

## **Written evidence submitted by Mencap (MRS0294)**

### **About Royal Mencap Society and learning disability**

We support the over 1.5 million people with a learning disability in the UK and their families to change laws and improve health and care services as well as access to education and employment.

We also directly support over 5,000 people with a learning disability to live their lives the way they want. This support goes to the heart of what we do to support people with a learning disability. A learning disability is caused by the way the brain develops before, during or shortly after birth. It is always lifelong and affects intellectual and social development.

### **Introduction**

1. Mencap welcomes the Committee's inquiry as COVID-19 and the Government's response is having a disproportionate effect on people with a learning disability across a number of areas.
2. This disproportionate impact is due to a combination of factors including the closure or reduction of access to services (such as social care), the introduction of self-isolation, social distancing and shielding, a lack of accessible information and potential discriminatory treatment by health and other services.

### **Equal access to critical care**

3. We remain concerned about the ability of people with a learning disability to access healthcare and the potential for treatment to be denied, or wrongly treated as a lower priority due to their disability.
4. The lack of clarity from the Government around preventing the deprioritisation of people with a learning disability and other disabilities for life saving treatment is deeply concerning. Guidance and health sector publications, such as the British Medical Association's 'Ethical Guidance Note', which discusses the legality of indirect decision making at this time, only fuel this thinking rather than highlighting the right to equal healthcare.
5. The Government must make clear that given the available capacity within NHS critical care, no deprioritisation should be taking place. It must also provide clear guidance on how decisions should be made in cases where there are concerns with regards to capacity.
6. After challenges from Mencap and other organisations and campaigners, NICE updated their guidance on critical care for COVID-19 to clarify that the Clinical Frailty Scale should not be used to assess people with learning disabilities and/ or autism.
7. This is a welcome but we continue to see examples, especially in primary care, of the frailty scale being applied inappropriately and believe more action is needed to bring attention to this issue.
8. One such example is the encouragement of some social care services, and individuals, to consent to 'Do not resuscitate' decisions. An example from one surgery (for which the practice has since apologised) clearly references the Clinical Frailty Scale:

9. *“..we know that anyone who is frail enough to require full time care is unlikely to benefit from mechanical ventilation and that this is therefore unlikely to be offered in hospital. We would much prefer to keep your loved one in (name of setting) and provide them with the best care possible there, including good end of life care, if it becomes clear they are not going to survive the infection. If residents become unwell, we will endeavour to provide the best supportive care we can, with support from the community and palliative care teams.”*
10. While we welcome letters of clarification from NHSE England making clear that this behaviour is inappropriate and that the use of any blanket policy around DNACPR would be discriminatory, we continue to see examples of these letters arriving at services and individual’s doorsteps. We have also be made aware of several examples where individuals with a learning disability have received calls to their mobile phones from a GP surgery to have conversations around this topic.
11. Conversations about advanced care planning are important for those for whom it is clinically relevant. However, we do not believe that people with a learning disability, with no other clinical indication that their life may be limited, should be singled out to make these kinds of decisions. These conversations, where appropriate, need to be conducted sensitively, in accordance with the Mental Capacity Act: including making reasonable adjustments to communication, and involving those close to the patient as required by the law.

### **Access to everyday healthcare**

12. While COVID-19 is rightly consuming the attention of the NHS, people’s everyday health needs still need to be met. It is well understood that in ‘normal’ circumstances, both children and adults with a learning disability and/or autism are at risk of missing out on the healthcare they need, due to a number of factors, including diagnostic overshadowing, delays to diagnosis and treatment, failure to make reasonable adjustments and failure to comply with the Mental Capacity Act. In this new landscape are extremely concerned that people with a learning disability needing to access health care will be at even greater risk.
13. People with learning disabilities may not be able to communicate verbally, and/or may have difficulty expressing pain or discomfort. They may also struggle to navigate healthcare systems, including services such as 111. The Government must ensure necessary reasonable adjustments remain a priority for this group.
14. For many people with a learning disability or autism, having someone who knows them well with them in hospital can be a vital reasonable adjustment. Recent guidance from NHS England made some welcome steps allowing an exception for people with ‘mental health conditions’ including learning disability and/or autism’ to have visitors<sup>1</sup>. However, we have yet to see whether this guidance will be communicated effectively to healthcare professionals, and to families.
15. Conversely, services must not rely on an individual being able to be accompanied. In some circumstances family members will not be able, nor willing to attend, and due to impacts of coronavirus on staffing levels, and infection risks, there are likely to be circumstances where supporters are unable to accompany a patient.

