

# THE MENTAL HEALTH ACT

## AN ALTERNATIVE REVIEW



DECEMBER 2018

## Acknowledgements

This report was written by Akiko Hart and Rai Waddingham, trustees of the National Hearing Voices Network on behalf of the National Hearing Voices Network. We would like to thank the following people and groups for their support in creating this report.

### HEARING VOICES NETWORK MEMBERS AND SUPPORTERS

We would like to thank those members and supporters who attended our Mental Health Act event, completed our survey and/or shared their concerns with us in other ways. We hope that this review goes some way to redressing the failures of the official report and that it stimulates conversations that can lead to real change..

### SUPPORT WITH THE SURVEY

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### CONTRIBUTIONS TO CONTENT & MEDIA DISTRIBUTION

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## About the National Hearing Voices Network

The English National Hearing Voice Network (known as HVN England) is a registered charity which offers information, support and understanding to people who hear voices, see visions or have other unusual perceptions.

For more information, see: [www.hearing-voices.org](http://www.hearing-voices.org)

**Please note:** This version of the report was published on 8 December, featuring edits on p9 to clarify our section on short-term detention following feedback.



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# EXECUTIVE SUMMARY

The Mental Health Act (MHA) is not fit for purpose and needs to be radically overhauled for the 21st century. This is not the time to sweep key issues under the rug, or rush through timid changes which fail those most vulnerable to the use of the MHA. We call for a bold and ambitious rights-based approach to the Mental Health Act and its Code of Practice.

At the heart of this endeavour is centering service users and survivors. Whilst we acknowledge the challenges and complexities around the process of creating the MHA Review, and the conviction, integrity and heart of those who contributed to the process, we also believe that the MHA Review has been a missed opportunity.

We held an event on the MHA Review in April 2018 for over 100 of our members and supporters, and conducted a survey with them to elicit their views on the changes they would like to see in mental health legislation. Six main themes emerged: enshrining a rights-based approach in the legislation and practice; acknowledging both the institutional abuse and the institutional racism at the heart of the mental health system; ending Community Treatment Orders; making Advance Decisions which relate to Electro-Convulsive Therapy and medication, entirely binding; and creating and funding meaningful alternatives to detention.

The MHA and the Code of Practice should enshrine a rights-based approach. Reflecting the views of our membership, we recognise the need for short term detention (under 72 hours) in extreme circumstances. This should be understood as a grave decision of last resort, having exhausted all other options and should take place with the most stringent of safeguards. We call for an end to longer-term detention under the Mental Health Act in order to administer treatment, including forced medication. This can only take place alongside the implementation of a meaningful range of well-funded alternative mental health and social support.

We call for the abuse of service users who are detained under the MHA, to be acknowledged as a systemic, institutional issue, which needs to be addressed in multiple ways. This should include a review of the complaints procedures to ensure they are simple, transparent and effective, and that service user testimonies are not de-legitimised. We also call for an acknowledgement of the institutional racism at the heart of our mental health services, without which we will not be able to address the disproportionate number of racialised minorities who are subject to the Act. In line with the evidence, we advocate for an end to Community Treatment Orders, which have not been shown to reduce detention. Advance Decisions which are made when capacitous, and which relate to Electro-Convulsive Therapy and medication, should be entirely binding. Finally, we believe that meaningful changes to the MHA can only take place alongside the creation and funding of services and alternatives to detention that people want to use when they are distressed.



# INTRODUCTION

The Independent Review of the Mental Health Act (MHA) was set up in 2017 to look at how the legislation in the Mental Health Act 1983 is used and how practice can be changed. It produced a report with recommendations for change in December 2018.

As the interim report clearly states:

“The MHA confers powers on the state that do not exist across the rest of healthcare. These powers are usually exercised when people are at their most vulnerable ... the state is under a heavy obligation both to ensure they are no greater than necessary and to oversee and regulate their use”. (Wessely, 2018. p. 5)

The MHA has a deep impact on the lives of our members and supporters, many of whom have received diagnoses of severe mental illnesses such as schizophrenia, borderline personality disorder, bipolar disorder and acute psychotic disorder. Many have been detained under the MHA, or witnessed the detention of a loved one. We have heard, time and time again, how the threat of detention has prevented people from seeking help, raising concerns about the adverse effects of medication and making complaints about poor care. It is clear to us that the influence of the MHA reaches far beyond those subject to it, pervading the culture of mental health care in this country.

## CONTEXT

Detention rates are currently rising in the UK against a backdrop of austerity, cuts to services and punitive welfare reforms. Austerity policies and welfare reforms have been linked to an increase in suicides and mental health issues (Barr, 2016; Cummins, 2018). At this time of increased need, cuts to mental health and social care services have left an increasing number of people turned away from support and the rise of what has been called ‘psychiatric neglect’ (Spandler, 2016). This, plus the gutting of the voluntary sector, has helped to create the circumstances where people are more likely to reach a crisis point and be detained under the MHA. We therefore believe it is vital for any review to highlight the role of society and government policy in creating and/or compounding mental health issues. Detention is not an ethical response to government-sanctioned neglect.

This review is a valuable and timely opportunity to critically evaluate the underpinnings of the MHA to ensure they are in line with current knowledge. The MHA is built on the concept of mental disorder, stating when and how the state should intervene and deprive an individual of their right to liberty and autonomy. However, concepts such as mental disorder, capacity, insight and risk are contested (Cooke, 2017; Pūras, 2015) and we believe no review of the MHA can afford to side-step these debates. We call for a re-evaluation of the fundamental concepts underpinning the MHA and a deep dialogue with the service users, survivors, family members, practitioners, and academics who are critically interrogating these constructs, in order to create mental health services and legislation fit for the 21st century.

## A MISSED OPPORTUNITY ...

From the legal complexities to the political constraints and down to the administrative hurdles, we understand that undertaking a Review of the Mental Health Act is littered with challenges. We recognise and acknowledge the conviction, integrity and heart of those who contributed to the process, often working under great pressure. However, given the gravity of the MHA, we also believe that the MHA Review has been a missed opportunity.

We have concerns both around the structure of the Review board and its process.

### ... FOR A REVIEW THAT SERVICE USERS & FAMILY MEMBERS CAN TRUST

The MHA Review was mired in controversy before it even began, partly due to the choice of Professor Sir Simon Wessely, a psychiatrist and former President of the Royal College of Psychiatrists, as its lead:

“Professor Wessely no doubt has the skills and knowledge required to lead such a report — but, to be frank, the optics on this could not be worse. Why is this? Detention under the MHA is a complex, contentious and deeply painful issue to many. It can be divisive, ‘them and us’, service users versus psychiatrists. It is, at its most basic, pared-down level, about power: about the state removing the rights of individuals, with this decision determined by psychiatry. In order to navigate this intensely difficult terrain, and for all stakeholders to enter into dialogue, this power imbalance needs to be acknowledged. Many people who identify as survivors of the psychiatric system may feel intense wariness around contributing to a report which is led by the person who used to be, at least in titular form, the most powerful psychiatrist in the UK.” (Hart, 2018).

### ... FOR A REVIEW THAT HAD THE TIME & SUPPORT TO MEANINGFULLY INVOLVE SERVICE USERS AND FAMILY MEMBERS

Many feel that it has been rushed, and indeed, a pressing reason for completing the Review by December 2018 was to feed its recommendations into the 10-year NHS funding framework. Certainly, the MHA is seen by Wessely as a way of focusing policy and funding on the sharper end of services, which have been neglected in recent years in favour of mental health awareness campaigns. However, the relatively short timeline may have limited the potential for stakeholders, in particular service users and family members, to contribute meaningfully.

In our view, meaningful involvement in the topic groups which formulated specific recommendations to the Chair would have required an in-depth understanding of the legal concepts, informed and enriched by lived experience. This could have been achieved by a longer lead-in time and the provision of preliminary and ongoing training and support around the legal framework, measures that would have been invaluable for all members of the topic groups. Sadly, this did not happen and, as such, the potential for people to more actively shape the review was lost.

## **.. FOR A REVIEW PROCESS THAT GOES THE EXTRA MILE TO INVOLVE MARGINALISED & EXCLUDED GROUPS**

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One of the claims of the MHA Review is that it has engaged comprehensively with service users. 2000 service users and family members responded to their initial survey. They convened stakeholder engagement events in a variety of locations. They invited people to join the Service User and Carer Group as well as each of the seventeen topic groups. Steven Gilbert, a service user and serious mental health living consultant was appointed at the Review's Vice Chair. In many countries, this degree of service user representation would be unthinkable – reflecting the progress we have seen around service user engagement and involvement in the UK.

However, this claim obscures some of the current difficulties within service user involvement. There are important questions around which service users are invited to the table, and how much they can influence any process; which voices and views are welcomed, and which are unheard. The 'service user community' is not a monolith: it is a rich, diverse world, with many contrasting and conflicting experiences and opinions. How far did the Review go in inviting service users from marginalised communities, including people with learning difficulties/disabilities, D/deaf and physically disabled people, ex-offenders and ex-users of forensic mental health services, people from disadvantaged socio-economic groups and LGBT and transgender people?

Beyond the issue of representation, the structure of the stakeholder consultations was flawed and systematically excluded those most likely to be affected by the Act. For example, the early starts are blatantly unrealistic for those who are on high doses of medication that can be extremely sedating and those who are struggling with motivation. The lack of financial support for childcare excluded those with least financial or social resources. Moreover, those most excluded and fearful of the Mental Health Act are unlikely to feel confident enough to attend such an event or believe that their voice is likely to be heard.

Given the power and importance of the official MHA Review, any unintended – but systematic – exclusion of stakeholders damages its credibility and increases the likelihood that pertinent and important issues have been missed.

## **... TO ENGAGE THE REAL EXPERTS IN SERVICE USER INVOLVEMENT – SERVICE USER GROUPS**

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Rather than actively and meaningfully involving the many service-user/survivor-led organisations, the advisory panel chose instead to privilege relationships with those mental health charities who have contact with service user groups. This added level of abstraction may have resulted in some of the mistakes in engagement, detailed above, and changed the direction of the report itself. Research suggests that user-led organisations are "inclined to advocate for stronger measures to reduce and end coercion and to aim for more ambitious change in practice, compared to other stakeholder groups, such as clinicians or clinician researchers who have led most of the published intervention studies." (Gooding, McSherry, Roper & Grey, 2018).

