Written evidence submitted by Liberation (MRS0362)

Introduction

Liberation is a newly formed, user-led organisation, operating in England. Its aim is to promote the implementation of full human rights for people with lived experience of a mental health diagnosis/mental trauma, in particular the fundamental rights set out in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[1]. Liberation's work includes a particular focus on human rights for people with lived experience who encounter more than one form of discrimination. The views expressed in this submission stem from Liberation members and associated networks.

Reason for submitting evidence to the enquiry

Liberation would like to focus government attention on some key issues for people with protected characteristics during the current coronavirus outbreak, in particular issues for people with lived experience of a mental health diagnosis/mental trauma whom it represents. As a user-led organisation, Liberation has information to convey which may well not be taken into account otherwise. As an organisation with a strong focus on intersectional issues, Liberation also has important evidence to submit about these.

Summary of the report

Liberation wishes to highlight five key areas for people with lived experience of a mental health diagnosis/mental trauma:

1. Socio-economic issues relevant to the coronavirus situation

- People from already disadvantaged socio-economic groups have fared particularly badly since 2008, after austerity measures were introduced in response to the financial crisis
- In this context, a particular concern is that the government has not yet triggered Section 1 of the Equality Act
- The impact of austerity measures has been particularly acute for people with lived experience of a mental health diagnosis/mental trauma
- The current coronavirus situation is now exacerbating socio-economic disadvantages.

What is needed

1. Recognition of additional issues stemming from the coronavirus outbreak for people with lived experience who were already experiencing major socio-economic disadvantages.

2. Priority action to address these, based on major institutional changes.

3. Activating Section 1 of the Equality Act.

4. Meaningful involvement of user-led organisations in decisions made and solutions adopted, in line with Article 4.3 of the UNCRPD.

2. Physical health factors

- Existing shortfalls in physical health care provision for people with lived experience of a mental health diagnosis/mental trauma puts them at particular risk of the coronavirus
- In relation to this, many *Health Lives* study participants also regarded physical healthcare as unduly linked to the medical model dominant in psychiatric services and to the Mental Health Act 1983, which they experience as discriminatory, and wanted physical healthcare to be better suited to demographic diversity
- People with lived experience have expressed widespread anxiety about the initial guidance from the National Institute for Health and Social Care Excellence (NICE), about who should receive critical care. Despite NICE's revised guidelines, many people with lived experience remain frightened that they will be left to die
- Rough sleepers, and/or homeless people with lived experience are worried about the coronavirus particularly affecting them, because of their underlying health conditions and over-crowding in hostels
- A further fear is that over-representation of Black men in prison will raise coronavirus deaths amongst Black men
- People with lived experience are extremely angry about the huge numbers of deaths amongst care home residents.

What is needed

1. Urgent government action on behalf of people with lived experience, including a clear focus on those who encounter more than one form of discrimination.

2. Further reassurance that those who also have underlying physical health conditions will receive the same quality of physical healthcare as any other members of the public.

3. Use of the expertise held by people with lived experience from particular demographic groups.

3. Mental health law

- For many people with lived experience of a mental health diagnosis/mental trauma, a serious human rights problem with the Coronavirus Act 2020 is the provision for the Secretary of State to weaken already unsatisfactory safeguards in mental health law, if there is a major shortage of mental health professionals
- Existing mental health law is itself in breach of the fundamental human rights set out in the UNCRPD. If the Coronavirus Act powers are activated, there will be a still worse breach
- People with lived experience who are already over-represented amongst detained patients, for example Black men, will fare worst of all.

What is needed

1. Immediate government agreement to refrain from implementing these increased powers and to withdraw them at the time of the six-month review.

2. Active discussion with user-led organisations about feasible ways of accelerating deinstitutionalisation, in line with the *Joint Statement* from the Chair of the United Nations Committee on the Rights of Persons with Disabilities, followed by sustained action to bring institutionalisation to an end.

