a wide range of other user-led groups and individuals with lived experience, drawn mainly from England, but also from other parts of the UK. NSUN’s purpose is to be a voice for people with lived experience.

NSUN takes a rights-based approach which is summed up in the six points of its Manifesto[[2]](#footnote-2). It aims to:

1. Campaign against the injustice and harm caused by cuts to public funding and welfare benefits
2. Challenge the abuse and coercion that continue under mental health legislation and work to ensure that people understand and can enforce their rights under the United Nations Convention on the Rights of Persons with Disabilities
3. Actively promote the need to work with us in decisions about strategy, commissioning and how services are decided, as well as the need for services to be user-led
4. Challenge personal, institutional and structural inequalities, injustices, disadvantages and discrimination for everyone with experience of mental distress/trauma
5. Promote people’s right to informed choice so that people are in a position to understand their difficulties in whatever way they choose and to access the support that they find best
6. Promote the validity and vital role of survivor knowledge and research.

**Scope of this report**

The report relates to law, policy and practice in the UK as a whole, but concentrates especially on England, given that most NSUN members are located in England. The report also focuses essentially on issues for adults with lived experience, because NSUN’s brief is to work with the latter.

**Report structure**

The report will deal thematically with key issues for people with lived experience in relation to the International Covenant on Civil and Political Rights ICCPR). It will address:

* Self-determination (Articles 1 and 17 of the ICCPR)
* Being treated without distinction (Articles 2, 3, 26 and 27 of the ICCPR)
* Eliminating inhuman and degrading treatment (Articles 2, 3, 7, 10, 18, 20.2 and 27 of the ICCPR)

**Section One: Self-determination (Articles 1 and 17 of the ICCPR)**

**Issues related to mental health law in the UK**

It is positive that the UK government has ratified the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006)[[3]](#footnote-3). However, a difficulty is that, in contrast to the European Convention on Human Rights (Council of Europe, 1950)[[4]](#footnote-4), the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has not been enshrined in domestic law. For that reason, UK law continues to authorise substitute decision-making, involuntary detentions in psychiatric hospitals, compulsory treatment and the use of community treatment orders for people with lived experience, when they have been diagnosed with ‘a mental disorder’ and they, or others are thought to need protection. Whilst we fully recognise that change takes time, the current position is in breach of the right to self-determination (Article 1) and represents interference in privacy, family and home life (Article 17).

**The Independent Mental Health Act Review**

Between 2017 and 2018, there was a Review of the Mental Health Act 1983, the mental health legislation which currently applies to England and Wales. This Review has resulted in a report containing extensive recommendations (Wessely, 2018)[[5]](#footnote-5). The UK government’s Department of Health and Social Care (DHSC)[[6]](#footnote-6) has been working intensively on the recommendations with a view to there being a White Paper in the near future.

On the face of it, it is beneficial and welcome both that the Mental Health Act (MHA) Review has occurred and that a large number of improvements has been put forward. However, concerns have been expressed by a wide range of user-led organisations that, whilst there has been user involvement in the Review, there have also been some significant limits to this. For instance, people with lived experience of mental distress have mostly been under-represented numerically in the Review; information about alternatives to the Act is not well known and was not circulated by the MHA Review team, so that it was difficult for people to put forward informed choices; the focus of consultations tended to be on improvements to the Act, which limited scope to put forward alternatives; extensive concerns raised by user-led organisations in letters to the Review Chair and Vice Chairs and in a series of Review meetings have not been addressed satisfactorily.

A positive aspect of the recommendations in the MHA Review report is that they advocate a decreased use of compulsion. However, the recommendations do not include pathways towards ending substitute decision-making, involuntary detentions in psychiatric hospitals, compulsory treatment and the use of community treatment orders, despite the UNCRPD Committee’s recommendation to the UK government (2015) to take this step[[7]](#footnote-7). The omission also represents a breach of Articles 1 and 17 of the ICCPR. The Review recommends a legal principle of autonomy, but not an end to compulsory detentions in hospital, despite limited research evidence that detention is even effective[[8]](#footnote-8). People assessed as having capacity would be able to draw up statutory advance choice documents setting out what treatment they did and did not wish to have when detained in hospital; their wishes could include refusals of interventions such as electroconvulsive therapy. This would be a further step forward. However, clinicians could still overrule such choices. In addition, advance choice documents from people judged not to have capacity would not have the same weight, despite many service users’ concerns that capacity assessments are too often affected by epistemic injustice and the success of supported decision-making mechanisms such as the ombudsman initiative in Sweden[[9]](#footnote-9).