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## ... TO CREATE A RIGHTS-BASED MHA THAT IS FIT FOR PURPOSE

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Sadly, the above concerns point to a MHA review which is both timid and limited in its scope. It suggests a review that has shied away from some of the more complex, emotive and controversial issues that are entwined with the Act and its implementation. We recognise the difficulties inherent in trying to find a consensus between multiple stakeholders with vastly different interests, a process which often results in small and incremental changes. We acknowledge the wish to create a set of recommendations that would realistically satisfy Parliament, who may have a more conservative approach to mental health rights. We acknowledge the difficult position anyone conducting such a review is in.

However, we believe that service users and survivors are not just one of many stakeholders: their voices should be centred. We believe that the MHA is not fit for purpose and that it needs to be radically overhauled for the 21st century. This is not the time to sweep key issues under the rug, or rush through timid changes which fail those most vulnerable to the use of the MHA. We call for a bold and ambitious rights-based approach to the Mental Health Act and its Code of Practice, which we set out below.



# AN ALTERNATIVE REVIEW

## 1. A RIGHTS-BASED APPROACH

“The Mental Health Act 1983 is based on major breaches of human rights, has no sound foundation in evidence and results in essentially degrading, disempowering, racist and detrimental approaches. Unless and until legislation starts from a human rights basis and one which is equally appreciative to both majority and marginalized communities, the situation will not change.”

Respondent, HVN England survey, 2018

In line with other organisations such as the National Service User Network, we believe the MHA and the Code of Practice should enshrine a rights-based approach. From a legal perspective, we believe that the UN Convention on the Rights of Persons with Disabilities (UN CRPD), which the UK has ratified, provides a comprehensive framework covering detention, restraint, forced treatment, legal capacity, and autonomy, amongst other issues. However, we also recognise that the UN CRPD’s call for an end to detention is contentious and a matter of fierce debate by service users/survivors and family members/carers. Some of our members have expressed the view that, in their case, detention has been helpful and indeed life-saving. This is also reflected in the MHA Review’s survey of service users and carers. Others have told us that the use of detention, or its ever-present threat, has increased their risk of suicide and contributed to the deaths of their friends and loved ones.

As a membership organisation we respect the diverse views of our members and, as such, are not calling for an absolute end to detention. We acknowledge the terrain is complex and politically and personally fraught. However, we call for a more nuanced conversation around a rights-based approach in mental health legislation that recognises the difference between short term (under 72 hours) detention in the case of immediate risk to life, and the use of long-term detention to administer treatment/forced medication. We want there to be deep and searching discussions around these painful issues, including all views.

### SHORT TERM DETENTION

Whilst we recognise the current need for short term detention in extreme circumstances, we believe the state has a duty to reduce its use as far as possible. Detention involves the denial of a basic human right – the right to liberty. As such, it should be understood as a grave decision of last resort, having exhausted all other options and should take place with the most stringent of safeguards.

From this perspective, use of short-term detention requires a deep reflection on, and dialogue about, the way risk of harm is understood to minimise its use. These concepts are far from self-evident, and are hotly contested, yet the implementation of the Act hinges on their interpretation. In addition, for detention to be at all ethical, people should have access to a meaningful range of well-funded alternatives to provide less restrictive supportive options (e.g. peer-run crisis houses) and the certainty that the support provided whilst detained will be compassionate, humane and

rights-based. Detention environments should take into account the rights and needs of those detained, for example by providing single-sex wards, or making reasonable adjustments for service users who have learning disabilities or autism, considering lighting, noise, etc, which might create additional distress.

Rather than accepting the inevitability of detention, it should be regarded as a potential failure of services to meet someone's need. As such, we call for a thorough reflection on the circumstances leading to the use of the MHA – in partnership with the person detained – that explores what the services could have done differently and creates actionable information for service improvement.

## LONG-TERM DETENTION TO ADMINISTER TREATMENT

We call for an end to detention under the Mental Health Act in order to administer treatment, including forced medication.

This can only take place alongside the implementation of a meaningful range of well-funded alternative mental health and social care and support.

## CREATING A MENTAL HEALTH SERVICE THAT IS HEALTHY FOR STAFF

We believe a right-based approach to practice can help create services which are more supportive and meet service users' needs, and are also beneficial for staff:

"I have worked in a CMHT for two years. During that time, I have been involved in two MHA assessments. Both experiences were deeply unsettling and left me wishing there was an alternative and less brutal system. My involvement felt contrary to all the other work I do with people and why I work in the field. At the moment I have an inner debate about whether it is better to work within the system and try to make it more tolerable or to leave it" (Respondent, HVN England survey, 2018)

The use of coercion and restraint creates a "broken system; staff not given enough training or compassion themselves; place of safety (hospital) is often traumatising, terrifying, chaotic and not therapeutic at all - just a means of control and managing symptoms in crisis, not recovery or wellbeing." (Respondent, HVN England survey, 2018)

## UNTANGLING CAPACITY AND INSIGHT

We believe that a rights-based approach in mental health goes beyond the legislative framework and practice. It extends to our right to define and understand our experiences in a way that is meaningful for us. However, as some beliefs and experiences are seen as indicative of a mental disorder, protecting our right to them can be pathologised as a lack of insight. Such judgements threaten our right to our beliefs, and risk the MHA being used to enforce medical or psychological beliefs that are deemed normal. The presence of an unusual or idiosyncratic belief about one's experience is not, necessarily, linked with a lack of capacity to make decisions about one's own life. However, the everyday conflation of insight and capacity in mental health services threatens our right to freedom of thought and belief.