4. Support

- The negative impact of the coronavirus has been heightened by previous major cuts in social care budgets
- For many people with lived experience of a mental health diagnosis/mental trauma, it is proving hard to access basics such as food, medicine and support services during the coronavirus outbreak, not least because of the absence/shortages in personal protective equipment
- People with lived experience have huge fears about the easement of the Care Act 2014 which is now permitted under the Coronavirus Act

- Full, in fact increased community support needs to be available currently, including a full range of alternatives to the dominant medical model approach, user-led options and services which are culturally appropriate.

What is needed

1. Further urgent action to address the social care funding gap which is worsening the impact of the coronavirus outbreak.

2. An early repeal of the Care Act easements currently permitted under the Coronavirus Act.

3. In place of decreased safeguards against sectioning and forced treatment, a major increase in wide-ranging, community-based resources which support the independent living and community involvement approach set out under Article 19 of the UNCRPD.

4. A meaningful influence for user-led organisations over all three of the actions above, including organisations which represent people with lived experience who encounter more than one form of discrimination.

5. Hate crime

- The sheer level of hate crime against Disabled people is a serious issue for Liberation; Home Office records demonstrate a rise in hate crime of 14%
- The user-led, co-produced *Keeping Control* research study highlights the increased risk of targeted attacks faced by Disabled people, especially people with lived experience of a mental health diagnosis/mental trauma
- The research study findings also demonstrate serious weaknesses in safeguarding processes under the Care Act 2014 and the need for insights from people with lived experience to be central to safeguarding law and approaches.
- Feedback to Liberation is that the position has worsened further since the start of the coronavirus outbreak.

What is needed

1. Immediate action against rising hate crime encountered by people with lived experience, including a clear focus on those who are targeted because they have more than one protected characteristic.

2. An effective use of the expertise held by user-led organisations in the drawing up and implementation of both short-term and longer-term solutions and in the monitoring of outcomes.

In conclusion

Liberation hopes that the issues highlighted in the five spheres set out above will receive detailed attention from the Women and Equalities Committee and that full use will also be made of Liberation's recommendations for action.

Main report

1. Socio-economic issues relevant to the coronavirus situation

People from already disadvantaged socio-economic groups have fared particularly badly since 2008, following the introduction of austerity measures in response to the financial crisis that year. As a result, when the United Nations Special Rapporteur for Extreme Poverty and Human Rights visited the UK, he issued a highly challenging statement (Alston 2018)[2] about the extent of poverty in the UK, including the fact that 1.5 million people in the UK are so destitute that they cannot afford even basic essentials. He also 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 has 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 disability, race, age, sex and sexual orientation. However, because the government has not yet triggered Section 1 of the Act, technically, public bodies do not yet have a socio-economic equality duty. This is a major issue for Liberation and many other user-led organisations, given the high level of socio-economic disadvantages which Disabled people experience.

For people with lived experience of a mental health diagnosis/mental trauma, the impact of austerity measures has been particularly acute, because they form the largest number of benefit claimants (Bond, Braverman and Evans, 2019)[3]. In addition, homelessness numbers have been rising to as many as one in every 200 people in England (Shelter, 2019)[4]. This has again been particularly affecting people with lived experience of mental trauma; as many as

80% of homeless people have pre-existing mental health diagnoses, or have developed related difficulties since losing their homes[5].

The current coronavirus situation is now exacerbating existing inequalities. As Alston has said of the UK's current measures (Booth, 2020)[6]:

> *… many of the worst and most damaging aspects of 'austerity' cannot and will not be undone. The damage caused to community cohesion and to the social infrastructure is likely to prove permanent.*

There is a continuing need to rely on food banks, still more so for people experiencing more than one form of discrimination. As a Black disabled woman with lived experience has commented:

> *I have food coming in from the food bank, because I have no wage. Why is that when I'm advising ministers?*

Food banks are also struggling to maintain supplies, because there have been fewer donations during the coronavirus crisis, but an increased demand. Poverty is escalating further because of job losses; in the fortnight leading up to 5th April, practically a million adults applied for Universal Credit (UC), an almost tenfold increase in the usual numbers[7]. It is positive that the government has increased payments of UC by up to £1,040 a year. However, this still leaves payments lower than the amount considered sufficient to keep people out of poverty. A further issue is that, whilst the increase to UC represents a rise for new disabled claimants, people already receiving disability benefits remain on previous levels which have fallen considerably behind the cost of living.

