

# United Response's submission to the Government's Mental Health and Wellbeing Discussion Paper



## About United Response

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Since 1973, United Response has been supporting people with learning disabilities, mental health or physical support needs to live their life to the full. Our team of 3,400 staff works across 330 locations in England and Wales to support around 2,000 people aged 16 to 65+. We campaign to ensure the people we support have equal access to the same rights and opportunities, as well as challenging the negative attitudes and discrimination they face.

## Introduction

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1. United Response welcomes the opportunity to contribute to the Government's public consultation on developing its Mental Health and Wellbeing Plan for England.
2. As we emerge from COVID-19 and begin our collective transition back to regular life, we must ensure that this is a just and supported transition for all our citizens, particularly those who draw on social care.
3. In doing so, policymakers must recognise from the outset how disproportionately affected our community's mental health and wellbeing has been from over two years of disruption.
4. Our organisation notes that disabled people were identified as – and remain – high-priority groups by the Department of Health and Social Care and National Health Service (NHS) during the pandemic and in its aftermath.
5. It is to be welcomed that, as part of the NHS's Long-Term Plan (2019), total mental health funding (including learning disabilities and dementia) has increased from £11 billion in 2015/16 to £14.31 billion in 2020/21<sup>1</sup>.
6. Equally, United Response welcomes the Government's commitment to put disabled people "*at the heart of government policy-making and service delivery*" in its renewed

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<sup>1</sup> Garratt, Karen, and Laing, Julia. (June 2022) *House of Commons Library: Mental Health Policy in England*. Pg.26.

National Disability Strategy (2021)<sup>2</sup>, as well as its pledge to modernise the Mental Health Act 1983 and tackle disability hate crimes (DHS).

7. As we set to address the questions and themes within the Government's discussion paper, we would be remiss if we did not impress the importance of developing solutions in a *holistic* manner.
8. Our community members live with whole-of-life conditions, and as such, it is only appropriate that equally wide-ranging and tailored mental health and wellbeing support is made accessible to them, their families, and the circle of support around them.
9. Going forward, policymakers and stakeholders must bear these crucial factors in mind if we are to deliver better, and more responsive services, develop earlier interventions, and place all people at the heart of the decision-making process.

## Executive Summary

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- **Implement an awareness-raising programme aimed at adults drawing on social care of their rights and protections available to them during times of mental health crises.**
- **Devise and pilot a dedicated training programme in close consultation with stakeholders for health and social care professionals on engaging with autistic patients, as well as patients with learning and intellectual disabilities, to make service provision more accessible from the outset of care journeys.**
- **Recognise the unique vulnerability to mental health challenges frontline social care workers face in their duties, particularly in a post-COVID context<sup>3</sup>, and implement a fast-track mental assessment process and targeted support for the social care workforce.**
- **Implement the new guiding principles recommended by the White Paper on Reforming the Mental Health Act<sup>4</sup> as a matter of urgency, to reform the Act's**

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<sup>2</sup> HM Government. (July 2021). *National Disability Strategy*. Pg28.

<sup>3</sup> According to their latest survey, Carers UK found that as many as 30% of caregivers reported that their mental health was either bad or very bad, along with 34% surveyed saying they often or always felt lonely. (Carers UK. [2021]. *State of Caring Survey 2021: A Snapshot of Unpaid Care in the UK*. Online. Available at: <https://www.carersuk.org/news-and-campaigns/state-of-caring-survey-2021>)

<sup>4</sup> Department of Health and Social Care. (August 2021). *Reforming the Mental Health Act*. Online. Available at: <https://www.gov.uk/government/consultations/reforming-the-mental-health-act/reforming-the-mental-health-act>

provision of services into a more person-centred system where disabled people are given better choices and accessible information about their care options<sup>5</sup>.

- Commission a large-scale study and data collection exercise to measure the impact of social prescribing, to develop a standardised evaluation framework and performance standards.
- Recognise social isolation and loneliness as key mental health challenges to people who are autistic and or live with a learning/intellectual disability, and invest in a data collection exercise to measure the impact of social prescribing to develop a standardised evaluation framework and performance standards
- Invest in additional advocacy services provided to disabled citizens and their families at the point of need, empowering them to actively pursue redress and better care during a crisis.
- Publish a renewed and updated Hate Crime Action Plan that offers an explicit parity of protection to victims of disability-motivated hate crime, as recommended by the Law Commission in its recent review<sup>6</sup>.
- Provide greater and more explicit protections for disabled people in the Online Safety Bill, placing a greater onus on social media companies to tackle abusive language and harassing behaviour against disabled users<sup>7</sup>.