In practice, insight, a clinical term, is often used as a measurement of capacity, a legal term, despite neither the MHA nor the Mental Capacity Act defining capacity in this way. The definition of insight, and its significance, is so contested that it can be argued along with Høyer that “those agreeing with their treating psychiatrist have insight, those who disagree have not” (Høyer, 2000). In the face of such deep questions, we believe that insight should not feature in decisions to detain a person who disagrees with the treating team.

As the English National Hearing Voices Network, we believe that experiences such as voices and visions can be understood in many different ways and that people have the right to define their experiences in their own way. We recognise that, whilst some people view their experiences as symptoms of an illness, they can also be understood as meaningful responses to trauma, as neurodiversity, as a spiritual experience and so on. If we disagree with our psychiatrist about the nature of our voices, does this mean we lack insight? And following this, does this mean we lack capacity, and are therefore more likely to be subject to the MHA?

“The term, insight, does not appear in any mental health or capacity legislation. Nor does it appear in the MHA Reference Guide and only once is it mentioned in the Code of Practice. And we talk about it all the time in mental health. Indeed, it has been described as the single most consistently discussed symptom of mental illness amongst tribunal members. (...)”

Insisting on one’s mental order should not inevitably be seen as evidence of mental disorder. Nor should it inevitably be equated with incapacity. After all, psychiatry itself is not an exact science.” (Allen, 2014).

## 1. RECOMMENDATIONS

- A rights-based MHA legislation and services
- A deep and searching dialogue on short and long-term detention, attending to all voices and positions - especially those from marginalised communities.
- Short-term detention (under 72 hours) to be understood as a grave decision of last resort, having exhausted all other options and taking place with the most stringent of safeguards
- Detention environments should take into account the rights and needs of those detained
- A meaningful range of well-funded alternatives to provide less restrictive supportive options (e.g. peer-run crisis houses)
- Support whilst detained which is compassionate, humane and rights-based
- End to long term detention for treatment
- Insight not used as a factor in decisions around the use of the MHA

## 2. INSTITUTIONAL ABUSE

At present, those detained under the Mental Health Act cannot be guaranteed protection from abuse and harm. There are multiple reports of physical, sexual and emotional abuse occurring in hospital settings. For example, we are aware of reports of rape, sexual and physical assault by both members of staff and other patients. Physical restraint has led to bruises, injury and – in tragic cases – even death. A terrifying experience for many, those with a history of trauma may be even more seriously affected by being held down by staff and injected with powerful sedatives – re-traumatising the person and leaving lasting emotional scars. Instances of emotional maltreatment, bullying and manipulation by staff members and other patients are regularly shared within service user and survivor groups.

“One nursing assistant always chose the youngest, most sedated patients to play the board games with. It sounds small, but it was part of a bigger picture of humiliation and control. She seemed to relish beating us. She lied to other staff about us and made jokes when one of us attempted suicide or self-harmed. I was even put in seclusion because she said I tried to attack her. No-one would believe me. It was clear I had no rights. Yet who would believe me, a sectioned schizophrenic? It was hell”. (Respondent, HVN England survey, 2018)

The MHA Reviews’ own survey echoes this. For example, only a third of the MHA Review survey respondents who expressed a strong view in their survey felt they were ‘treated with dignity and respect’ when sectioned, and two thirds did not. The report states:

“Throughout all of our engagement with service users and carers, we have been made aware of a wide variety of distressing experiences including but not limited to, experiencing or witnessing physical violence, verbal abuse and threats, bullying and harassment, sexual predation, pain-based restraint, coercive reward and punishment systems for access to open air, leave or family contact.” (Wessely, 2018).

### Our survey reflects these findings.

- 78% said that they were never or rarely treated with dignity and respect when detained under the MHA.
- 70% said their human rights were not respected by the staff sectioning them.

### Our survey participants described their experience of being detained in the following ways:

“Made me feel more suicidal and hopeless.”

“Further trauma, including being restrained and also raped on the ward.”

“Dismissed experience of trauma and just locked up and drugged.”

“Kept me alive but could have been done in a more compassionate way”

“Staff are extremely heavy handed when you are detained. I have been flung about on numerous occasions and it is terrifying. Nobody listens to you and there are so many people involved in restraint, the level of force is shocking. I have also worked on a ward where people’s rights are given and taken away according to “good” or “bad” behaviour.”

Whilst there are many caring staff and many examples of good practice, the prevalence of extremely damaging experiences cannot be minimised and must be addressed. It is our view that it is not enough to understand the testimonies of the many service users who responded to the MHA Review, and who regularly share their negative experiences of detention in public forums, as isolated actions carried out by individual staff members. The high prevalence and lack of organisational acknowledgement or action indicate that the abuse which takes place on locked wards in the UK is in fact institutional.