16. Services must be able to meet the basic needs of people with a learning disability by utilising aids such as hospital passports and ensuring they have relevant contact details. Healthcare staff must be able to access support to meet the needs of a patient that go beyond their ability, for example by seeking the support of a Learning Disability Nurse.
17. People with a learning disability, and their families and supporters, must be reassured that they will not be discriminated against due to a disability. Without reassurance families and supporters might discourage people with a learning disability from attempting to access health services for fear that their needs will not be met, or that they may not receive treatment. The Government must provide clear guidance to reassure families/supporters.
18. Many people with a learning disability have long term health conditions, such as epilepsy or diabetes, and/or require extra support to remain healthy. There is a growing body of anecdotal evidence which suggests that many people with a learning disability are struggling to access the support and healthcare they need, in a timely manner, resulting in later presentation and more severe deterioration of symptoms. It is vital that, at this time when so much focus is on COVID-19, individuals still receive the support they need from their supporters, community healthcare professionals and general practice.

### **Access to social care**

19. As both a campaigning organisation and a social care provider we are deeply concerned about the impact that the measures taken to combat COVID-19 will have on access to social care for people with a learning disability.
20. We are already seeing a number of local authorities implementing the easements permitted under the Coronavirus Act and expect many more to do so over the coming weeks.
21. The easements change the requirements on local authorities from having a 'duty' to provide social care to having a 'power'. This dramatically reduces the hard fought for gains made in the Care Act 2014.
22. These easements allow local authorities to use a very high threshold when assessing who requires social care. This high bar is based on preventing breaches to an individual's human rights under the European Convention on Human Rights. Government guidance lists Article 2 (the right to life), Article 3 (the right to freedom from inhuman and degrading treatment) and Article 8 (the right to private and family life) as examples of breaches local authorities must prevent.
23. The setting of this high bar is likely to impact the social care received by many people with a learning disability who receive 'non-personal care' social care. This type of social care often includes support to manage finances, access healthcare and access social and leisure activities.
24. Any reduction to these services is likely to increase issues around loneliness and isolation which people with a learning disability are already more likely to experience than the general population<sup>2</sup>.
25. The provision of accessible information is required under the Care Act 2014 and Equality Act 2010 but we have not had clarification from local authorities that communications

around the activation of easements or reduction in support will be provided in accessible formats.

26. While the provision of a clear pathway for individuals to challenge a (re)assessment decision under the Care Act easements is affirmed in the Government's guidance on the Care Act easements<sup>3</sup>, the Local Government and Social Care Ombudsman's announcement to stop investigations significantly weakens individuals' opportunities to pursue such a challenge.
27. The Government and local authorities must provide clarity on how this pathway would work in practice especially given that the easements are designed to be used when a local authority is under considerable strain. Additionally, other support avenues such as helplines and legal assistance are facing a surge in demand reducing their capability to pick up the slack from the Ombudsman's decision.
28. Access to testing for people with a learning disability and the staff who support them has been treated largely as an afterthought by the Government.
29. The initial rollout of the testing was disjointed and difficult to understand with local authorities running tests in some areas, the CQC in other areas and the military providing mobile testing centers. These testing centers required people to travel them however, this can be difficult for social care workers who are working increased hours, on low pay, have reduced access to public transport and many do not have access to a car.
30. We welcome the more centralized approach as well as the increase in testing capacity but are concerned that demand still vastly outstrips supply and that people with a learning disability could be put at the back of the queue in any prioritization of testing even though many people with a learning disability are in the high-risk category.

### **Easements to the Mental Health Act**

31. While easements to the Mental Health Act (MHA) have not been activated, we have concerns about the impact they could have.
32. Already people with a learning disability are sectioned inappropriately under the MHA<sup>4</sup> meaning they are ending up in inpatient units when they should be supported in the community. We know that people with a learning disability are at increased risk of neglect and abuse in these settings, including misuse of restraint and overmedication and neglect of physical health needs. With likely staff shortages during the pandemic, people with a learning disability are likely to be at increased risk in these settings. We are also very worried about the direct risk of COVID-19 and whether people with a learning disability will be able to access appropriate timely treatment if they are infected in these settings.
33. While we welcome the mention in the Government's guidance on MHA easements that extra considerations should be provided to people with a learning disability, the language is not tight enough to prevent the misuse of these easements.
34. In particular, the power for individuals to be sectioned by only one medical professional rather than two (one of which should be acquainted with the individual) is deeply concerning. This is especially the case as the guidance only outlines that a "relevant expert should be consulted" rather than must.