Liberation welcomes the fact that the government has taken steps to ensure provision for rough sleepers and to pre-empt evictions from the private rented sector, for example has required local authorities to house the former in hotels, or emergency accommodation and stated that evictions of private tenants unable to pay their rent should be halted for three months. However, significant obstacles remain, not least because of ongoing government failures to address critical housing issues. Immediate problems include the provision of accommodation at an unacceptable standard[8], resource and support issues and the risk that private renters will fall still further into arrears, because they continue to be in poverty. What remains to be seen is whether the Housing, Communities and Local Government

Committee's inquiry into the effectiveness of government measures will result in a resolution of these problems.

What is needed
1. Recognition of additional issues stemming from the coronavirus outbreak for people with lived experience who were already experiencing major socio-economic disadvantages. 2. Priority action to address these, based on major institutional changes. 3. Activating Section 1 of the Equality Act. 4. Meaningful involvement of user-led organisations in decisions made and solutions adopted, in line with Article 4.3 of the UNCRPD.

2. Physical health factors

Because of existing shortfalls in physical health care provision for people with lived experience of a mental health diagnosis/mental trauma, the coronavirus outbreak represents a particular risk for them. For example, as the *Healthy Lives* research study has illustrated (Gould, 2016)[9], it is already the position that people diagnosed with serious mental illnesses are more at risk of long-term physical health problems, receive poorer physical healthcare and die an average of 15-20 years earlier than others, not least because of side-effects of psychiatric drugs.

Many study participants regarded physical healthcare as unduly linked to the medical model which is dominant in psychiatric services and to the compulsory powers of the Mental Health Act 1983, which they experienced as discriminatory, and were not confident of receiving adequate physical healthcare unless there were fundamental changes in these factors. They also emphasised the need for physical health services to be better suited to the extensive demographic diversity amongst people with lived experience.

For instance, one lesbian participant explained:

> *I've had bad experiences with nurses and GPs assuming I'm heterosexual and asking what I felt to be intrusive questions about contraception and not believing me, or showing visible disbelief that I've never had sexual intercourse with a man.*

A request from a gay man was for a gay men drop-in facility.

An Indian participant commented:

> *But if they had a properly holistic service … exercises, natural herbal remedies, breathing techniques, meditating practices … reflexology … Even if you were just told about them, I think that would make a good start.*

A Black Liberation member also wanted to emphasise the likely role played in increased coronavirus deaths amongst people from Black, Asian and other minority ethnic (BAME) communities by a lack of cultural awareness amongst clinicians. As she explained:

> *There is a lack of understanding of the makeup of the BAME human body – in some things we are different.*

People with lived experience have expressed widespread anxiety about the initial guidance to clinicians from the National Institute for Health and Social Care Excellence (NICE)[10]: that clinicians should use a triage system, based on a frailty score, to decide which patients were given critical care and which received end of life care. Although NICE has subsequently issued revised guidelines which are phrased more reassuringly, many people with lived experience remain very frightened that they will be left to die because of a serious underlying condition and/or because they are not regarded as being valuable members of society.

As has been mentioned above, many rough sleepers and homeless people also have lived experience. A further anxiety for many of them is the quite strong likelihood that they will become infected with the coronavirus; not only do they often have much poorer health than the public in general, but many are in crowded hostel facilities which enable the coronavirus to spread easily. A study from University College London's Collaborative Centre for Inclusive Health provides evidence that such fears are far from groundless[11] The worrying initial findings from this study are that the coronavirus death rate among homeless people living in London's hostels is 25% higher than that among the general adult population. However, there is no indication to date of government plans to take action about the situation.