## 2. RECOMMENDATIONS

- We call for the abuse of service users who are detained under the MHA, to be acknowledged as a systemic, institutional issue and failing, which needs to be addressed in multiple ways, including in the first instance:
- Complaints procedures to be made more simple, transparent and effective, with advocacy available to any service user or family member at any stage in the process
- A review of the complaints procedures to ensure that service user testimonies are not delegitimised and dismissed because patients’ views of situations are seen as inherently less accurate than staff
- Staff who are found guilty of abuse in internal investigations to be prosecuted
- A zero-tolerance approach to abuse which is upheld by senior management and leadership
- Meaningful investment in the training of all staff in rights-based approaches, de-escalation and alternatives to coercion and restraint

### 3. INSTITUTIONAL RACISM

One of the drivers of the MHA Review was to address the over-representation of racialised minorities who are detained under the Act, restrained, and are subject to Community Treatment Orders (CTOs).

As yet, there has been no public acknowledgement in statutory mental health services of the existence of institutional racism. Instead, racism is framed on an individual level rather than a systemic one. Reports often focus on vague notions of ensuring services are culturally appropriate, neatly sidestepping those core issues that they appear to address. Racism is deeply ingrained in our society and therefore in the very structures of our mental health institutions and practice, and is continuously enacted in both visible and invisible ways (Fernando, 2017).

We call for an acknowledgement of the institutional racism at the heart of our mental health services, without which we will not be able to address the disproportionate number of racialised minorities who are subject to the Act. We also believe we should engage with the scholarship and activism around schizophrenia as a racist diagnosis, which specifically targets racialized minorities, in particular black men (King, 2016, Fernando, 2018a).

“All that we can hope to achieve in the short (& medium?) term is to minimize the effects on people and groups and this should be possible by a combination of legal safeguards (against harm), education (curriculum changes?) and bringing about culture change in the psy disciplines.”

Suman Fernando (2018b).

### 3. RECOMMENDATIONS

In line with Race on the Agenda (ROTA) and the Race Equality Foundation (REF), we call for the following:

- The MHA should set out principles that define human rights, anti- discriminatory practice and a commitment to combat institutional racism.
- Statutory bodies should be regularly inspected by the CQC or other appropriate body to ensure that training of professionals working in mental health services addresses issues of racial bias and cultural competence.
- The MHA should be amended to include a clause that states explicitly that a diagnosis for a ‘mental disorder’ must take account of the patient’s social and cultural background.
- The MHA should allow for appeals against diagnoses via a Tribunal, with a panel that includes experts from BAME backgrounds.

## 4. ADVANCE DECISIONS AND AUTONOMY

### 69% of the respondents to our survey believed that Advance Decisions should be upheld under the Mental Health Act

Advance Decisions provide a way for people to express their wishes for treatment and support, should they ever be deemed to lack capacity. However, in practice these documents carry little weight beyond potentially alerting staff to people's preferences. Preferences that can easily be overridden should they be in opposition with the clinician's perspective.

I was clear, when I had capacity, that I wanted to try a new medication that wasn't sedating. Yet, when I was at my most vulnerable the psychiatrist decided to err on the side of caution and begin me on a drug that I'd had previously that caused massive sedation and made it hard for me to think. It was scary that my reasonable and informed choice could be overridden on a whim. Once I felt better I was stuck with their choice. I didn't feel able to ask for anything different. Respondent, HVN England Survey (2018)

The Mental Capacity Act specifically protects people's right to make decisions that are considered unwise, if they are assessed as having the capacity to do so. That people's decisions, made at a time when they have the capacity to make informed choices, are overridden is yet another infringement on people's human rights.

"I was going to get one [an Advance Decision] and it's terrifying they can be over-turned"  
 "Very important so person has voice / some control"  
 "Important to respect peoples' decisions as would be done for medical treatment"  
 Respondents, HVN England Survey (2018)

We call for Advance Decisions which are made when capacitous, and which relate to Electro-Convulsive Therapy and medication, to be entirely binding. We also call for all service users who are detained to have easy access to an independent advocate at any point whilst they are subject to the Act. For those service users who are understood to be lacking capacity, we ask for a move towards a supported decision-making framework, as advanced by the UN CRPD. This would ensure that the individual is enabled to make and communicate decisions with respect to personal or legal matters, and promotes self-determination, control, and autonomy.

## 4. RECOMMENDATION

- We call for Advance Decisions which are made when capacitous, and which relate to Electro-Convulsive Therapy and medication, to be entirely binding.

## 5. COMMUNITY TREATMENT ORDERS

### **77% of respondents to our survey did not believe it was ever acceptable to use forced treatment in the community (CTOs) against someone's will, because the person hears voices or has beliefs which others find unusual**

At our events, we have heard from a number of family members about the devastation caused by the use of CTOs on their loved one. These stories typically involve people being required to take medication that is either ineffective or has debilitating side effects, the erosion of their loved one's willingness to talk about their voices or beliefs for fear of medication increases and the intense powerless they feel to change the situation. One parent described it as being forced to stand by and watch as their child withdraws further inside themselves.