35. We are also concerned about the weakening of safeguards around medication, if the MHA easements are switched on. Where someone does not consent to their medication, the requirement for a second opinion from a second opinion appointed doctor (SOAD) is relaxed.
36. This potential change, combined with any reduction in people's care services due to easements to the Care Act, could lead to crisis situations and unnecessary in-patient admissions. This would of course go directly against the objective of the Government's Transforming Care programme.
37. We are also concerned that Care and Treatment Reviews for people with a learning disability – which are regular independent reviews brought in under the Transforming Care programme - will not be effective during the pandemic because they are happening 'virtually' and likely with reduced capacity.
38. We are concerned that potential for these MHA powers to be used for up to 2 years could see people with learning disabilities spending significant time in inpatient units without proper review by an objective external clinician who has expertise around learning disability and the right community support. Before this crisis, the average stay of a person with a learning disability is around 5 years and more must be done to ensure that no person with a learning disability faces this length of stay.

#### **Monitoring, role CQC and access to independent advocacy during the pandemic**

39. The Government must review the impact of the easements on people with a learning disability, and at the 6 month Parliamentary review remove easements (particularly the MHA easements) found to not be required or those which are having a detrimental impact on the health and wellbeing of people with a learning disability.
40. In the short-term, we have concerns about the ability of the Government to monitor the use of the easements unofficially by local authorities and the impact they are having.
41. We are also concerned by reports we are hearing from individuals in local authorities which have not officially activated the easements but are informing people about reducing their care along the same lines as the easements. This action is unacceptable. LAs continue to have a duty to meet people's eligible needs under the Care Act if they have not activated the Care Act easements. This means that if day services close etc. then they need to explore alternatives with the individual and their family to ensure the person's needs are met e.g. creative options using direct payments.
42. The Secretary of State for Health and Social Care has the power to withdrawal the Care Act easements at his leisure and we urge him to reinstate the full duties of the Care Act as soon as possible. The easements must only be temporary and not become the new norm.
43. With the CQC suspending routine inspections we have concerns about ensuring the quality of care people are receiving, particularly with regards to in-patient units. This decision weakens safeguards put in place to ensure that people within settings such as in-patient units are protected from poor treatment and in the worst-case scenarios subjected to abuse, over medication and unnecessary physical restraint.

44. In addition we are concerned about access to effective independent advocacy during the pandemic. The Coronavirus Act has not made changes to duties around statutory advocacy. Care Act advocates, Independent Mental Health Advocates, and Independent Mental Capacity Advocates all have crucial roles in helping to ensure the human rights of people with a learning disability are upheld.
45. We have heard examples of face-to-face meetings with advocates mainly being on hold with advocates using phone calls and video calls where these are meaningful. However, there will be many people with a learning disability for whom these will not be meaningful, and for whom face-to-face advocacy where an advocate can pick up cues from the environment will be very important. It is vital that reasonable adjustments are made to enable effective advocacy during the pandemic and it is important the Government is monitoring this situation.

### **Increased isolation**

46. People with a learning disability are seven times more likely to be socially isolated and our survey found that just 30% of young people with a learning disability spend more than one hour outside of their home on a Saturday (before the current crisis)<sup>5</sup>.
47. Like everyone else, people with a learning disability have seen their daily routines and support networks completely altered as places of activity and leisure shut and face to face contact is not possible.
48. This is having a disproportionate effect on people with a learning disability who might not understand what is happening, can find it hard to adapt to sudden change and are less likely to have access to technology to keep in touch with loved ones and friends.
49. As the lockdown measures continue, the Government must turn its attention towards tackling the issues of isolation and loneliness which we know have a huge impact on mental and physical health. It is crucial that support is provided for projects aimed at tackling loneliness and isolation.
50. We are stepping up our efforts through working with external organisations and launching new initiatives such as Mencap TV, to provide people with activities and entertainment.

### **The pandemic is exposing inequalities**

51. It is of great concern that it has taken campaigners, charities and lawyers to highlight the deeply concerning issues outlined in this submission. At such a worrying time people should be able to trust that national and local policies and practices are robustly underpinned by the Human Rights Act and Equality Act.
52. We welcome the Committee's monitoring of the impact of Coronavirus on people with a learning disability and their families during and in the aftermath of the pandemic and we would be happy to provide further evidence at other stages.

April 2020

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<sup>1</sup> [https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0030\\_Visitor-Guidance\\_8-April-2020.pdf](https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0030_Visitor-Guidance_8-April-2020.pdf)

<sup>2</sup> <https://www.mencap.org.uk/press-release/people-learning-disability-seven-times-likely-be-lonely-christmas>

<sup>3</sup> <https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities>

<sup>4</sup> <https://www.mencap.org.uk/press-release/mencap-responds-cqcs-report-how-mental-health-act-code-practice-failing-people>

<sup>5</sup> <https://www.mencap.org.uk/press-release/almost-1-3-young-people-learning-disability-spend-less-hour-day-outside-homes-survey>