There are ongoing fears, too, that, because of their over-representation in prisons, more Black men will die of coronavirus there, despite the government bringing in some preventative action on behalf of prisoners. A Black Liberation member expressed the following plea on behalf of Black men and their families:

Culturally, our men are being very trodden on, so much so that they cannot get off the floor. So their families are falling apart as well - lots of the fathers are in prison.

A massive cause of anger for people with lived experience is the huge number of deaths amongst older care home residents, many of whom have mental health diagnoses as well as underlying physical health conditions; people with lived experience find it hard not to attribute the sheer scale of deaths (4,343 between 10th and 24th April alone) to catastrophic government neglect.

What is needed

1. Urgent government action on behalf of people with lived experience, including a clear focus on those who encounter more than one form of discrimination.
2. Further reassurance that those who also have underlying physical health conditions will receive the same quality of physical healthcare as any other members of the public.
3. Use of the expertise held by people with lived experience from particular demographic groups.

3. Mental health law

For many people with lived experience of a mental health diagnosis/mental trauma, a serious human rights problem with the Coronavirus Act 2020 is the provision for the Secretary of State to authorise a reduced use of the already unsatisfactory safeguards in mental health legislation, if a shortage of mental health professionals is thought to justify this. In the case of the Mental Health Act 1983, they are extremely worried that it will then be possible for:

- An Approved Mental Health Professional (AMHP) to detain someone in mental distress under a section 2, or a section 3, with a recommendation from one doctor, instead of two;
- There to be longer holding powers under sections 5, 135 and 136
- Compulsory treatment to last longer than 3 months without a Second Opinion Appointed Doctor (SOAD) being consulted first
- Related changes to be introduced in the case of Part Three patients.

Mental health legislation is already in serious breach of the fundamental human rights set out in the UNCRPD, despite the fact that the UK government is a signatory to this treaty. Implementation of the above measures will represent a still more serious breach of human

rights. It will also be in contravention of point 5 in the recent *Joint Statement: Persons with Disabilities and Covid-19* (Chair of the United Nations Committee on the Rights of Persons with Disabilities, 2020)[12], which advocates accelerated deinstitutionalisation of Disabled people from all types of institutions. In addition, this situation will be compounded for people who are already over-represented amongst those subjected to mental health law, for example Black men who are detained in psychiatric hospitals, including high security hospitals, and prisons.

What so often happens at a time of crisis is that already disadvantaged people lose still more of their human rights. It will be totally unacceptable if the Coronavirus Act has this effect on the rights of people with lived experience. As one Liberation member has said:

> *I just want the same human rights as anyone else. All these plans under the Coronavirus Act just make me feel even more of a nonentity.*

What is needed

1. Immediate government agreement to refrain from implementing these increased powers and to withdraw them at the time of the six-month review.
2. Active discussion with user-led organisations about feasible ways of accelerating deinstitutionalisation, in line with the *Joint Statement* from the Chair of the United Nations Committee on the Rights of Persons with Disabilities, followed by sustained action to bring institutionalisation to an end.

4. Support

In this sphere, too, the negative impact of the coronavirus outbreak has been heightened by previous cuts. There has been a £7billion reduction in adult social care since 2010. The problems faced by local authorities and service providers have become progressively worse since then (Association of Directors of Adult Social Services, 2019)[13]. On average, local government spending on services has fallen by 21% in real terms since 2009-10, with poorer areas particularly badly affected (Smith and Phillips, 2019)[14]. This position has not been countered by the Care Act 2014, nor by aftercare provisions of the Mental Health Act 1983. As a result, services were already at crisis point prior to the coronavirus outbreak.

In his *Joint Statement* (2020)[15] about the provision of support during the coronavirus outbreak, the Chair of the United Nations Committee on the Rights of Persons with Disabilities has emphasised the need to safeguard the supply of items such as food and

medicine during periods of isolation and quarantine for Disabled people and for a full range of community support to continue. However, Liberation has heard from a large number of people with lived experience of a mental health diagnosis/mental trauma that accessing these has been problematic, not least because of the absence/major shortage of personal protective equipment. As one person has said:

> *I didn't hear from my local authority until two or three weeks into the lockdown. The information was mostly only useful to people who have computers, which quite a lot of us don't, and it was almost 6 weeks before a note was put through my door about members of a mutual aid group who could do my shopping, or collect prescriptions. I've managed, but I'm really concerned about people who vitally need this sort of support.*

Feedback has also illustrated huge fears about the easement of the Care Act 2014 which is now permitted under the Coronavirus Act. Limited though the Care Act is, people with lived experience of a mental health diagnosis/mental trauma do not want even to lose such support as is provided under that Act.

At times of crisis, too, it is more important than ever for there to be a full, in fact increased amount of community support available if involuntary detention in a psychiatric hospital and forced treatment are to be avoided. For so many of us, it is vital that they are. As one person has expressed it:

> *Going through lockdown feels very restricting - and incredibly tough, for those of us who are meant to be 'shielding'. But it pales into insignificance in comparison with the trauma of being sectioned and forcibly treated.*

A strong focus on wide-ranging community resources is also very important if the diverse needs of people with lived experience are to be met. Alternatives to the dominant white western medical model, user-led options and services which are culturally appropriate are highly important to many people with lived experience, but often receive very limited, or no funding and so are in short supply.

What is needed

1. Further urgent action to address the social care funding gap which is worsening the impact of the coronavirus outbreak.
2. An early repeal of the Care Act easements currently permitted under the Coronavirus

Act.
3. In place of decreased safeguards against sectioning and forced treatment, a major increase in wide-ranging, community-based resources which support the independent living and community involvement approach set out under Article 19 of the UNCRPD.
4. A meaningful influence for user-led organisations over all three of the actions above, including organisations which represent people with lived experience who encounter more than one form of discrimination

5. Hate crime

A serious issue for Liberation is the sheer amount of hate crime against Disabled people. Existing evidence from hate crime records clearly demonstrates that further, concerted action is needed to tackle such crime. The records illustrate the fact that there was a 10% overall increase in hate crimes between 2017/2018 and 2018/2019 (Home Office, 2019)[16], including intersectional crimes. Hate crimes related to disability rose by 14%. 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. That would not make the reasons for concern less strong, however. What would then emerge from the evidence is that instances of disability hate crime are considerably higher than has been realised.

The *Keeping Control* research study[17], a user-led study co-produced with Middlesex University staff, has specifically highlighted the fact that disabled people, particularly people with lived experience of a mental health diagnosis/mental trauma, are at higher risk of targeted attacks than others, often on a prolonged and intersectional basis. A further, highly concerning finding which emerged from the study is that safeguarding reforms set up under the Care Act 2014 have proved far from adequate for people with lived experience, a situation which urgently needs addressing. The report findings also demonstrate the need for the experiences and insights of people with lived experience to be central to adult safeguarding legislation and approaches, if safeguarding is to prove effective.

Feedback to Liberation from people with lived experience is that the position has worsened further since the start of the coronavirus outbreak. At a time when many people with lived experience of a mental health diagnosis/mental trauma are already under acute additional pressure and numbers of people experiencing major mental distress are rising because of the coronavirus outbreak, this situation is completely unacceptable.

What is needed

1. Immediate action against rising hate crime encountered by people with lived experience, including a clear focus on those who are targeted because they have more than one protected characteristic.
2. An effective use of the expertise held by user-led organisations in the drawing up and implementation of both short-term and longer-term solutions and in the monitoring of outcomes.

Concluding comments

There are major issues arising from the coronavirus outbreak and measures taken to tackle it in all five spheres outlined above. Liberation hopes that these will receive detailed attention from the Women and Equalities Committee and that full use will also be made of Liberation's recommendations for action.

April 2020

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