Many countries besides the UK discharge people from involuntary hospitalisation using compulsory community treatment (CCT), including Australia, Canada, Israel, New Zealand, and the US. It typically involves forced medication under the threat of being forcibly returned to hospital if the person is 'non-compliant'. It is usually justified by the claims that it is consistent with the notion of 'community care' and that it is less restrictive than forced hospitalisation. It is also sometimes argued that it somehow improves mental health and quality of life outcomes and that, compared to voluntary/ordinary discharge, it leads to fewer re-hospitalisations.

In the UK, a Community Treatment Order (CTO) is part 17A of the Mental Health Act. The criteria are vague: 'The patient is suffering from a mental disorder of a nature or degree which makes it appropriate for the patient to receive medical treatment' and 'It is necessary for (i) the patient's health, (ii) the patient's safety, or (iii) the protection of other persons'.

A CTO means that you have to keep to certain conditions while living in the community. These always include having to take your medication, but may also include where you take the drugs and even where you live. A CTO initially lasts six months and can be renewed. Breaking conditions can result in the person being 'recalled' into hospital, bearing worrying similarities with people in prison being released 'on license'.

CTOs were introduced in the UK in 2008 without any randomised control trial to assess their efficacy in the UK, and two in the USA showing they are ineffective.

A 2017 Cochrane review (Kisely et al., 2017) found that there have only ever been three randomised control trials (RCTs) of CCT. It is reasonable to expect that any legal framework to force people to take medication in their own home would only be considered viable after extensive piloting and robust evidence that concluded the benefits gained were substantial enough to justify the extreme restriction of human rights involved.

Two of the three studies were conducted in the USA (Swartz 1999; Steadman 2001). They both compared court-ordered 'outpatient commitment' (OPC) with entirely voluntary community treatment in a total of 416 people. There were no significant differences between OPC and voluntary treatment, after a year, in the variables which proponents of CCT claim are improved: medication 'compliance', number of arrests, homelessness, and the Lehman Quality of Life Scale, which measures eight life domains including 'Satisfaction with physical and mental health'. One of the two trials did find that those in the OPC group were less often the victims of crime (Swartz, 1999).



The third, more recent, RCT compared community treatment orders (CTOs) with less intensive and briefer supervised discharge (Section 17) in 333 people in England diagnosed with psychosis. The study found no difference between the two groups, after one year in terms of: number of readmissions to hospital, number of days spent in hospital, alcohol and drug use, Brief Psychiatric Rating scale and Global Assessment of Functioning scale. The lack of any difference between the two groups remained after three years.

The nine authors, led by esteemed British psychiatrist Professor Tom Burns, concluded:

“We found no support in terms of any reduction in overall hospital admission to justify the significant curtailment of patients’ personal liberty.” (Burns et al., 2013, p. 1627).

The authors of the Cochrane review concluded that:

“Our findings of limited effectiveness of CCT based on the three RCTs are consistent with several other independent reviews of CCT, which have concluded that CCT has little positive effect on outcomes such as hospital admissions, length of stay or compliance with medication.

....

Based on results from this review, there is no strong evidence to support the claims made for CCT that make it so attractive for legislators. It does not appear to reduce health service use or improve people’s social functioning.” (Kisely et al., p.30).

## 5. RECOMMENDATION

- HVN England calls for an end to Community Treatment Orders. This should only take place alongside the implementation of a meaningful range of well-funded alternative mental health and social care and support.

## 6. ALTERNATIVES TO ADMISSION

“Any legislation needs to focus on the right to support and services including alternative crisis support provided in each locality. Detention may be acceptable if place of safety is genuinely therapeutic, but it rarely is.” [Respondent, HVN England survey, 2018]

“What may be needed at times are places where people can be supported safely when things feel overwhelming. This is about allowing their experience to be held, for them to be listened to deeply, for them to feel felt and understood, perhaps to feel that their experiences, that they can be safely contained in a way that feels helpful and supportive for them not for them to be restrained.” [Respondent, HVN England survey, 2018]

One of the key principles of the Mental Health Act is that if there is a less restrictive option available that will keep someone safe, it should be used instead the Act. However, the availability of viable alternatives to admission is often extremely limited. As such, detention under the MHA effectively fills and obscures a serious gap in service provision and investment. As suggested by our survey respondents, the provision of supportive environment (respites, crisis houses, peer-run services) where people can stay and feel confident that they will be treated with respect and listened to may significantly reduce the need for detention. It seems strange, for example, that despite the need for appropriate crisis care only a handful of crisis houses exist. Furthermore, unlike in the USA, statutory funded peer-run crisis houses and respites are as rare as unicorns.

If we step back from the reactive question of whether someone needs admission in a crisis situation when there is an imminent risk to life, the belief that detention is an inevitable part of mental health care hides yet another gap. Believing detention will always be necessary because of a particular way of understanding mental ill health and ‘insight’, is a convenient way of avoiding questions about the suitability of services in the weeks, months and years prior to detention. It enables us to continue providing services and implementing policies that may contribute to the crises that are responded to with coercion. Framed in this way, it is clear that the state has a clear mandate to couple mental health act legislation with the provision of a range of services that people trust and actually want to use when they are struggling.