## **How can we all prevent the onset of mental ill-health?**

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10. It is well-documented that disabled adults, as a whole, are more likely to experience suicidal thoughts and attempt to take their own lives than the rest of the population<sup>8</sup>.
11. Rates vary across different cohorts of the community, but two common denominators manifest themselves through an absence of broader mental health awareness and dialogue between people drawing on social care and frontline mental health services, leading to a lack of tailored prevention support available to those in need.

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<sup>5</sup> United Response shares the concerns indicated by Mind in [their response to the White Paper](#) (April 2021) that these new principles must focus on promoting and protecting patients' human rights; the European Convention on Human Rights must be explicitly referenced within any amended Mental Health Act. Regarding persons availing of social care and or those with a learning disability, this is especially crucial, where a clear need exists to make individuals actively aware of their rights during mental health and care crises.

<sup>6</sup> Law Commission. (December 2021). *Hate Crime: Final Report Summary*. Pg.19.

<sup>7</sup> United Response supports the recommendations proposed by the House of Commons Petitions Committee in their report on reforming the Online Safety Bill ([January 2022]. *Taking Online Abuse: Second Report of Session 2021–22*. Online. Available at: <https://committees.parliament.uk/publications/8669/documents/89002/default/>

<sup>8</sup> Milner, Allison, Bollier, Anne-Marie, Emerson, Eric, and Kavanagh, Anne. "The relationship between disability and suicide: prospective evidence from the Ten to Men cohort." *Journal of Public Health*, (41:4). December 2019. Pgs.707–713. Online. Available at: <https://doi.org/10.1093/pubmed/fdy197>

12. Limited statistics are available to construct a precise picture of how many adults with a learning disability in social care are experiencing suicide ideation, and even less on how many have attempted to and or successfully taken their own lives.
13. A robust data collection process must be devised so that clinicians and stakeholders can develop responsive solutions to what is often an overlooked cohort within already identified high-risk suicide groups.
14. We acknowledge the acute sensitivity surrounding this topic and that several unique barriers exist for families and professionals during such a process (namely in terms of explaining what suicide is, the concept of death's finality, and its wider socio-emotional effects, etc.).
15. Nevertheless, we believe that establishing formal data collection on this issue with adults in care settings will ultimately deliver better solutions in the long run.
16. From here, policymakers will possess a more accurate and up-to-date picture of the challenges people with a learning disability drawing on social care face.
17. In turn, better training programmes may be developed so that clinicians and social care workers alike might avail of to intervene earlier and more responsively to potential mental health crises.
18. We recommend instituting a formal process of robust data collection on suicidal behaviours amongst adults who are autistic and or have a learning disability living in social care settings.
19. Service providers and advocacy groups should be given a collaborative role as part of this initiative to help involve the people they support and their families.
20. In parallel, the National Institute for Care and Research should be commissioned to investigate incidences, rates, and contributing factors motivating suicidal behaviour in disabled people drawing on social care, to develop and ultimately recommend actionable clinical and policy solutions in the short and long-term.
21. And finally, the Department of Health and Social Care should collaborate with service providers and advocacy organisations to develop and pilot a dedicated training

programme for health and social care professionals on suicide prevention for autistic people and people who have a learning/intellectual disability.

