

Liberation's response: consultation on

Shaping Future Support: the Health and Disability Green Paper



Liberation as an organisation

Liberation is a recently formed, user-led organisation, operating in England. Its focus is the implementation of full human rights for people with lived experience of a mental health diagnosis/mental trauma, in particular the rights set out in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). We have both organisational and individual members. The views expressed in this submission stem from consultation with members.

Key concerns related to the Green Paper

1. The Green Paper talks about independent living as a priority, but is very narrow in scope. Article 19 of the UNCRPD and related Articles should be employed as the baseline for understanding independent living; the UNCRPD is a treaty which the UK government has signed and which is of major importance to many Deaf and Disabled people. Until the UNCRPD is utilised, neither the benefit system, nor employment issues will be tackled adequately; they need to be addressed as part of a larger whole. Similarly, the Paper's talk of a 'holistic approach' does not fit its actual ethos. As a result, any gains from the Paper's proposals will be limited (in addition to specific shortcomings in it).
2. Running together health and disability issues in the Green Paper is likely to lead to an increased emphasis on a medical as opposed to a social model. It is noticeable, for example, that mental distress/trauma is defined through a medical model, diagnostic approach. Similarly, paragraph 32 recognises that there are more people experiencing mental distress/trauma, but does not address the fundamental causes of that; until the government takes action to address its shortcomings during the coronavirus pandemic, major disabling factors in society and the dominant use of a medical model, which has badly let down so many of us, this increase is unlikely to change.
3. It is important that Disabled people have equal access to employment, including equal representation in senior roles. However, there is a failure to recognise that people should be regarded as valuable members of society whether they are able to work or not.

4. There is a complete absence in the Green Paper of any inclusion of intersectional issues. It is vital that particular disadvantages for people who experience more than one form of discrimination are recognised and addressed. There should also be a focus on people who are both service users and carers; it is often assumed that people can only be one or the other.

5. The Green Paper leaves question marks about how meaningful consultation with Deaf and Disabled people and organisations led by them (DDPOs) was. For example, precise numerical detail is lacking at a number of points and the organisations listed in the Annex, as groups which facilitated online responses, all appear to be non-DDPOs. Because we are the experts in our own needs, it is vital that we play a key role in developments. Under the UNCRPD, the government also has a responsibility to involve us in this way.

6. The high levels of satisfaction cited (for example in paragraphs 157, 211 and 217) seem to fly in the face of contrary evidence from many Disabled people and of key reports. The Green Paper fails to address in any adequate way findings by the [UNCRPD Committee](#) and by [Philip Alston](#). The statements in these paragraphs also run contrary to recent material from lead organisations such as the [Joseph Rowntree Foundation](#) and to other statistics held by the government, for instance those which can be found in the [data tables](#) of the *UK Disability Survey Research Report*.

7. In addition to issues raised in the points above, it is worrying that there is no current plan to overhaul the benefit system radically. In paragraph 11 of the executive summary, this is raised as a possibility, but the actual content of the Green Paper is about ‘improving’ the system. As with so many recent government proposals, the emphasis seems to be on ‘improving’ a broken system instead of on the radical transformation needed; this is very much the approach taken to ‘reform’ of the Mental Health Act 1983, for example.

8. The Green Paper is generalised in its focus and, despite the inclusion of some material, does not take adequate account of the lived experiences of people in mental distress/trauma, particularly because it is based on a medical model understanding of mental trauma/distress instead of on a social model. The Green Paper also falls short on addressing issues for people with learning disabilities/difficulties.

9. The consultation survey needs significant changes if it is to be a suitable instrument for obtaining the views of Deaf and Disabled people. Effective surveys designed for Deaf and Disabled people need to be drawn up in close consultation with them, or produced by them with funding made available for that purpose. However, it seems that relevant lessons have not been learnt from strong concerns which DDPOs expressed about the National Disability Strategy survey. The extent of information requested in the Green Paper's demographic questions comes across as intrusive and the questions fail to draw on the social model of disability which lies at the heart of the UNCRPD. The survey is also unduly long and, in addition to the fact that the easy read version does not give an adequate sense of the Green Paper, neither the Paper itself nor the survey questions adequately reflect issues for DDPOs.

Chapter 1: Providing the Right Support

A constant issue for people with lived experience of a mental diagnosis/mental trauma is that their needs are not well accommodated in the benefit system. There are many outstanding concerns in the [Money and Mental Health Policy Institute's report](#) (2019) which have not been addressed adequately. This issue needs a much stronger focus in the Green Paper.

Advocacy support would be very welcome. However, this needs to come from fully independent bodies, in particular from DDPOs; the latter have lived experience both of issues faced and of what is needed. To achieve this, funding will need to be made available and there will need to be commissioning of a wide selection of DDPOs covering the full diversity of Deaf and Disabled people and of intersectional issues. It will also be important that, when people validly challenge decisions made, they are not then just labelled as 'the problem'.

Physical access issues need much more attention in the Green Paper; accessible transport and accessible buildings remain major issues for people with lived experience of a mental health diagnosis/mental trauma who also have physical/sensory impairments. Access issues relating to psychological issues for us also need considerably more focus.

Chapter 2: Improving employment support

On the face of it, supporting employers to improve ‘mental health’ in the workplace is important. However, as James Davies (2021) has pointed out¹, approaches put forward in the workplace tend to locate problems within individuals instead of addressing the environment in which they are working. This is very true of IAPT, for example, quite apart from evidence that IAPT does not work particularly well and that official IAPT statistics are misleading in conveying that it does. The dominance of the government-endorsed, medical model approach to mental trauma and mental distress itself reinforces an essentially individualistic approach and so also reinforces the shortcomings outlined above. There will not be adequate change unless the Green Paper addresses these issues.

A further issue is that employers often seem not to recognise that they have a responsibility to address reasonable adjustments issues for people with lived experience of a mental health diagnosis/mental trauma. When they do address reasonable access factors, the focus seems to be on access for people with physical/sensory impairments. The Green Paper needs to tackle this shortfall.

The Green paper completely fails to recognise the huge damage which conditionality has done and is continuing to do, including a worsening of mental trauma and distress which is itself a barrier to obtaining/retaining employment. Research evidence also suggests that conditionality is ineffective; see for example the ESRC’s 2018 paper on [Welfare Conditionality](#).

The success of employment initiatives mentioned in the Green Paper, for example Health Model Offices, personalised support and Job Centre Plus input, will rest to a considerable extent on who is commissioned to train staff. As lived experience experts, DDPOs need to have a lead training role if these initiatives are to work well for people with experience of a mental health diagnosis/ mental trauma and other Deaf and Disabled people, including those experiencing intersectional discrimination.

The growing emphasis on digital approaches in this Green Paper and other government initiatives is concerning in the sense that there is a failure to recognise

¹ Davies, J. (2021) *Sedated. How Capitalism Has Created Our Mental Health Crisis*, London: Atlantic Books,

the numbers of people who are disadvantaged by it, the growing digital ‘under class’. One key issue is who will pay for computers and digital access for people who cannot afford them, for IT skills training where people have so far had no input and for necessary adaptations where people have a physical/sensory impairment which make the latter necessary. However, internet usage is not suitable for everyone; for example, in some cases, it exacerbates mental trauma/distress for people who are already experiencing this. Therefore, a key principle should be that people can choose in what ways they receive communications.

Chapter 3: Improving current services

The Green Paper’s assertion that most people are ‘content with our services’ is baffling. What has happened to any recognition that, because benefit rates are failing to keep up with the cost of living, people are falling increasingly below the poverty line, still more so if they already experience more than one form of discrimination, for example belong to a BME (racialised) community, that the withdrawal of the £20 increase in Universal Credit will have a dire effect and that there have literally been deaths and suicides because of people’s problems in accessing benefits? In the Mental Health Act White Paper, bad experiences were very much downplayed and in the recent report from the Commission on Race and Ethnic Disparities (CRED) structural racism was denied, in the teeth of evidence about its reality. Has the same thing happened here?

There needs to be an improvement in assessments for people with lived experience of a mental health diagnosis/mental trauma; feedback which Liberation has received is that the methods used do not relate well enough to the issues which they experience, still less so when they experience intersectional disadvantages.

As has been indicated above, the methods used for assessments and reassessments should rest on the preferences of individual claimants. Options available should include home visits, phone calls, assessment centres, videos, online contact and paperwork (with large print and easy read versions also available), together with funded access to translators and interpreters for people whose first language is not English and/or who use BSL. There has been important campaigning about the need for audio-recordings of assessments, given that quite a few benefit claimants have had concerns about the accuracy of notes made.