The alternatives we believe would have the support of our membership, based on feedback during our events and our information service include:

- Peer-run respites, crisis houses and/or sanctuaries
- Medication-free wards (such as those piloted in Norway)
- Respites and crisis houses with access to therapeutic support
- Crisis support that is well co-ordinated, offers continuity of care and is flexible (e.g. the Open Dialogue Approach).
- Drop-in crisis cafés
- Residential spaces to work with difficult voices and beliefs and the reasons for admission (with, or without, medication)

We recognise that this requires a significant investment in addition to a radical re-think of the way mental health services are structured. Of equal importance is a willingness to actively engage with service users, survivors and family members to create the services people want to use when they are in distress – rather than continue to create ones they either avoid or run away from.

## RECOMMENDATIONS

- The right to a meaningful and informed choice of support when people are distressed, reducing the likelihood that people will reach crisis point and be detained.
- Alternatives to admission that can be used when people are in significant distress, reducing the use of detention as far as possible.
- An increase in services which are user-led and appropriate for marginalised communities, including people with learning difficulties/disabilities, D/deaf and physically disabled people, people from disadvantaged socio-economic groups and LGBT and transgender people
- A commitment to engage with service users, survivors and family members from diverse communities to rethink the structure of mental health services.
- A serious commitment to the necessary investment in mental health services, the voluntary sector and social care

## CONCLUSION

Whilst we made efforts to consult with our members and supporters, we recognise a full review must go further in engaging with even the most marginalised of voices. Rather than attempt to cover the vast scope and the detail of the MHA Review, we focused instead on the urgent and important themes which our members and supporters raised. We also recognise the limitations of the question format, when these are issues which invite nuanced and contextual responses. However, we believe this report presents an important alternative to the official Mental Health Act Review and hope that it stimulates conversations and dialogues that will influence future mental health legislation. Whilst we are one organisation, our conversations with other survivor and service user groups suggest our concerns are not unique. We call for the government to lead a bold and optimistic revision of the Mental Health Act; to create and fund services and alternatives to detention that people want to use when they are distressed; and to centre the voices of survivors and service users.

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# APPENDIX 1

In April 2018, we talked to our members and supporters to find out their views on the MHA Review, and what changes they would like to see in mental health legislation. We conducted a small survey at our annual event, and the survey was also emailed out to HVN England members after the event. Respondents included people with lived experience of voices, family members, and professionals. The survey was in two parts. The first part contained 8 questions and was for everyone. The second part contained 10 questions and was for those who had been detained under the MHA. We used 5 point Likert scales and also provided comment boxes. 90 people in total responded to the survey, and 23 people responded to the second half relating to being detained under the MHA.

## THE MENTAL HEALTH ACT: A HUMAN RIGHTS PERSPECTIVE

### SECTION 1: FOR EVERYONE

#### 1. IS IT EVER ACCEPTABLE TO DETAIN SOMEONE AGAINST THEIR WILL, BECAUSE THE PERSON HEARS VOICES OR HAS BELIEFS WHICH OTHERS FIND UNUSUAL?

- YES: 3%
- IT DEPENDS: 33%
- NO: 61%
- NOT SURE: 2%
- LEFT BLANK: 1%

#### 2. ARE MEDICAL PROFESSIONALS, INCLUDING PSYCHIATRISTS, THE PEOPLE MOST ABLE TO PREDICT WHEN A PERSON MIGHT HARM THEMSELVES OR OTHERS?

- YES: 4%
- IT DEPENDS: 19%
- NO: 74%
- NOT SURE: 3%

### **3. IS FORCED MEDICATION AGAINST YOUR WILL, BECAUSE YOU HEAR VOICES OR HAVE BELIEFS WHICH OTHERS FIND UNUSUAL, EVER ACCEPTABLE?**

- YES: 1%
- IT DEPENDS: 25%
- NO: 67%
- NOT SURE: 6%
- LEFT BLANK: 1%

### **4. IS IT EVER ACCEPTABLE, ON MENTAL HEALTH GROUNDS, TO USE FORCED ELECTRO-CONVULSIVE THERAPY (ECT) AGAINST SOMEONE'S WILL?**

- YES: 2%
- IT DEPENDS: 6%
- NO: 88%
- NOT SURE: 4%
- LEFT BLANK: 2%

### **5. IS IT EVER ACCEPTABLE TO USE FORCED TREATMENT IN THE COMMUNITY (CTOS) AGAINST SOMEONE'S WILL, BECAUSE THE PERSON HEARS VOICES OR HAS BELIEFS WHICH OTHERS FIND UNUSUAL?**

- YES: 2%
- IT DEPENDS: 17%
- NO: 77%
- NOT SURE: 3%
- LEFT BLANK: 2%

### **6. SHOULD ADVANCE DECISIONS BE UPHELD UNDER THE MENTAL HEALTH ACT?**

- YES: 69%
- IT DEPENDS: 19%
- NO: 4%
- NOT SURE: 8%



## 7. SHOULD A PERSON'S UNDERSTANDING OF THEIR EXPERIENCES (VOICES, BELIEFS, SENSATIONS) HAVE EQUAL WEIGHT UNDER THE LAW AS THE PSYCHIATRIST'S UNDERSTANDING OF THE PERSON'S EXPERIENCES?