If the MHA Review’s proposals were intended as a half-way step towards full implementation of the UNCRPD’s recommendations, or engaged with the spirit and complexity of the UNCRPD, that would seem more fundamentally encouraging. However, it is made clear in the Review report (Wessely,2018: 60-63) that this is not the intention. It is unacceptable that, in the twenty first century, UK citizens with lived experience of mental distress continue to be denied full human rights.

**Shortfalls in community resources needed for independent living**

A compounding factor is the shortfall in community resources required both to pre-empt crises in mental distress so far as possible and to ensure that viable alternatives to compulsion are available for those who nonetheless reach a crisis. Ending, or significantly limiting detention and compulsory treatment will not in fact be possible until alternative community services have been put in place and not making alternatives available, or cutting those services which do exist can inadvertently lead to compulsion being the only option.

The straits reached by social care is one aspect of this shortfall which needs addressing urgently, for example the fact that there has been a £7bn reduction in adult social care since 2010[[10]](#footnote-10). This is seriously affecting the amount of support which can be provided. There are also major concerns that the current Prime Minister’s legislative programme of 36 Bills does not include initiating a plan to address the current social care quandary (Morris, 2012)[[11]](#footnote-11). Putting in place a full and effective range of community resources will be essential, if compulsion is to come to an end and if people with lived experience are to exercise their rights under Articles 1 and 17 of the ICCPR. It is important that the MHA Review recommendations advocate increased community services. However, achieving the community resources needed will involve more fundamental change than that put forward in recommendation 36 of the Review report, for ‘more accessible and responsive mental health crisis services that respond to people’s needs and keep them well’.

User-led groups have been disappointed that recommendation 36 does not specify the need for a full range of alternative, non-clinical support and crisis services as well, including user-led and culturally-based services; many people with lived experience have been repeatedly asking for a large increase in these sorts of resources. The request from a wide range of user-led groups is for a model such as the National Independent Living Support Service (NILSS)[[12]](#footnote-12), drawn up by the Reclaiming Our Futures Alliance[[13]](#footnote-13) (2019), a user-led coalition. The NILSS model emphasises the importance of a support service which is in line with Article 19 of the UNCRPD and of enshrining this in UK law. However, the UK government has not so far been responsive to requests to implement this model.

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| **Recommended** **questions for the UK List of Issues**  1. What steps will the UK government now take to ensure that legislation affecting people with lived experience of a mental health diagnosis/mental distress is fully compliant with the UNCRPD in bringing an end to substitute decision-making, involuntary detention in psychiatric hospitals, compulsory treatment and community treatment orders?  2. What reassurance will the UK government now provide that legal changes made will include an independent living service which is fully in line with Article 19 of the UNCRPD? |

**Section Two: Being treated without distinction (Articles 2, 3, 26 and 27 of the ICCPR)**

It is positive that the state currently has in place various pieces of legislation which put a focus on equality issues, including the Human Rights Act 1998[[14]](#footnote-14) and the Equality Act 2010[[15]](#footnote-15). Additional progress is needed, too; people with lived experience continue to experience some marked inequalities, still more so when they encounter intersectional issues.

**Lived experience of a mental health diagnosis/mental distress**

A major distinction in the way that people with lived experience of mental distress are treated is that, unlike the public in general, people with lived experience can be detained purely on the basis of potential risk. This represents a breach of Article 2 of the ICCPR. It also means that, contrary to Article 26, they do not have equal legal protection. In addition, there are growing challenges to the medical model on which current mental health law is based. For example, the psychiatrist Moncrieff (2009)[[16]](#footnote-16) seriously questions the assumption that psychiatric conditions are parallel to physical health diseases and so require specific medication. Whilst we fully understand that there are varied understandings of mental distress and that consensus is neither likely, nor indeed desirable, what we would expect is for mental health policy to reflect and engage with the contested nature of the field. The various critiques of the dominant medical model from within psychiatry itself, from other mental health professionals and, of course, from service users’ experiential knowledge, raise fundamental queries about the ethics and legality of psychiatric detention and treatment. It is deeply troubling that such severe breaches of human rights so often take place unquestioned, despite these scientific, legal, ethical and experiential critiques.

**Socio-economic status**

It is people from already disadvantaged socio-economic groups who have fared particularly badly since 2008, following the introduction of austerity measures in response to the financial crisis that year. Thus, when the United Nations Special Rapporteur for Extreme Poverty and Human Rights visited the UK in November 2018, he issued a highly challenging statement (Alston 2018)[[17]](#footnote-17) about the extent of poverty in the UK. He highlighted the fact that, although the UK is the world’s fifth largest economy, a fifth of the UK’s population live in poverty, four million of its people are more than 50% below the poverty line and 1.5 million people in the UK are so destitute that they cannot afford even basic essentials. He emphasised that austerity measures have disproportionately affected people from often marginalised communities such as women, disabled people, single parents, racial and ethnic minorities, asylum seekers/refugees and rural dwellers.

In this context, a particular concern is the current status of Section 1 of the Equality Act 2010. The Equality Act brought in a Public Sector Equality Duty. Under this Duty, public bodies are required actively to promote equality for people whom the Act classifies as having protected characteristics such as their race, or disability. However, technically, because the government has not yet triggered Section 1 of the Act, public bodies do not yet have a socioeconomic equality duty.

The Equality and Human Rights Commission (2019) has also drawn attention to the fact that disabled people are more likely to be living in poverty, experience poorer health and have problems with access to suitable housing. In addition, intersectional issues, related, for instance, to gender, or ethnicity, may compound the situation. The combination of such factors means that disabled people are often unable to participate fully in society, but, at the same time, have difficulty in obtaining redress for rights breaches, because of increased restrictions on legal aid and the introduction of employment tribunal fees[[18]](#footnote-18). What is concerning is that, despite this report from the Commission and the report which the Special Rapporteur produced in support of his statement (UN Human Rights Council 2019)[[19]](#footnote-19), there continues to be limited evidence of significant change.

The impact of austerity measures on people with mental health diagnoses is particularly acute, because they form the largest number of benefit claimants. For example, in a report from the Money and Mental Health Policy Institute, Bond, Braverman and Evans (2019) found that a third of those claiming Housing Benefit (35%), nearly half (47%) of those aged 16-64 and 66% of people claiming Employment and Support Allowance had mental health problems[[20]](#footnote-20).

In addition, a further outcome of austerity measures has been a 23% increase in homelessness between April to June 2018 and April to June 2019 (Busby, 2019)[[21]](#footnote-21). This is again particularly affecting people with lived experience of mental distress; as many as 80% of homeless people have pre-existing mental health diagnoses, or have developed related difficulties since losing their homes[[22]](#footnote-22). A Conservative pledge during the recent general election was to provide funding for the reduction of rough sleeping. However, it is currently unclear what plans, if any, the newly elected Conservative government has to achieve such a reduction.

It is again apparent, therefore, that there are significant breaches of Article 2 of the ICCPR (the right to be treated without distinction) and Article 27 (equal legal protection for everyone) which need to be addressed. It is clear, too, that there are continuing shortfalls in meeting the requirements of Article 3 (equal rights for men and women).

**Intersectional issues in the Mental Health Act Review recommendations**

It is positive that the Review recommendations have a focus on people with lived experience from black and minority ethnic communities, given the over-representation of Black and Black British groups in particular amongst detained patients[[23]](#footnote-23); on people with learning difficulties and or autism who are often detained, because (Aspis, 2019)[[24]](#footnote-24), they do not fit society’s norms and so are particularly at risk of being diagnosed with a mental disorder; on children and young people and acute issues which they face. How effective implementation of the recommendations will be remains to be seen. For example, there has been a series of failed attempts to address racism in the UK adequately. A key example is the five-year Delivering Race Equality programme which originated from a government report (Department of Health, 2003)[[25]](#footnote-25). As Fernando (2017)[[26]](#footnote-26) has highlighted, problems arose from factors such as a lack of consultation with people from black and minority ethnic communities and failures to make a satisfactory use of other publications such as *Inside Out* (National Institute for Mental Health in England, 2003)[[27]](#footnote-27) and the David Bennet Inquiry report (Norfolk, Suffolk and Cambridgeshire Strategic Health Authority, 2003)[[28]](#footnote-28). We would therefore welcome seeing an evidence base behind the assumption that the planned Patient and Carer Race Equality Framework is more likely to be successful than previous initiatives to reduce racism in mental health services.

What is concerning is that, despite frequent requests from user-led groups, the Review recommendations have almost no focus on other intersectional disadvantages, for example those experienced by people with lived experience who are female, identify as lesbian, gay, bisexual, or transgender, or are older. This lack of focus comes across as discriminatory and is in breach of Articles 2, 3, 26 and 27 of the ICCPR,

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| **Recommended questions for the UK List of Issues**  1. What action will the UK government take to ensure that people with lived experience of mental health diagnoses are no more subject to detention on the basis of potential risk than anyone else?  2. How will the UK government meet its obligation to address effectively major socio-economic disadvantages highlighted by bodies such as the UN’s Human Rights Committee and the Equality and Human Rights Commission, including those related to intersectional issues?  3. What measures will the UK government adopt to address intersectional shortcomings in the Mental Health Act Review recommendations? |