## How can we all intervene earlier when people need support with their mental health?

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22. As many as 78% of disabled people feel that the pandemic affected their lives negatively compared to 69% of non-disabled people<sup>9</sup>, reporting marked increases in anxiety, isolation, stress, and uncertainty about the future.<sup>10</sup>
23. These are sobering figures, particularly when one considers the pre-pandemic context where more than half of Britons with a learning disability also lived with a co-occurring mental health challenge.<sup>11</sup>
24. Moreover, as COVID-19 bore out, mental health and wellbeing are inextricably linked to the present policy landscape, from meaningful inclusion and robust welfare to reliable income and housing security.
25. Today, as the cost-of-living crisis bears down on households right across the country, we have already seen how our community's mental and physical wellbeing will be disproportionately impacted by rising energy bills and food insecurity<sup>12</sup>.
26. Too often we see how people with a learning disability and autistic people face mental health inequalities; United Response would like to see a robust awareness-raising campaign aimed at people with a learning disability and autistic people, drawing on social care so that they and their care teams can recognise the warning signs of potentially developing problems in their mental health.
27. It is welcomed that in the Draft Mental Health Bill that autism will no longer be defined as a mental disorder<sup>13</sup>, but there still needs to be a culture shift within professional circles

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<sup>9</sup> Office for National Statistics. (February 2022). *Coronavirus and the social impacts on disabled people in Great Britain*. Online. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/datasets/coronavirusandthesocialimpactsondisabledpeopleingreatbritainmay2020>

<sup>10</sup> *Ibid*.

<sup>11</sup> Cooper, S.A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. "Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors." *The British Journal of Psychiatry*. 190. 2007. Pgs.27–35. Online. Available at: <https://doi.org/10.1192/bjp.bp.106.022483>

<sup>12</sup> Disability Rights UK. "Pushed to the Edge: Poverty, food banks and mental health." Online. Available at: <https://www.disabilityrightsuk.org/news/2022/march/pushed-edge-poverty-food-banks-and-mental-health>

from looking at mental health as a separate issue. Closely tied to this is the importance of recognising ‘dual diagnoses within a formal clinical framework when devising treatment plans.

28. We would also like to see the Department of Health and Social Care devise and pilot a dedicated training programme in co-production with people drawing on social care for the health and social care professionals to make mental health service provision more accessible from the outset of care journeys.
29. This should be done in conjunction with improving existing signposting across Government Departments (specifically in Education, Health and Social Care, Justice, and Work and Pensions) to relevant services so that disabled people and their families can navigate systems easier and access support quicker.
30. Social prescribing can be hugely successful as an early intervention measure, but there is limited data available to support this as a wholesale practice; as highlighted by the King’s Fund, there have only been small-scale studies to evidence impact.<sup>14</sup>
31. United Response would therefore recommend that the Department of Health and Social Care commission a large-scale study and data collection exercise to measure the impact of social prescribing, to develop a standardised evaluation framework and performance standards.
32. The pandemic highlighted the vital role that the social care workforce plays in ensuring everyone in society has a good quality of life, but after two long years of delivering care and support under restrictions and incredibly challenging circumstances, our workforce is facing poor mental health and wellbeing.
33. Stress is now one of the highest reasons for workforce absence<sup>15</sup> and this is unlikely to reduce without investment in a fast-track mental health assessment process for the social care workforce and targeted mental health and wellbeing support.

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<sup>13</sup> Department of Health and Social Care. (July 2021). *Reforming the Mental Health Act: Government Response to the Consultation*. Pg.79. Online. Available at: <https://www.gov.uk/government/consultations/reforming-the-mental-health-act>

<sup>14</sup> Buck, David and Ewbank, Leo. (November 2020). “What is Social Prescribing?” Online. Available at: <https://www.kingsfund.org.uk/publications/social-prescribing>

<sup>15</sup> Health and Safety Executive. (December 2021). *Work-related stress, anxiety or depression statistics in Great Britain, 2021*. Online. Available at: <https://www.hse.gov.uk/statistics/causdis/stress.pdf>

34. We are also echoing the Social Care Leaders' calls for a national social care workforce strategy<sup>16</sup>, with a clear need to recognise the unique vulnerability to mental health challenges that frontline social care workers face in their duties, particularly in a post-COVID context.
35. There also needs to be additional mental health resources to better support disabled colleagues and employees in the workplace through initiatives such as the Disability Confident scheme<sup>17</sup>. Similar supports should also be made available to self-employed disabled people and disabled entrepreneurs.