- YES: 78%
- IT DEPENDS: 7%
- NO: 11%
- NOT SURE: 4%

## 8. HAS THE MHA EVER MADE YOU FEEL UNSAFE TO COME FORWARD AND ASK FOR SUPPORT?

- YES: 58%
- IT DEPENDS: 3%
- NO: 33%
- NOT SURE: 5%
- LEFT BLANK: 1%

## SECTION 2: FOR PEOPLE WHO HAVE BEEN SECTIONED UNDER THE MENTAL HEALTH ACT

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### 1. IN YOUR CASE, HOW HELPFUL WAS BEING DETAINED UNDER THE MENTAL HEALTH ACT?

- VERY: 0%
- MODERATELY: 17%
- SLIGHTLY: 9%
- NOT AT ALL: 74%

### 2. IN YOUR CASE, HOW HELPFUL WAS THE TREATMENT YOU RECEIVED UNDER THE MENTAL HEALTH ACT?

- VERY: 4%
- MODERATELY: 9%
- SLIGHTLY: 26%
- NOT AT ALL: 61%

### 3. HOW HELPFUL WAS BEING DETAINED UNDER THE MENTAL HEALTH ACT IN PREVENTING YOU FROM ATTEMPTING SUICIDE?

- VERY: 5%
- MODERATELY: 4%
- SLIGHTLY: 13%
- NOT AT ALL: 70%
- NOT SURE: 4%
- BLANK: 4%

### 4. HOW HELPFUL WAS TREATMENT YOU RECEIVED UNDER THE MENTAL HEALTH ACT IN REDUCING THE LIKELIHOOD OF YOU HARMING OTHER PEOPLE?

- VERY: 0%
- MODERATELY: 4%
- SLIGHTLY: 22%
- NOT AT ALL: 70%
- NOT SURE: 0%
- BLANK: 4%

### 5. HOW HELPFUL WAS BEING DETAINED UNDER THE MENTAL HEALTH ACT IN REDUCING THE LIKELIHOOD OF YOU HARMING OTHER PEOPLE?

- VERY: 0%
- MODERATELY: 0%
- SLIGHTLY: 4%
- NOT AT ALL: 83%
- NOT SURE: 0%
- BLANK: 13%

## 6. HOW HELPFUL WAS THE TREATMENT YOU RECEIVED UNDER THE MENTAL HEALTH ACT IN REDUCING THE LIKELIHOOD OF YOU HARMING OTHER PEOPLE?

- VERY: 4%
- MODERATELY: 0%
- SLIGHTLY: 4%
- NOT AT ALL: 83%
- NOT SURE: 0%
- BLANK: 9%

## 7. I WAS TREATED WITH DIGNITY AND RESPECT

- ALWAYS: 0%
- MOSTLY: 0%
- SOMETIMES: 22%
- RARELY: 39%
- NEVER: 39%

## 8. I WAS INFORMED OF MY HUMAN RIGHTS BY THE STAFF SECTIONING ME

- YES: 0%
- NO: 0%
- NOT SURE: 22%
- BLANK: 39%

## 9. MY HUMAN RIGHTS WERE RESPECTED BY THE STAFF SECTIONING ME

- YES: 4%
- NO: 70%
- NOT SURE: 22%
- BLANK: 4%

## 10. I FELT SAFE AND SECURE WITH THE STAFF SECTIONING ME

- ALWAYS: 0%
- MOSTLY: 0%
- SOMETIMES: 26%
- RARELY: 22%
- NEVER: 52%

## 11. MY HUMAN RIGHTS WERE RESPECTED BY STAFF PROVIDING TREATMENT AND CARE

- ALWAYS: 0%
- MOSTLY: 0%
- SOMETIMES: 26%
- RARELY: 35%
- NEVER: 39%

## 12. STAFF ASKED FOR MY OPINION ON MY OWN NEEDS

- ALWAYS: 0%
- MOSTLY: 0%
- SOMETIMES: 17%
- RARELY: 35%
- NEVER: 48%

## 13. STAFF ASKED FOR MY OPINION ON THE TREATMENT I WAS GIVEN

- ALWAYS: 0%
- MOSTLY: 0%
- SOMETIMES: 13%
- RARELY: 22%
- NEVER: 65%

## 14. MY OPINION AND VIEWS ON MY NEEDS AND TREATMENT WERE TAKEN INTO CONSIDERATION BY STAFF

- ALWAYS: 0%
- MOSTLY: 0%
- SOMETIMES: 17%
- RARELY: 31%
- NEVER: 52%

## 15. I FELT SAFE AND SECURE WITH STAFF PROVIDING TREATMENT AND CARE

- ALWAYS: 0%
- MOSTLY: 4%
- SOMETIMES: 26%
- RARELY: 30%
- NEVER: 39%

## 16. . I FELT SAFE AND SECURE IN THE SETTING/PLACE WHERE I WAS DETAINED

- ALWAYS: 0%
- MOSTLY: 4%
- SOMETIMES: 22%
- RARELY: 13%
- NEVER: 61%

# NATIONAL HEARING VOICES NETWORK

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