However, questions which need addressing are who will pay for the necessary equipment (it should not be the claimant), whose recording will it be and how secure it will be.

Using the term ‘holistic’ here for the decision-making process described is misleading, an example of the government taking over language and using it differently; ‘holistic’ means taking into account the whole of a person’s life circumstances. The definition needs to have the UNCRPD as its basis. In addition, the example given about someone in mental distress is worrying. It encapsulates the idea that ‘professionals know best’. As a result, it feeds into the stereotype that people in mental distress ‘lack insight’ about their problems and so that others need to take the lead about what happens to them.

It is intensely stressful to have to appeal to a Tribunal, because it is a lengthy, daunting process and one which is hard for average members of the public to get their heads around. As a result, people who are already living with mental trauma may not even feel able to apply and so become still more traumatised when benefit decisions are faulty. This is particularly concerning because there is clear [evidence](#) that the current assessment system is failing a significant number of people; the larger number of Tribunal appeals are successful according to data from the BBC (2021). It will be very important not only that there is a radical transformation of the whole welfare benefit system, but that, when there is a case for Tribunals, the process is very different from the present one. Legal aid needs to be readily available, access issues should be taken fully into account, including reasonable adjustments for people experiencing mental trauma, and the current, intimidatory format needs to be replaced with a user-friendly approach. This approach should be one which is also gender-friendly, age-friendly and anti-racist.

It has been shocking that people with terminal illnesses can die before they receive financial assistance to which they are entitled. An improved fast track approach, together with eligibility to draw on this at least 12 months ahead of the time when their lives are likely to end, is very much needed. It will also be very important that there is a simplified process for people with major impairments. A simplified process needs, too, to be available for all Disabled people, including people with lived

experience of a mental health diagnosis/mental trauma; the current system is daunting for most of us.

Chapter 4: Re-thinking future assessments to support better outcomes

Here as well as in the Green Paper as a whole, the underlying problem is that the proposals relate to improving the current system instead of altering it fundamentally in line with the independent living and holistic model set out in the UNCRPD. The UNCRPD also includes an important emphasis on intersectional issues such as ethnicity, gender and age which should be utilised fully.

If there is to be adequate change, it will, too, be important that people with lived experience of a mental health diagnosis/mental trauma and organisations led by them, alongside Deaf and Disabled people and their DDPOs in general, are given an influential role in reshaping assessment criteria and processes used, including those related to ‘fluctuating conditions’.

Chapter 5: Exploring ways to improve the design of the benefits system

A concerning feature both of this chapter and of the Green Paper as a whole is that independent living is looked at in narrow terms; the concept used mainly relates to getting people into employment. In addition, the focus is very much on the wellbeing which can result from appropriate employment. However, unless the underlying structural issues which result in mental trauma/distress are tackled, high levels of mental trauma/distress are likely to continue. Shortfalls in physical healthcare, inclusive education, decent, appropriately adapted housing and access to information, community facilities and community participation, together with the government’s failure to address the prevalence of systemic discrimination, all need tackling.

There is clear evidence that the introduction of Universal Credit (UC) has caused major problems both for people with lived experience of a mental health diagnosis/mental trauma and for Deaf and Disabled people as a whole; this is apparent, for instance, in the [Paper](#) from the House of Lords (2020). Therefore, these issues need addressing comprehensively in the Green Paper. Personal Independence Payments (PIP) should not be merged with UC. Quite apart from the fact that a fundamental transformation of the whole benefit system is needed,

serious disadvantages would be that the PIP element of UC would presumably then become means-tested and contribution-based. Instead, the benefit system needs to be based on the human rights model set out in the UNCRPD. As part of this, monies allocated to Deaf and Disabled people should allow for the additional expenses which we often have and the frequently negative impact of these on our quality of life; Article 28 of the UNCRPD calls for an adequate standard of living and social protection for Disabled people.

Whilst an important principle is that people should be able to decide how they use benefit money, there are also fundamental issues which fail to be addressed in the Green Paper's material on extra costs. A major issue is the need to scrap charges for social 'care'. In addition, aids and appliances need to be available without cost from the NHS.

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