## How can we improve the quality and effectiveness of treatment for mental health conditions?

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36. United Response supports Dimensions' calls<sup>18</sup> for the existing Care and Treatment Review (CTR) to be carried out every six months for every person who is autistic and or has a learning disability as a statutory requirement.
37. Equally, we also believe that clear guidelines should be issued for carrying out a CTR, with a mandatory role for someone who has lived experience and monitoring of progress against a person's individual care plan.
38. As a matter of urgency, we believe the Government needs to implement the new guiding principles recommended by the White Paper on Reforming the Mental Health Act, to reform the Act's provision of services into a more person-centred system where disabled people are given better choices and accessible information around their care options.

## How can we all support people living with mental health conditions to live well?

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39. Social isolation and loneliness are key mental health challenges that disproportionately impact people who live with a learning disability<sup>19</sup> and or who are autistic.

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<sup>16</sup> Social Care Leaders. *Our vision for a future workforce strategy*. Pg.3. Online. Available at: <https://www.local.gov.uk/our-vision-future-care-workforce-strategy>

<sup>17</sup> United Response fully supports the objectives set out in the National Disability Strategy around supporting disabled people's mental health and wellbeing in work, particularly the measures around disseminating best practices for engagement to employers, Disability Workforce Reporting, and strengthening employment rights.

<sup>18</sup> Dimensions UK. (21<sup>st</sup> January 2021). "Mental Health Act White Paper – Dimensions' key points and message." Online. Available at: <https://dimensions-uk.org/press-release/mha-white-paper-key-points/>

<sup>19</sup> According to their *Loneliness after Lockdown* report (2021), Hft found that 36% of people with a learning disability surveyed post-lockdown said they felt lonely nearly always or all the time, while 37% also said that

40. We urge the Government to actively invest in anti-loneliness initiatives in communities across the UK.
41. We would also like to see investment in additional advocacy services provided to disabled people and their families at the point of need, empowering them to actively pursue redress and better care during a crisis.
42. We have concerns that the Government's proposed Bill of Rights will hurt the rights of people with a learning disability, autistic people and those with mental health conditions.
43. We are specifically anxious that by removing the clear duty of positive obligation in the Human Rights Act<sup>20</sup>, professionals will have a complex maze to navigate to protect people's rights and keep them safe. This places disabled people, who already struggle to access adequate support from what can be an inaccessible healthcare system, at particular risk of further harm and marginalisation.
44. Any modernisation of the Mental Health Act 1983 and subsequent plans should include explicit safeguards that protect disabled people's rights, namely those respecting one's decision-making capacity, individual liberty, and bodily integrity.
45. United Response echoes calls from Mencap<sup>21</sup> and the National Autistic Society<sup>22</sup> for a cross-departmental roadmap that can deliver on the Government's pledges to transition autistic people and individuals with learning disabilities from in-patient mental health units into community services.
46. Through our work we see the devastating impact disability hate crime can have on people's mental health and wellbeing, therefore we would like to see as a matter of urgency the publication of a renewed and updated Hate Crime Action Plan, that offers an

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they hardly ever or never go out to socialise (Online. Available at: <https://www.hft.org.uk/blog/loneliness-experienced-by-people-with-learning-disabilities/>).

<sup>20</sup> Scottish Human Rights Commission. (22<sup>nd</sup> February 2022). "Defending the Human Rights Act: why the UK Gov's Bill of Rights should be of grave concern to all." Online. Available at: <https://www.scottishhumanrights.com/blog/defending-the-human-rights-act-why-the-uk-govs-bill-of-rights-should-be-of-grave-concern-to-all/>

<sup>21</sup> Mencap. (13th January 2021). "Mencap responds to Mental Health Act reform proposals and calls for the Government to deliver on its promises to transform care for people with a learning disability and/or autism." Online. Available at: <https://www.mencap.org.uk/press-release/mencap-responds-cqcs-report-how-mental-health-act-code-practice-failing-people>

<sup>22</sup> National Autistic Society. (2021). "Transforming Care is failing autistic people." Online. Available at: <https://www.autism.org.uk/what-we-do/campaign/transforming-care>




explicit parity of protection to victims of disability-motivated hate crime, as recommended by the Law Commission in its recent review.

47. There must be explicit and robust protections for disabled people in the Online Safety Bill, placing a greater onus on social media companies and instilling a culture of responsible conduct to penalise harassing behaviour against disabled users on their respective platforms.

## Contact

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