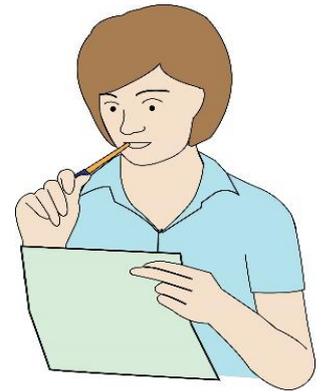


Date:

Address:

Dear

We are writing to you about the Mental Health Act **Independent Review**. We are mental health service users, survivors, members of user-led organisations and **allies**.



Independent Review: this means a review that is done to see what is going well and what is not going so well. It is done by people or an organisation that are not the main decision makers in the area. This is so that they are not one sided and can look at all the ideas and choices for change.

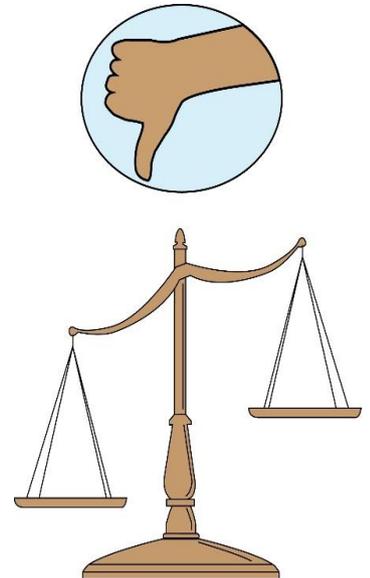
Allies: these are people or organisations that support the work that we do.

We are very happy that you see the need for a review. However, we are very worried about the way that they review is being done. We would like to tell you how you could make improvements. We hope that you will find this feedback helpful.



Issues with the Terms of Reference for the Review: this is a document which tells us what the review is there to do, how it should be done and what the limits are to what it can do.

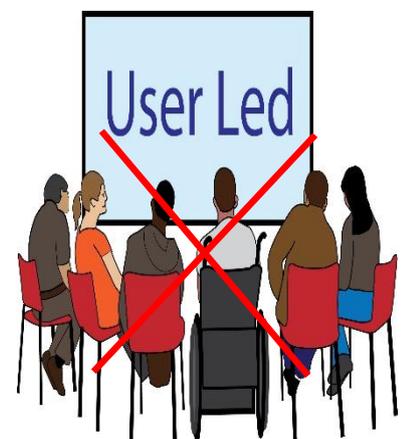
In the Terms of Reference, it says that there will be **co-production** with mental health service users and carers. This has not been done very much. For example, service users do not have equal power and or an equal voice to make change happen in the review. The Review chair, Professor Sir Simon Wessely, is a psychiatrist and not a service user. There is a vice chair with lived experience of **detention**, Mr Steven Gilbert, yet he is only one of three vice chairs.



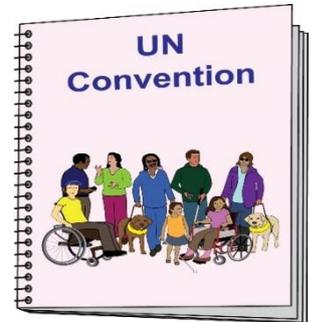
Co-production: this means working together with the people that use or are affected by services or decisions in a real way.

Detention: this means being held by the state, this could be in a hospital, a unit or in prison.

There are also more professionals and non-user academics than service users, survivors and user-led organisations in key areas of the Review such as in the Advisory Panel. There are also not enough user-led groups taking part in other Review work which is being done.



The Review focus: In the Review, improvements to the Mental Health Act 1983 are seen as more important. We think that bigger change is needed if mental health service users are to have equal human rights. For this kind of change to happen, the Government needs to work to the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)**. The Government also needs to agree to the **recommendations** made by the United Nations Committee last October.

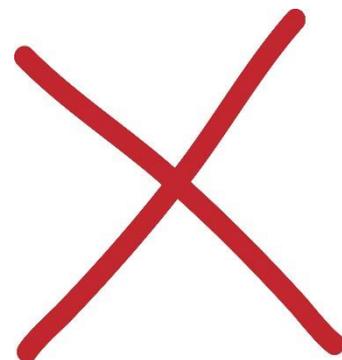
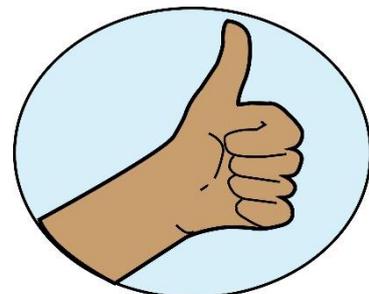


United Nations Convention on the Rights of Persons with Disabilities: this is an agreement that the UK Government signed up to, to push forward Disabled People's rights.

Recommendations: these are ideas for making something work better.

This can be done by doing things such as using a human rights model of disability instead of the medical model being used now. It would also mean ending:

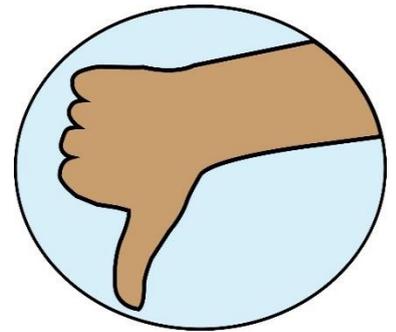
- Detentions, being held or locked up
- Substitute decision-making, this is a list of people who can make decisions about a persons treatment
- Compulsory treatment, this is a court order which means that a person must get treatment



This would need to be done working closely with user-led organisations (Articles 1-4, 12, 14, 15 and 17). However, because of the short amount of time given for this review, there is not time for making bigger human rights changes.



As well as this, there are some worries about Brexit and losing rights given under the European Union Charter of Fundamental Rights. As a result, mental health service users' access to **supranational institutions** for support in accessing equal human rights, will be harder.



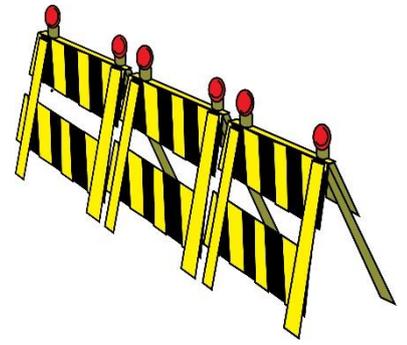
Supranational Institutions: here, these are organisations that are part of the European Union that member countries can use for support, such as the European Parliament or the European Courts.

Working together with service users in consultations:

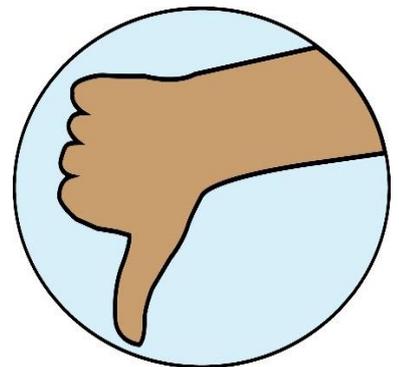
Service users and carers have not been able to really take part. In the Information given about the Review process, there has been no information on the options for laws that could be used in the place of the Mental Health Act 1983. There has also not be any information about the United Nations Convention of the Rights of Person's with disabilities, even though user-led organisations have said how much this is needed.



Many service users are still not aware of options for laws that could be used in place of the Act and so have not had the change to give full responses to the consultation, such as the service user survey. The review has been so quick that it has caused some big barriers for service users and carers taking part in it.



As well as this, information has not been collected from service users from **marginalised groups**. For example, the service user survey was not inclusive of people with learning difficulties/disabilities, people who are deaf, or have physical/sight impairments, people from low income groups and trans people. As well as this, only 8% of survey responses came from people belonging to black, Asian and other minority ethnic (BAME) communities with lived experience of detention and compulsory treatment.



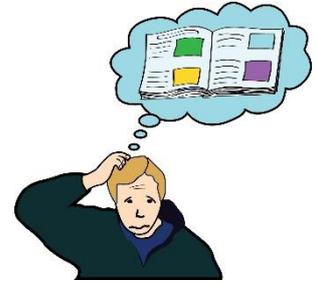
Marginalised groups: these are groups that are often left out of consultations and society because of barriers that are put up mean that they cannot take part.

We also have big worries that both what was in the survey and the focus group guidance pack, pushed for ideas about making changes to the Mental Health Act 1983, rather than being open to other ideas.



The quality of evidence in the interim report:

There seems to not be enough specific information and we have worries about where the information is coming from and it is being shown.



For example, extra information that we got, make it clear that only 537 people who replied to the survey were people with lived experience of detention. That is a small number of people to use for the report findings from the survey. The number of people with experience of detention who took part in the focus groups has not been given.



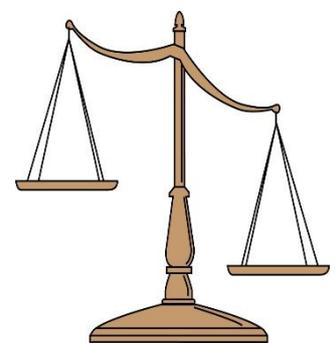
It is also not clear enough when report information comes from the survey findings, focus group findings and when it comes from groups set up as part of the review.



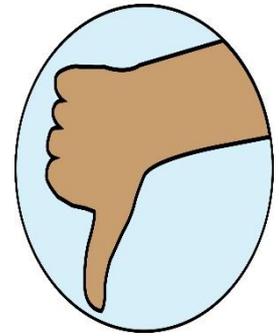
We are told in the Executive Summary that many service users had a good or mainly good view of being detained and that almost the same amount of people did not. The views of the people that did not have a good experience are not written about in a clear way in the findings.



As well as this, even though only 37% of the 48 Black Asian and Minority Ethnic people who talked about detention in a good way, this information is not given in the report. The voice of older service users are almost completely missing from the report. User-led groups were not given a role in reviewing the data.



Also some studies with reported weaknesses are used as examples, for example the Mental Health Alliance report. Service user and survivor researchers have pointed out the problems with the way that this research was run and to the fact that Black, Asian and Minority Ethnic Groups are not included properly at all in the research.



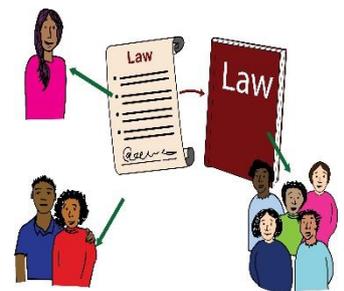
Wording and models used in the interim report:

The language and model used for experiences of mental distress are clinical. This means that they do not properly show the big numbers of service users who do not agree with this way of running the research and who find it very important to use other ways of working. There are worries, too, about what changes to the Mental Health Act will mean for NHS services.

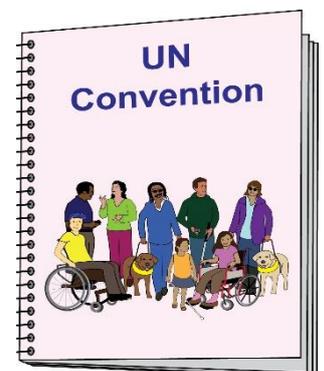


What we would like to see in the way that the Review is done:

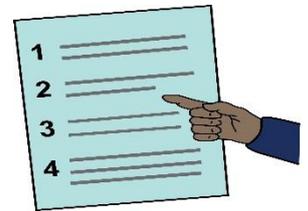
1. Change the way that the Review is set up and how it is carried out to make sure that services users who have experience of detention and compulsory treatment can take part equally



2. Change the Terms of Reference so that the focus is on what will need to be done to make sure mental health law is in line with the United Nations Convention on the Rights of Persons with Disabilities



3. Have a full discussion about the steps and **resources** needed to change the focus and make sure that these are put in place



Resources: this could mean time, funding or money, staff to work on this, office space etc.

4. Set a new longer time frame for the Review, one which means that the recommendations above can be put into place



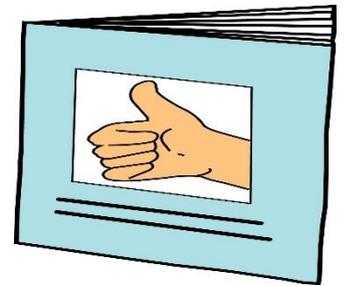
5. Make the way that information is collected better to make sure that consultation is done with the right number of service users who have lived experience of detention and compulsory treatment.



There should be a strong focus on people from Black, Asian and Minority Ethnic communities, and/or who face more than one type of disadvantage. This should also mean people with a learning difficulty/disability, not 'a mental disorder'



6. Deal with the issues around the interim report



7. Make sure the Review focuses on social models of mental distress/disability, as well as the way that services are run, for example a big number of other types of services (not just clinical), including user-led options and options for different cultures.



Yours sincerely