**Section Three: Freedom from inhumane and/or degrading treatment (Articles 2, 3, 7, 10, 18, 20.2 and 27 of the ICCPR)**

**Hate crimes**

Whilst the UK government clearly has some relevant equality legislation in place, as mentioned in Section Two above, evidence from hate crime records makes it hard to avoid the conclusion that further, concerted action is needed to tackle hate crime. There has been a 10% overall increase in hate crimes between 2017/2018 and 2018/2019 (Home Office, 2019), including intersectional crimes. The majority of hate crimes (around 76%) have related to race. However, hate crimes based on transgender identity rose by 37% and those related to sexual orientation, or disability by 25% and 14% respectively.[[29]](#footnote-29) The Home Office report suggests that a main reason for the higher figures is that there has been an improvement in the recording of crime by police. Whether this is so, or not, it is worrying that overall figures for hate crime in 2018/19 amounted to 103,379 and that there have been such major rises in the case of transgender identity, sexual orientation and disability.

The records in question cover hate crimes against people with one, or more of five characteristics which have protected status under the Equality Act 2010. These are:

* Race or ethnicity
* Religion or beliefs
* Sexual orientation
* Disability; and
* Transgender identity.

A point of concern is that records of hate crimes based on other characteristics are limited and/or attacks related to them are not necessarily classified as hate crimes. Thus, for example, the Fawcett Society[[30]](#footnote-30), a women’s rights charity, has called for an acknowledgement of gender as the most frequent cause of hate crime against women and, in light its extent, for misogyny to be recognised as a hate crime.

The *Keeping Control* research study (Carr *et al, 2019)[[31]](#footnote-31),* a user-led study co-produced with Middlesex University staff, has also specifically highlighted that disabled people, particularly people with lived experience of mental health problems/mental distress, are at higher risk of targeted attacks than others, often on a prolonged and multi-factorial basis. A key factor which emerged from the study is that safeguarding reforms set up under the Care Act 2014[[32]](#footnote-32) have proved far from adequate for people with lived experience. The report findings also demonstrate a strong need to make sure that the experiences and insights of people with lived experience are central to adult safeguarding legislation and approaches.

If, therefore, the UK government is fully to meet its responsibilities under Articles 2, 3, 7, 18, 20.2 and 27 of the ICCPR, then additional measures against hate crime need to be in place.

**Conditions in psychiatric facilities**

There is disturbing evidence of conditions on psychiatric ward that can amount to inhumane and/or degrading treatment. People with lived experience who participated in the *Keeping Control* research study gave some heartrending examples of abusive or degrading treatment to which they have been subjected on psychiatric wards. There were similar, moving accounts from people with lived experience of sectioning and forced treatment who contributed to the MHA Review. It is positive that the Review recommendations advocate a series of improvements to psychiatric wards, if on a somewhat less fundamental level than might have been hoped. Nonetheless, more remains to be done.

Some parallel examples have emerged about conditions that people with learning difficulties/disabilities and/or autism have encountered in facilities provided for them. For example, the British Broadcasting Corporation’s Panorama programme has twice uncovered serious abuse, once at Winterbourne View Care Home in South Gloucestershire, in 2011, and then, despite action pledges made by the government, at Whorlton Hall in County Durham last year (DPAC, 2019) [[33]](#footnote-33) The latest Panorama programme findings have led to further, strong calls from user-led groups of people with learning difficulties/disabilities and/or autism[[34]](#footnote-34) to abolish adult assessment and training units (ATUs) also and to enshrine Article 19 of the UNCRPD in domestic law, so ensuring that people with learning difficulties/disabilities and/or autism have the necessary support and advocacy to live in the community..

Inhumane treatment is in breach of Articles 7 and 10 of the ICCPR and strongly needs addressing. It is also vital for the UK government to take on board the call from user-led groups representing not only people with lived experience of mental health diagnoses/mental distress, but also people with learning difficulties/disabilities and/or autism to put steps in place which can achieve an end to involuntary detention and forced treatment in psychiatric wards and ATUs alike, in line with Articles 1 and 17 of the ICCPR.

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| **Recommended questions for the UK List of Issues**  1. What additional measures will the UK government be adopting to increase state effectiveness in addressing hate crime?  2. What reassurance can the UK government provide that it will not only take action which people using services find effective in ending inhumane treatment on psychiatric wards and in ATUs, but take progressive action to bring involuntary detention in hospital and forced treatment to an end? |

**Conclusions**

There are some positive examples of ways in which the UK government is working to meet its obligations under the ICCPR. However, as this submission demonstrates, considerable further progress is also needed.

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13. https://www.rofa.org.uk/ [↑](#footnote-ref-13)
14. *Human Rights Act 1998, c.42.* Available at:<http://www.legislation.gov.uk/ukpga/1998/42/contents> (Accessed: 23 September 2019) [↑](#footnote-ref-14)
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