

A photograph of two women sitting in a room. The woman in the foreground is a woman of South Asian descent with dark hair, wearing a bright yellow top and a red beaded necklace. She is looking off to the side with a slight smile. The woman in the background is a white woman with blonde hair, wearing a black and white striped shirt, also looking off to the side. A large, semi-transparent red circle is overlaid on the bottom half of the image, containing the title and subtitle.

..... **My Health, My Life:**

Barriers to healthcare for people
with a learning disability during
the pandemic



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Care for people with a learning disability in hospital

Reasonable adjustments are vital to accessing healthcare for people with a disability. These can be relatively simple things, such as waiting in a quiet area or being accompanied by a supporter on an overnight stay in hospital, or quite complex adjustments, requiring whole teams to work together and do something very differently. Sometimes these adjustments need specialist input.

Reasonable adjustments are a requirement of the Equality Act 2010²². This law has remained in place throughout the pandemic and was not impacted by 'easements' in the Coronavirus Act.

It is known that a lack of adjustments to care even in 'normal' times can have fatal consequences for people with a learning disability.

In the CIPOLD report in 2013, it was found that a lack of reasonable adjustments to care had contributed to a significant number of deaths²³. The LeDeR 2019 report showed that people with a learning disability were four times more likely to die of a treatable healthcare condition, and that despite some pockets of excellent practice, a lack of reasonable adjustments remained one of the biggest reasons why people with a learning disability can still find it difficult to access care²⁴.

With the situation already critical before the pandemic, the level of risk for these kinds of poor outcomes and ultimately avoidable deaths during the pandemic cannot be underestimated.

When admitted to hospital during the pandemic, some people with a learning disability have not been given the level of support they need, as reasonable adjustments have in many cases been limited as part of the emergency response to COVID-19. Though this may appear an understandable consequence during times when the health service is exceptionally stretched, a careful balance must be found between emergency response and best practice, in order to protect one of the most marginalized patient populations in the UK.

Many nurses surveyed by Mencap were critical of the care that has been given to people with a learning disability during the COVID-19 pandemic, with one participant remarking, "Unfortunately the support I have witnessed in hospitals falls very short of even basic nursing care."²⁵

Only 1 in 5 LD nurses surveyed said they had always seen reasonable adjustments made for people with a learning disability.²⁵

References

²²Equality Act 2010: <https://www.legislation.gov.uk/ukpga/2010/15/contents>

²³Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) (2013): <https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>

²⁴Learning Disability Mortality Review (LeDeR) Annual Report (2019): http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

²⁵Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

Some nurses suggested that this is due to the exceptional demands placed on healthcare services throughout the COVID-19 pandemic, with one participant commenting, “I fear that taking the extra time to ensure reasonable adjustments may not be a priority.” As such, a couple of nurses argued that “More learning disability nurses working within acute services would benefit the NHS.”²⁶ Specialist learning disability support was also one of the most requested reasonable adjustments highlighted by the LeDeR report²⁷.

What is reasonable?

There is no set definition of exactly what ‘reasonable’ means. So to calculate this, organisations take in mind the practicality of the change, and the resources involved, and whether making the adjustment might disadvantage others.

Some adjustments, for example, may require changes to stringent infection control policies - if someone’s treatment required multidisciplinary teams to work together (potentially from different locations within the hospital). We do not believe that every Trust would consider these changes reasonable in the current circumstances – however, they may be crucial to providing equal healthcare for someone with a learning disability.

The way the NHS has functioned during the pandemic has been fundamentally different, and patients have been given little information about how to navigate the new landscape. It has been difficult for patients and those who support them to know what to expect, and even what support they can ask for at this time. Equally it has been difficult to know when to challenge and when not to.

For example, we have encountered questions such as, ‘If my loved one requires 24 hour care, and has to go to A&E, is it ok for the hospital to say they cannot be accompanied?’²⁸. Things that in normal times would have automatically triggered people to raise the alarm, may simply have been accepted during the pandemic, or only questioned later.

Though some adjustments may no longer be considered ‘reasonable’ during the pandemic, and a certain amount of procedural change is crucial to keeping everybody safe, not delivering reasonable adjustments, such as support for patients who require 24-hour care or communication support, places them at increased risk of poor outcomes from diagnosis or treatment.

COVID-19 has created extra risk that people may need to attend hospital unaccompanied, and infection control measures may have made it more likely that items such as hospital passports and other important communication aids are lost. This will have created extra barriers to people’s support needs even being flagged to hospital staff in the first place.

References

²⁶Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

²⁷Learning Disability Mortality Review (LeDeR) [Annual Report \(2019\): http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf](http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf)

²⁸Enquiry to Mencap Helpline

Many healthcare staff have been also redeployed throughout the NHS and may be working in unfamiliar environments, stressed and exhausted – making it harder for them to make adjustments to the care they’re providing under such pressures. Among those redeployed were a number of learning disability nurses, meaning that in some trusts, there may have been a lack of specialist support for patients needing adjustments to their care. Around 11% of acute learning disability nurses we surveyed said they or a team member had been redeployed; for community based learning disability nurses it was 34%.²⁹ One nurse commented, “I was redeployed for four weeks to [another] ward. During this period there was no specialist learning disability service provided across the Trust.”

Numerous participants in the survey also said that a reduction in respite and community-based services had resulted in patients and families being left without support, which they believe has led to a deterioration in mental and physical health, and even to crisis in some cases.

References

²⁹ Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife