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My Health, My Life:

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

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Thank you



We would like to say a huge thank you to all of the people who shared their story with us.

It is important that people with a learning disability get the right access to better healthcare, reasonable adjustments and support to communicate.

Treat me well is Mencap's campaign to transform how the NHS treats people with a learning disability. The campaign is steered by a group of experts by experience. The steering group make sure the voices of people with a learning disability are at the heart of decisions, and make sure the campaign is inclusive and accessible.

The changes of the rules and regulations surrounding COVID-19 have been very confusing. COVID-19 is dangerous. There is not enough information that is accessible to people with a learning disability. We feel the government doesn't care about us. They categorise us as vulnerable and this is unfair.

During the COVID-19 pandemic, asking for reasonable adjustments has been confusing. Reasonable adjustments are really important to make sure people with a learning disability get equal access to healthcare and stay fit and healthy.

We want healthcare professionals to continue to make reasonable adjustments, including making information Easy Read, longer appointments and priority appointments for people with a learning disability.

Some virtual appointments can make people feel uncomfortable or they may need extra support with using technology. We want to feel reassured that healthcare professionals, understand us, we don't want to miss anything. It's also very frustrating as it's hard to communicate with people wearing PPE (personal protective equipment), it can be a scary experience.

We should be treated with respect as individuals.
We should be allowed to make our own decisions.
Healthcare professionals often do not listen to us
and this can have serious consequences.

This report will help us continue to raise awareness of the healthcare needs of people with a learning disability. Most importantly we would like the government and the NHS to listen to people with a learning disability.

We want our Treat me well campaign to continue to give people with a learning disability a voice.

The Treat me well steering group

The Treat me well steering group is made up of people with learning disabilities. They make key decisions about Mencap's Treat me well health campaign and ensure the campaign is inclusive.



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Introduction



Healthcare has been a focus of Mencap's campaigning for decades. While health bodies have moved some way to addressing inequalities in recent years, progress has been frustratingly slow in ensuring that people with a learning disability have access to the same health care and outcomes as the rest of the population.

Now, during the COVID-19 pandemic, people with a learning disability are facing further barriers in access to equal healthcare.

Data released in November 2020 shows the devastating impact of the pandemic, with the rate of people with a learning disability dying from COVID-19 estimated to be 3 – 4 times the rate in the general population¹.

And shockingly, when comparing deaths in populations with the same age and sex, the death rate for people with a learning disability could be as high as over 6 times the general population².

The data also highlights the disproportionate impact on people with a learning disability from Black, Asian and Minority Ethnic (BAME) backgrounds³.

As with the general population, there is far more to the story than the death toll. This report explores the healthcare experiences people with a learning disability have had throughout the pandemic so far, and the key role of government policy and guidance in shaping this. Many people with a learning disability have felt let down by a systematic lack of inclusion.

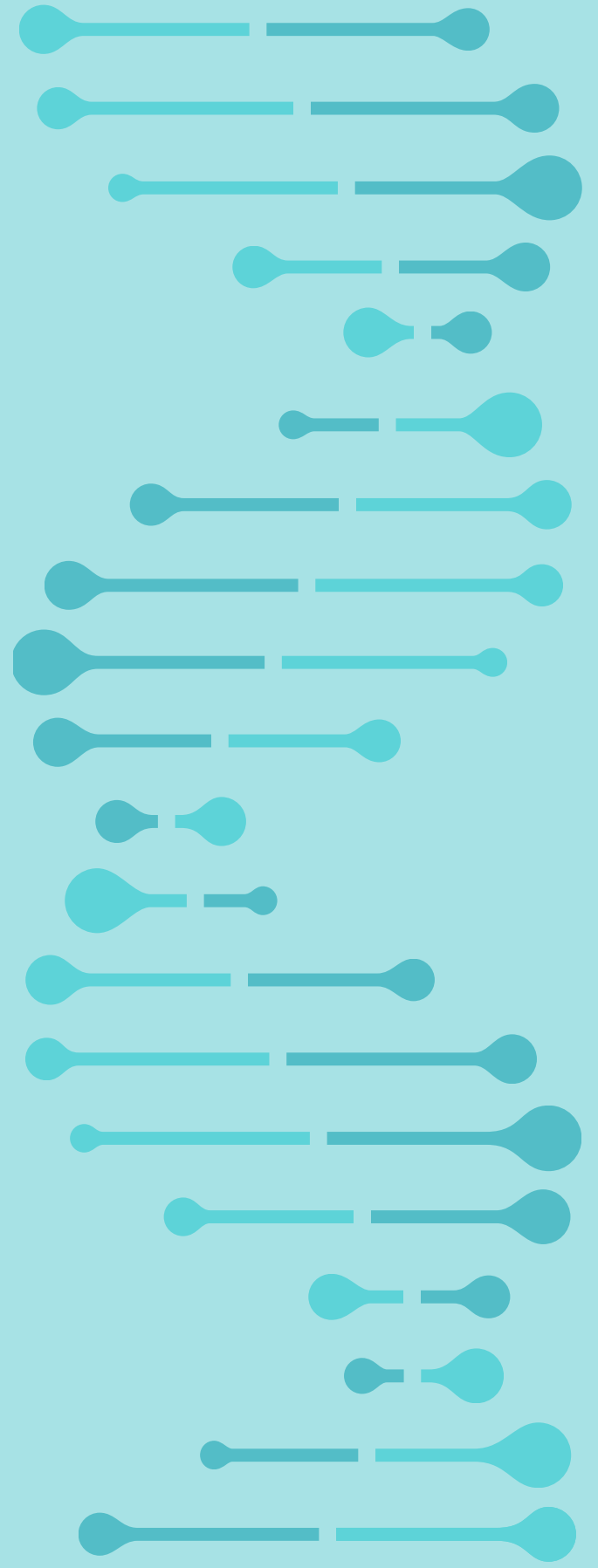
Many factors have contributed to the disproportionate number of deaths of people with a learning disability during COVID-19, and this will leave a lasting mark on the health and wellbeing of people with a learning disability well into the future.

References

¹Public Health England (2020) [COVID 19 deaths of people identified as having learning disabilities: summary](#). These figures are based on deaths reported the Disabilities Mortality Review (LeDeR) programme, and deaths in hospitals from NHS England's COVID-19 Patient Notification System (CPNS), and are adjusted for under-reporting.

²Standardising for age and sex, the rate of COVID-19 deaths notified to LeDeR, from 21st March to 5th June 2020, was 4.1 times the rate for the general population. Adjusting this for under-reporting, the rate is estimated at 6.3 times the general population rate.

³The proportions of COVID-19 deaths for people with a learning disability who are Asian or Asian British, or Black or Black British, were around 3 times higher than the deaths from all causes in these groups in the corresponding period of the previous 2 years.



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Healthcare pre-COVID-19

Evidence shows that long before the coronavirus pandemic, people with a learning disability experienced shockingly high levels of health inequality. The 2019 Learning Disability Mortality Review (LeDeR) report reflects the picture before COVID-19 hit the UK, showing that in 2019, the difference between the age of death for people with a learning disability and the general population was 22 years for men and 27 years for women.

Additionally, people with a learning disability from BAME groups were disproportionately dying at a younger age – 43% of children with a learning disability who died in 2019 were from BAME communities⁴.

Furthermore, 1,200 people with a learning disability die avoidably every year when timely access to good quality healthcare could have saved them⁵.

Over the last three years, Mencap's Treat me well campaign⁶ has aimed to transform how the NHS treats people with a learning disability. Its goal is to find solutions to healthcare inequalities, and bringing about practical changes, so people with a learning disability always get the treatment they need and the equal access to healthcare that is their right.

Main focuses of the original Treat me well campaign included training for healthcare professionals, reasonable adjustments within healthcare settings, and empowering people to work with their Trusts to make change happen locally.

The biggest achievements of the campaign to date have been to support the establishment of campaign groups of people with a learning disability across England who are working to change things in their local areas, as well as supporting Paula McGowan's successful campaign to secure mandatory training for all health and care staff across England. The Oliver McGowan Mandatory Training in Learning Disability and Autism, named after Paula's son who died avoidably in hospital in 2016, is in the first stages of being piloted⁷.

As well as training, other, potentially transformational changes have been highlighted as part of the NHS 10 Year Plan, including new learning disability improvement standards and a new flagging system. However, these important system wide changes could be years away from being fully implemented, and sadly we continue to see evidence of inadequate and potentially discriminatory practice in some parts of the NHS, and avoidable deaths of people with a learning disability. Urgent action was needed long before the COVID-19 pandemic to prevent further lives being cut short by this inequality.

References

⁴Learning Disability Mortality Review (LeDeR) Annual Report (2019): http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

⁵Glover, G. and Emerson, E. (2013), "Estimating how many deaths of people with learning disabilities in England could be prevented by better medical care", [Tizard Learning Disability Review](#), Vol. 18 No. 3, pp. 146-149.'

⁶Treat me well campaign report (2017): <https://www.mencap.org.uk/sites/default/files/2018-07/2017.005.01%20Campaign%20report%20digital.pdf>

⁷'Right to be heard': The Government's response to the consultation on learning disability and autism training for health and care staff (2019): https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/844356/autism-and-learning-disability-training-for-staff-consultation-response.pdf

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Healthcare for people with a learning disability during the COVID-19 pandemic

With this widespread and shocking inequality as a backdrop, the healthcare sector was subsequently hit by the COVID-19 pandemic. This resulted in a range of new and heightened problems for people with a learning disability in healthcare settings, despite the unstinting efforts of medical and nursing teams up and down the country who have been addressing the Coronavirus pandemic.

Evidence has been building throughout 2020 showing the devastating impact of COVID on the people with a learning disability;

- The Learning Disability Mortality Review (LeDeR) released an initial report in May highlighting concerns about the care some people received⁸.
- This was followed in June by a CQC report that showed a 134% increase in the number of death notifications for disabled people at the height of the pandemic⁹.
- The Office for National Statistics (ONS) then released further data in September that showed disabled people made up 60% of all deaths involving COVID-19 for the period to July 2020¹⁰.

But the shocking death figures only tell part of the story. The troubling healthcare experiences and inequalities that people with a learning disability have faced during this pandemic are outlined in this section, alongside the impact this has had on them and their loved ones.

The data and case studies collected in this report clearly demonstrate that official healthcare guidance around healthcare for people with a learning disability during the COVID-19 pandemic has been unclear, inconsistent, and in some cases unlawful. There have been multiple examples of poor guidance that has exacerbated existing difficulties accessing health services, and put the 1.5 million people with a learning disability in this country at risk of serious harm.

Despite all the research and all the data, people with a learning disability continue to lose their lives because of unacceptable barriers to healthcare. We need urgent action to address this now. This report makes recommendations on what we need to do to address these enduring health inequalities.

References

⁸Learning Disability Mortality Review (LeDeR) Annual Report (2019): http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf

⁹CQC data on deaths with people with a learning disability: <https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability>

¹⁰<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/2marchto14july2020>



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Guidance on Ambulance Transports

Many urgent admissions to hospital begin with a call to 999, and a journey by emergency ambulance. This first step in the admissions process is an important opportunity to get a fuller picture of someone's medical history and support needs.

This is particularly crucial for many people with a learning disability, who are dependent upon family and paid supporters to communicate, understand their environment and ensure their support needs are met. These people may struggle to pass on information about their medical history and to communicate with healthcare professionals. This means that during a hospital admission, or a trip to A&E, it is **absolutely essential for many people with a learning disability that they are able to be accompanied by someone that knows them well.**

However, throughout the pandemic, guidance on transporting patients to hospital by ambulance has meant that adults with symptoms of coronavirus (including a temperature) **could not be accompanied when travelling to hospital by emergency ambulance.** This places someone with a learning disability at significant risk of their support needs going unmet, and **creating heightened levels of anxiety and distress.**

The guidance states: 'Non-essential persons (such as observers, family members) are not to travel within the patient compartment with a possible or confirmed case [of COVID-19], unless the patient is a child who requires conveyance, in this case it is acceptable for a parent or guardian to accompany the child.'¹¹

There is no definition of 'essential' or 'non-essential' persons provided within the guidance, so whether a support worker or essential carer would be recognised is down to personal judgement of the healthcare professionals involved, and in many cases, luck.

Mencap Learning Disability Nurse Survey

In order to gather information on how healthcare for people with a learning disability was being affected by COVID-19, Mencap ran a survey with 239 learning disability nurses working in an acute hospital or community based role. The survey ran for 2 weeks from 17/06/2020 to 01/07/2020. This report draws on the data and experiences found in the survey.

A number of nurses who took part in the Mencap learning disability nurse survey have witnessed instances where family members and support staff were not allowed to accompany a patient with a learning disability onto a hospital ward. One nurse recounted a time "when ambulances took someone in hospital [and] no one was allowed to accompany them. They weren't allowed to take any paperwork with them, so no hospital passports or drug charts."¹²

References

¹¹COVID-19: Guidance for Ambulance Trusts (2020): <https://www.gov.uk/government/publications/covid-19-guidance-for-ambulance-trusts/covid-19-guidance-for-ambulance-trusts#conveyance-and-patient-handover>

¹²Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

..... Hospital Passports

A hospital passport provides important information about a patient with a learning disability, including personal details, the type of medication they are taking, and any pre-existing health conditions.

The passport also includes information about how a person communicates and their likes and dislikes, which can be very important when they are first admitted to hospital.

Hospital passports allow health staff to the needs of the individual, and help them make the necessary reasonable adjustments to the care and treatment they provide.

When the people who regularly support a person with a learning disability are not only unable to accompany the patient on the frightening journey to hospital, but also unable to even share vital information such as medications and support needs, this places the patient in significant danger.



Hospital visiting guidance and support for people with a learning disability.

For someone with a learning disability, who may have difficulties in communicating what is wrong with them and understanding healthcare information, having the right person there to provide support and assist with communication can mean the difference between a successful intervention and a distressing, or even life-endangering event. With PPE and new procedures creating potentially challenging situations for people with a learning disability, this support is more important now than ever.

Though the exceptional circumstances of COVID may mean visiting policies have to change to keep everybody safe, there must be flexibility when considering the needs of those with a learning disability. Allowing visitors to accompany someone with a learning disability in healthcare settings, and especially in hospital, is a vital reasonable adjustment.

1 in 4 LD nurses surveyed said they had seen examples where people with a learning disability have not been allowed to be accompanied by a family member, carer or supporter in hospital¹³.

Guidance from NHS England issued on the 25th of March stated only three exceptions would be made to blanket bans on visitors, none of which were applicable to people with a learning disability¹⁴. The guidance was revised on the 9th of April, and made some welcome steps allowing an exception for people with 'mental health conditions' including learning disability and/or autism to have visitors to avoid 'distress'¹⁵. This was then superseded by further guidance issued in May which included exceptions for those in attendance to support the needs of any patient, following representations from disabled people with physical impairments.

Despite these updates showing some progress, Mencap continued to have concerns about how effectively these updates were communicated to healthcare professionals, and to families, and whether services were meeting the expectations of the guidance. We are unable to assess how widespread failure to adhere to these guidelines has been, but the Mencap helpline continued to receive calls on this subject in the months which followed the updated guidance.

Prior to the updates, we saw several examples in which people with a learning disability were not allowed visitors which we believe contributed directly to the poor outcomes experienced in these cases. We also continue to see examples of healthcare professionals interpreting the same guidance in different ways, even within the same hospital setting.

References

¹³Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

¹⁴25th March visitor guidance: <https://www.england.nhs.uk/coronavirus/publication/visitor-guidance/>

¹⁵9th April Visitor guidance: http://www.yhscn.nhs.uk/media/PDFs/mhcn/Dementia/Covid%2019/C0030_Visitor-Guidance_8-April-2020.pdf

The most recent version of the visiting guidance was released on 13th October¹⁶, and Mencap is extremely concerned by its contents. There is no specific mention of the duty to make reasonable adjustments for disabled people, nor any reminder to hospital staff of the importance of allowing disabled people to access any support they might require from family or paid support staff.

The accompanying decision making tool suggests that in any areas rated Tier 2 or 3, visiting can be suspended on recommendation of the Trust Incident Management team, but makes no mention at all of adjustments to this policy for disabled people. Mencap believes this fails to appreciate the huge importance of family members and carers supporting people with a learning disability in hospital. Despite Mencap raising concerns, at time of writing, no updates to the guidance published on the NHS England website have been made.

References

¹⁶Visiting healthcare inpatient settings during the COVID-19 pandemic: principles (13/10/2020): https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0751-visiting-healthcare-inpatient-settings-principles-131020_.pdf

Peter's Story



Peter has a learning disability, and is an Inclusion Consultant for Mencap.

I was in and out of hospital many times from December last year up to August this year, having surgery for hydrocephalus. Back in December I had one of my family by my bed most of the day. This was comforting and helped me deal with questions from doctors and nurses.

But when I went into hospital in June this year in the middle of the COVID pandemic things were very different. For the first few weeks it was especially hard because I was not allowed any visitors at all. The only way I could talk to family members was through Facetime or telephone. I found it very hard with no visitors and in a ward full of older people who were not my age. Visitors are important for people with a learning disability because for me it was very important to be able to see people who know me and can help me.

The staff who treated me were brilliant and very kind, but the problem was that some staff interpreted the rules differently than others. Towards the end of my time in hospital I was thankfully able to see one of my family for an hour each day. This was helpful, comforting and reassuring. But it could have been more.

The hospital visitor rules are still causing problems for people with a learning disability even now.

I have a learning disabled friend who has had to go into hospital very recently. At the beginning his carers were not allowed to go with him into the ward. Not having carers will have caused him great difficulty in understanding what was happening to him.

This problem was also caused by different staff applying the guidance that is in place differently. The staff are doing incredible work helping people every day under very difficult circumstances, but when they interpret the rules differently this causes real difficulties for patients with a learning disability and can affect their quality of treatment.

More understanding and empathy needs to be shown to people with a learning disability by allowing family and carers to come in and help them on wards in hospital. It needs to be underlined to staff that people with a learning disability may struggle to understand or question the condition they are in and the treatment they are receiving. Likewise, some people with a learning disability left by themselves may struggle to explain to staff if they are in pain or having any other problems.



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**Guidance advised
healthcare
professionals to
withhold intensive
care treatment
for people with a
learning disability**

Early on in the first wave of the pandemic, the National Institute for Health and Care Excellence (NICE) published new guidance on the treatment of patients in critical care, grading those patients on a Clinical Frailty Scale. These guidelines suggested that those who can't do everyday tasks like cooking, managing money and personal care independently – all things that people with a learning disability often need support with – would be considered frail, and as a result might not receive intensive care treatment¹⁷.

Mencap immediately responded to NICE with our concerns, and the guidelines were revised in April to make it clear that the Clinical Frailty Scale should never be used to assess patients aged under 65, or patients of any age with stable long-term disabilities (for example cerebral palsy), learning disabilities or autism¹⁸.

However, the original NICE guidance had ongoing damaging consequences. By the time clarification to the Clinical Frailty Scale was sent out, it came to Mencap's attention that many perfectly healthy individuals received letters from their GPs recommending they think carefully about whether they would want resuscitation if they went into hospital or would even want to be treated in hospital at all, should they get Covid-19.

“DNACPRs are constantly being put in place for people with LD and often inappropriately... [We] challenge them daily but still these are happening.” - learning disability nurse, surveyed June / July 2020¹⁹.

54% of LD nurses surveyed said that there was a moderate or high risk of people with a learning disability receiving an inappropriate DNACPR²⁰.

This represents a clear illustration of the discrimination many people with a learning disability face in the healthcare system. These notices would deny a person potentially life-saving treatment based on their learning disability – an act of discrimination which was unlawful. Mencap challenged this, NICE amended their guidance, and NHS England wrote a letter to all NHS Trusts, CCGs and GPs to address this and set out good practice²¹.

It is important to note, however, that even in cases when Mencap's concerns were listened to and acted upon, the lack of clarity surrounding the updates to guidance may have led to some healthcare professionals continuing to follow the original discriminatory guidelines. The drive to protect the NHS and prevent hospitals being overwhelmed at the height of the pandemic led to some poor implementation and discriminatory practices.

References

¹⁷Press release 22/03/2020: Mencap responds to “deeply troubling” new NICE COVID-19 guidance: <https://www.mencap.org.uk/press-release/mencap-responds-deeply-troubling-new-nice-covid-19-guidance>

¹⁸Press release 02/04/2020: Mencap responds to revised critical care guidance from NICE: <https://www.mencap.org.uk/press-release/mencap-responds-deeply-troubling-new-nice-covid-19-guidance>

¹⁹Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

²⁰Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

²¹<https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/maintaining-standards-quality-of-care-pressurised-circumstances-7-april-2020.pdf>

Worryingly, many individuals with a learning disability may still have DNACPR notices on their records without their knowledge, which could have tragic consequences for their future healthcare.

Despite official communications being sent out around best practice, Mencap's helpline in England is still receiving reports that DNACPRs are still being placed on people's records without their consent today, eight months after the first report of this occurring.

We welcome the review that the Health Secretary in England has commissioned from the Care Quality Commission. At the time of writing, CQC's interim report on use of DNACPR during the pandemic has reinforced concerns expressed by people with a learning disability, their families and care providers.

Steven's Story



Steven is 43 and has Down's syndrome, and normally lives in a supported living service. In March, he was admitted to hospital by ambulance after his temperature increased and he was found to have COVID. After recovering enough to return home, Steven deteriorated again, and had to be admitted to a different hospital.

After Steven had been admitted for a couple of days, his dad John recounts receiving a phone call saying Steven would not be given a ventilator if he needed one.

"I received a call from a doctor who told me that a decision had been taken - should Steven require the use of a ventilator then this would be denied. I was exercising in the park at the time of the call and had to find a bench to sit down - I was really taken aback.

When I asked why, the doctor told me that Steven had 'underlying issues'. It is true that Steven had been diagnosed with vasculitis last December and he'd undergone treatment which affected his immune system, but other than this, he was perfectly healthy, and his treatment was going well."

After receiving this stressful call, John phoned the doctor at the original hospital who was treating Steven for the vasculitis, and she too was shocked at this decision. She then arranged for a senior colleague of hers at the hospital where Steven was being treated to check in on him. As a direct result of their intervention, the hospital called John shortly thereafter to confirm that Steven would get a ventilator if required. Around two weeks later, Steven was discharged from hospital and returned home - the family is now doing really well and Steven's health has greatly improved.

Katie's Story



Katie* oversees a Mencap service where people received concerning letters from GPs in March as the pandemic began.

Katie says: “When the letters from the GP first arrived for the people we support, we were shocked. These are people who hadn’t received a shielding letter and, although some of them are older, none of them have underlying health conditions. The letters read like it was a blanket letter being sent to every person who is in receipt of care, regardless of their age, health or disability. Then a GP called us to ask what the people we support could and couldn’t do, like whether they can use stairs. Some of them are wheelchair users so of course they can’t use stairs but that doesn’t mean that they aren’t fit and healthy.

“The message from the GP was that if the people we support caught coronavirus there would be little point in contacting emergency services. It really felt as though they had been written off before they were even assessed for how they might benefit from medical intervention. It was clear that assumptions were made about the people we support because they need care, and that somewhere it has been decided that their lives are not worth trying to save. But people with a learning disability deserve to get treatment like anyone else – their lives are just as valuable as the next person’s.

“We were relieved when the GP surgery apologised and the issues were solved, and the people we support are safe and well. However it’s deeply concerning that this ever happened in the first place, and leaves fears around the health inequalities people with a learning disability have faced throughout the crisis.”

***Names have been changed to protect the identities of the people we support**



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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

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



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Communication and PPE – getting creative

Many of the issues previously raised in the Treat me well report surrounding communication have been a cause for significant concern during the pandemic.

While PPE was essential for infection control and kept healthcare professionals and patients safe, a number of nurses raised the concern that it is not always suitable when communicating with some people with a learning disability.

One person remarked, “PPE that doesn’t show our mouths [is] making it harder for us to be understood and our facial expressions to be seen.”³⁰ Learning disability nurses also discussed wearing full PPE on shifts, including for home visits, and wearing masks in communal and office spaces.

Despite these challenges, Mencap has also seen numerous examples of healthcare professionals finding flexible, personalized solutions for people with a learning disability.

Mencap’s learning disability nurse survey demonstrated that these solutions can be simple and low cost. “One lady had her teddy with her and the nurses on the ward and doctors carried out every procedure on the teddy first and had it fitted with the same PPE etc. This really helped the lady accept treatment and reduced distress and anxiety.”³¹

Another nurse commented that they “had to do desensitisation with patients, and [created] social stories about how nurses look with full PPE on,”³² when caring for patients with a learning disability. This solution satisfactorily balances out the requirement of PPE for safety purposes and the need to communicate clearly with people with a learning disability.

Communications technology was also used by many hospitals, not only for discussions around care, but also to ensure that hospital patients are able to stay in touch with their family members. One nurse explained that in her hospital, “tablets have been provided to people with learning disabilities, and the contact details of family and social workers have been added. Ward staff have supported them to regularly Skype family members who cannot be present.”³³

These examples and more demonstrate the vital role that learning disability nurses have played during the pandemic, ensuring that patients were supported and enabling accessible communication between staff and patient.

“The learning disability liaison nurse within the acute hospital has been [an] amazing source of support and communication with all [patients] that have attended hospital – worth her weight in gold, spending time with [patients] and staff reassuring and explaining individual needs.”³⁴

References

³⁰Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

³¹Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

³²Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

³³Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

³⁴Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

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The consequences of not making reasonable adjustments



Data from Public Health England shows 82% of people with a learning disability who died between April and June died in hospital.³⁵ People with a learning disability have always been found to be more likely to die in hospital, but the percentage during this period is particularly high. This mirrors an overall increase in hospital deaths during the same period, when 63% of general population deaths occurred in hospital³⁶.

These numbers do suggest that the majority of people were getting to hospital when they needed care, but the recent LeDeR report sets out key areas of concern including the care some received once admitted. The issues addressed in the original Treat me well report remain crucial in providing this support – without proper communication, training, and inclusive attitudes, people with a learning disability are clearly at risk of receiving inadequate and sometimes life-endangering care³⁷.

“Some areas do not accept hospital passports or COVID summary sheets into the ward. During appointments, some people with a learning disability (more so the mild cases) have been denied the right to allow another individual to support them.”³⁸

Reasonable adjustments must be based on upholding the rights of every individual, regardless of support needs. They should be implemented using a good level of judgement and understanding, and supported by clear guidance, explicitly informing professionals how to meet the needs of people with a learning disability in the new landscape.

However, in the main, this has not happened, and some of the guidance produced has failed to address the vital importance of making adjustments.

References

³⁵Public Health England (2020) [COVID 19 deaths of people identified as having learning disabilities: summary.](#)

³⁶Public Health England (2020) [COVID 19 deaths of people identified as having learning disabilities: summary.](#)

³⁷Treat me well campaign report (2017): <https://www.mencap.org.uk/sites/default/files/2018-07/2017.005.01%20Campaign%20report%20digital.pdf>

³⁸Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

In November 2020, LeDeR published their findings about the deaths of people with a learning disability from COVID. They found that:

Reviewers noted in 21% of cases that the need for reasonable adjustments was indicated, but such adjustments to service provision had not been made. This was more evident in people who died from COVID-19 than from other causes.

‘The most frequently reported required reasonable adjustments that were not made for people who died from COVID-19 were: the provision of specialist learning disability services in hospital; tailoring care provision to meet individual needs; and ensuring the person was supported in unfamiliar settings by those who knew them.’³⁹

Only 19% of LD nurses said they had always seen reasonable adjustments made as standard practice.⁴⁰

These findings support Mencap’s experience that while training specialists in learning disability support is a good step forwards, this must ultimately be supported by a widespread understanding of learning disability across all healthcare staff. If all responsibility for reasonable adjustments lies with one specialist who is then redeployed, or otherwise unavailable, people with a learning disability in that hospital may receive inadequate care and be put at increased risk.

References

³⁹Deaths of people with learning disabilities from COVID-19 (2020) <http://www.bristol.ac.uk/sps/leder/news/2020/leder-covid-19-reviews.html>

⁴⁰Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

Roy and his Daughter's Story



My wife and I care for my daughter aged 49 years. She has learning disabilities, is registered blind and had an organ transplant in 2017. She is extremely vulnerable due to the organ transplant and the anti-rejection drugs that she takes daily.

In April, our daughter's GP advised us to take her to A&E because of a suspected deep vein thrombosis. The experience was stressful. We asked the receptionist at A&E if my daughter could be seen as soon as possible because of her disability, and my wife explained that she gets very distressed if kept waiting. The request was ignored until after two hours' wait, when it became obvious to the receptionist that my daughter was becoming very distressed. The receptionist then called a nurse who allowed us to wait in a cubicle and my daughter was seen by a doctor within ten minutes.

The decision was that my daughter could go home but an arrangement made for her to have a scan. The technician who performed the scan had no empathy with a person diagnosed with a learning disability, and told to my wife he disliked dealing with children. My daughter has a learning disability and is blind, but her hearing is excellent and she does not like being referred to as a child. So that didn't go down too well, which made it even more difficult for more my wife to pacify and encourage my daughter through the scan.

My daughter had to have a liver scan at a different hospital. We had no issue, were seen straight away and the nurse who performed the scan was excellent. She left my daughter and my wife alone for a few moments which allowed my daughter to relax. She spoke to my daughter's face, and told my daughter what was happening, explaining everything as she did the scan.

On a later hospital visit we had our temperature taken at the door due to COVID guidance, but my daughter refused, which caused the staff member at the door some difficulty to understand. Saying you cannot enter until you have had your temperature taken just won't make any difference to my daughter. The extra precautions are incomprehensible for someone like her. The department didn't appear to have any special arrangements in place for a person with a learning disability during these COVID restrictions.

Since this ordeal, thankfully we have not had any more admissions, but my daughter is still wary of medical staff due to the mistreatment we received. What's partly to blame is that medical staff do not have the knowledge on how to treat people with a learning disability, and that must change.

Our real worry and concern is that if my daughter has to be admitted to hospital for whatever cause or condition then we dread that it will be to her demise. If we as parents cannot be with her and she refuses support and we are not able to give support or encourage her then she will die.



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**Being discharged
inappropriately
from hospital**

57% of learning disability nurses surveyed agree that healthcare professionals have not always had enough time to ensure the right support is in place for patients with a learning disability upon discharge.⁴¹

Rapid discharge guidance was introduced in March, with the aim of freeing up hospital beds. Any person who was clinically ready was to be discharged within a matter of hours. The guidance did not cater well for disabled people with existing care because support could not be arranged at short notice.⁴²

There was little guidance available on how to communicate with families and existing providers of social care, or how to allow for reasonable adjustments to respond to a patient's needs.

In accordance with these guidelines, many people who were 'clinically ready' but infected with COVID-19 may have been discharged to care homes without being tested in the first instance, which may have been partly responsible for the large numbers of infections, and subsequently deaths, in these settings.

Disappointingly, updated guidance released in September 2020 still has not considered the needs of disabled people.⁴³ While testing procedures are clearer, there is little in the guidance to ensure that disabled people are discharged safely with the support they need. Hospitals face pressure to discharge people within hours of making the decision, which can be at any time between 8am and 8pm, seven days a week. Many discharges are rushed, without time to put people's regular or additional support in place.

Mencap's experience during the pandemic shows that some people with a learning disability are still being discharged from hospital too soon, not only putting their health at risk, but additionally pressuring social care settings into accepting patients before they are ready to safely meet their needs. It is also likely that, in order to free up a hospital bed, people with a learning disability may be moved to unfamiliar surroundings, such as an unfamiliar care home, with people who may not be able to support them.

References

⁴¹Mencap Learning Disability Nurse Survey (2020) www.mencap.org.uk/myhealthmylife

⁴²<https://www.england.nhs.uk/coronavirus/publication/covid-19-hospital-discharge-service-requirements/>

⁴³<https://www.gov.uk/government/collections/hospital-discharge-service-guidance>

Leroy's Story



Leroy is 58 and has a learning disability, and was admitted to hospital with COVID-19 in mid-March after experiencing breathlessness and a very high temperature for around a week. After another week he was discharged despite not feeling well enough, having problems walking and feeling really out of breath.

‘I wasn’t happy because I didn’t think I was well enough for discharge. Me and my sister knew that it was too early. I said I’m not well enough and they said I was fit enough to go home and that I was going to be discharged, but a few days later I was back in there.’ When he returned home, Leroy continued to have problems breathing properly and eventually his sister had to call an ambulance. Leroy was readmitted to hospital – something he feels should never have had to happen: “I don’t think they listened. If they had they wouldn’t have discharged me.” After 3-4 more days in hospital, Leroy was discharged again and started to do better.

Leroy continued to recover but after falling over in August and breaking his shoulder, he went into rehab to convalesce in September. Leroy has diabetes and, in rehab, staff found him unconscious because his sugar levels were so low. The rehab staff called an ambulance immediately and were very professional – Leroy feels if it wasn’t for them, he may not be here today. After his experience in March, staff were much more careful to ensure Leroy was fit and well before discharging him, and he stayed in hospital and rehab for nearly four months.



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Remote consultations and accessible care for people with a learning disability

During the COVID-19 pandemic we have seen a widespread shift to the use of remote consultations in healthcare.

Remote consultation has the potential to exacerbate existing issues that people with a learning disability face in healthcare. One of these is diagnostic overshadowing, where changes in behaviour or presentation are attributed to disability, rather than recognised and investigated as symptoms in themselves. Another is communication - not being able to see the non-verbal cues, gestures, posture and general body language can make communication less effective than a face to face consultation.

We have been made aware of several cases of these issues with remote consultation leading to delays or inability to access care. This is alarming and in the worst-case scenario could have fatal consequences for people with a learning disability.

Remote consultation is not limited to primary care alone. As part of the NHS Long Term plan there is an aim to remove 1/3 of face to face appointments in outpatients, including the use of more remote consultations.⁴⁴ This has happened unexpectedly quickly due to the pandemic. A priority now must be to identify those patients who are having difficulty accessing services and ensure that they are able to access care.

There has also been more reliance on teleservices, such as NHS 111, which is already known to present issues for people with a learning disability. This was identified in the LeDeR COVID report, with the following troubling comment on the diagnostic capabilities of 111 for people with a learning disability:

‘Often the subtle signs that are picked up by carers about a deterioration in health are not always identified within the algorithm [used to prioritise calls to NHS 111] so may not trigger an alert. COVID-19 has caused a need to reassess what information is required from individuals contacting the 111 service, especially when the information is being given on behalf of someone who has communication difficulties. There does not appear to be any acknowledgement of level of concern by a carer’.⁴⁵

The impact of reduced face-to-face contact with patients with a learning disability was also highlighted by nurses in the Mencap learning disability nurse survey. A number of nurses said they were worried that limited contact with healthcare professionals and support services could contribute to delayed assessments and diagnoses, missed symptoms, increased feelings of isolation, a decline in people’s mental health.

References

⁴⁴NHS Long Term Plan (2019): <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>

⁴⁵Deaths of people with learning disabilities from COVID-19 (2020) <http://www.bristol.ac.uk/sps/leder/news/2020/leder-covid-19-reviews.html>

One participant explained they “have concerns that [a] reduced number of face-to-face contacts will miss more subtle signs and symptoms of ill-health that would otherwise be picked up in [a] person’s body language etc, leading to more serious health concerns for an already vulnerable patient group.” An example of this is one nurse reporting, “we have seen a sharp rise in patients admitted with complications of constipation,” which might otherwise have been picked up sooner.

Related to this, numerous participants feel that the postponement of annual health checks may lead to health problems being missed. A small number of participants also emphasised that people with a learning disability may not have the financial resources or skills to access to the internet or the latest technology, which may make it more difficult for them to access healthcare and support via telephone calls, video calls, or email.

Throughout the pandemic Mencap have called for guidance for healthcare professionals on how to meet the needs of people with a learning disability using remote consultations; and in what circumstances remote consultations can be used safely. Mencap have also called for more evidence of how the use of remote consultations has impacted more widely on people with a learning disability.

If the trend towards remote appointments and teleconsultations is to become NHS standard practice, exceptions must be made for people with a learning disability who cannot access services in this way. According to health secretary Matt Hancock’s statement in July, “From now on, all consultations should be teleconsultations unless there’s a compelling clinical reason not to.”⁴⁶ Guidance must therefore be issued to all healthcare professionals making it clear that a learning disability constitutes a compelling clinical reason to schedule an in-person appointment.

References

⁴⁶Matt Hancock public statement, 30/06/2020: <https://www.theguardian.com/society/2020/jul/30/all-gp-consultations-should-be-remote-by-default-says-matt-hancock-nhs>



Summary

This paints an incredibly troubling picture of the healthcare people with a learning disability have received during the pandemic so far. All of these factors - combined with the closure of the NHS for all but the most urgent care - have clearly had a devastating impact on people with a learning disability, and exacerbated already high levels of premature death and health inequalities.



Jo's Story



Jo is the mother of Bradley who is 27 and has a learning disability, severe epilepsy, cerebral palsy, is autistic and has other complex health issues. Recent months have been incredibly tough for the family because of the COVID crisis. Because of his epilepsy, Bradley is frequently hospitalised and has been in hospital 15 times since March.

While he is starting to use CBD (medical cannabis for treatment of epilepsy) and is improving now, his stays in hospital during the COVID crisis has caused huge stress for the family. The situation has worried them greatly, with fears around Bradley contracting the virus and bringing it back to the care home, and Jo's worries that if Bradley had contracted COVID then he wouldn't have been able to have anyone with him, despite it being a reasonable adjustment that people with a learning disability can have a visitor in hospital.

Furthermore, she feels the situation is compounded in hospital for those people with a learning disability who also present with behaviour that challenges and cannot be confined to one room. While Jo hasn't been able to be with Bradley in hospital during this time, as his carer has been the one accompanying him, she is well aware of the previous issues they've encountered in hospital. She says that 'learning disability is so badly understood in hospital' and Bradley can have challenging behaviour at times but healthcare staff will just ask 'why can't you just control him?'

In the past, Bradley ended up in ICU once because of his seizures and was on a ventilator. When he came round, hospital staff thought it would be best if he went home directly because they were concerned if they could manage him and his behaviour, yet normally they send people to another ward first. All of these previous experiences add to Jo's fear around if Bradley were in hospital because of COVID and about the treatment he'd receive.

Prior to COVID, Jo and Bradley have had all sorts of experience in hospital with patients complaining because Bradley made noise. Jo always said Bradley needed to be in a side room but it was never taken on board and she continued to have panic and anxiety around him being in hospital, worrying about how will he cope. In Jo's experience, she feels there are few nurses who have the training or time to support people with a learning disability.

Jo is also very concerned about a DNACPR being placed on those with a learning disability without full and proper consultation with their families, and feels that the process of making a best interest decision has been lost. Due to this she has had to complete an advanced care plan (ACP) to try and prevent this from happening to Bradley.



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**What needs to
happen now?**

Throughout this crisis, the government, health bodies and health authorities have not done enough to protect people with a learning disability. Though resources may be stretched, the basic rights to healthcare of people with a learning disability must be upheld, as for everyone else, even in a national emergency. This shocking health inequality can no longer be ignored – this crisis is a wake up call that must result in urgent system change.

Next steps:

Clearer guidance

Guidance around healthcare during COVID-19 needs to specifically address the needs of people with a learning disability. This must be addressed as part of the initial guidance, not once guidance has already been released. Best practice from across the UK should be looked at.

Ambulance guidance must be clear that carers and advocates can accompany people with a learning disability to hospital.

DNACPRs must be reviewed and removed from the records of patients who did not give informed consent, or for whom proper decision making did not take place.

Reasonable adjustments

As well as being a legal requirement within the Equality Act 2010, reasonable adjustments are vitally important for people with a learning disability. Though what is considered ‘reasonable’ may change in times of limited capacity, adjustments still need to be considered and made where possible – this can be a matter of life and death.

The government and national health bodies must issue clear communication about reasonable adjustments and use specific COVID examples to illustrate how hospitals can make reasonable adjustments, even in a time of crisis.

Remote consultations

An urgent review needs to take place of the equality impact of policy on remote consultations. This review should focus in particular on people with a learning disability, as well as other vulnerable groups who may be excluded from accessing healthcare services, such as older people.

Learning from deaths

We need further action to understand why so many people with a learning disability have died during the pandemic and prevent this from happening in the future.

Longer term, the forthcoming inquiry into the handling of the pandemic must look closely at why so many people with a learning disability died. Lessons must be learned from this tragedy, so that mistakes are not repeated in the event of a future pandemic or crisis.

Training

The last few months have clearly illustrated that healthcare is in desperate need of a culture shift, addressing how the healthcare system view people with a learning disability at times of crisis. These are valued, important human beings who are most in need of help in a healthcare setting – they must not be regarded as expendable, homogenous, or as ‘extra work’.

Training should therefore be prioritised to ensure that all healthcare staff are confident in providing flexible, personalised care for people with a learning disability within their specialties. The current trials of the Oliver McGowan mandatory training in learning disability and autism will be key in making this happen in England, and in Wales this will continue with the development of the Paul Ridd mandatory training.

Vaccination

The evidence from LeDeR and PHE shows that people with a learning disability have been disproportionately impacted by COVID. The government must prioritise vaccination for people with a learning disability, who have died at over 6 times the rate of the general population.

What you can do

If you have a learning disability or care for someone who does, there are some things you can do to make healthcare during COVID-19 as safe as possible.

- Ask your doctor about the Covid vaccination as they become available– this is one of the most effective things that you can do to protect yourself and those around you from COVID. Some people with a learning disability will be prioritised for the vaccine.⁴⁷
- Check your medical records for DNACPRs - these should not be on your records without your permission and full understanding of what they mean. It is your right to remove them at any time.
- Request an annual health check – having an up to date record of your health leads to better outcomes in the long term, and could be useful if you have to go to hospital.
- Request a flu jab – if you get flu and COVID at the same time, you are more likely to become seriously unwell. Flu jabs keep people healthy and will help to ease pressure on the NHS during the winter months, when they are more likely to be stretched.
- Continue to ask for reasonable adjustments - these are still required by the law, and make an enormous difference to someone’s healthcare experience and outcomes.
- Sign up to fight for healthcare equality in your local area through the Treat me well campaign.⁴⁸

References

⁴⁷https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/940936/Priority_groups_for_coronavirus_COVID-19_vaccination_-_advice_from_the_JCVI_2_December_2020.pdf

The Joint Committee on Vaccines and Immunisations published new advice on prioritisation for Covid-19 vaccines on 2nd December 2020. Adults with Down’s Syndrome sit within priority group 4, and people with a severe or profound learning group in priority group 6. People with a learning disability with other health conditions may also sit in other priority groups.

⁴⁸<https://www.mencap.org.uk/get-involved/campaign-mencap/treat-me-well>

If you've been affected by any of the information in this report, please contact Mencap. We are here to support people with a learning disability, their families and supporters.

Contact our learning disability helpline on **0808 808 1111**, or visit our online community at **[mencap.org.uk](https://www.mencap.org.uk)**.



Wales

Mencap Cymru has had a long history of campaigning and influencing on health improvements for people with a learning disability in Wales.

Health and Social Care have been devolved to the Welsh Government since the establishment of the National Assembly for Wales (now the Senedd Cymru – Welsh Parliament) in 1999. This means healthcare looks very different in Wales than the rest of the UK, and this was no different during the first wave of the COVID-19 pandemic.

Wales already had in place formal reasonable adjustments called the Learning Disability Care Pathways, a set of seven actions which hospital staff must follow if a patient with a learning disability is admitted to hospital. The pathway actions range from informing the learning disability liaison nurse that there is a patient with a learning disability in the hospital, to holding multidisciplinary discharge meetings with the patient, families or support providers to ensure the discharge from hospital is safe for the patient with a learning disability.

Since March, responding to the fast moving pandemic has been a core part of Mencap's work in partnership with the Paul Ridd Foundation and partners in the Wales Learning Disability Consortium. In April the learning disability strategy 'Improving Lives' was paused. Improving health inequalities was a key priority in this strategy, concerned with the impact on people with a learning disability. Mencap Cymru called for the Ministerial Learning Disability Advisory Group to continue meeting to discuss the impact of COVID 19 on people with a learning disability and their families, as well as what life would look like post-pandemic.

When guidance has been produced it is quickly assessed by members of the Learning Disability Consortium to ensure that it does not discriminate against people with a learning disability and their family carers and where we believe they do, we meet with officials to challenge and change flaws in the guidance/practice.

On October 6th, the Deputy Minister for Social Services announced that the Improving Lives strategy would be restarted with immediate effect, and would focus on health inequalities & premature deaths of people with a learning disability, anxiety brought about by social isolation and support for parents and carers during the COVID pandemic.

This announcement addresses some of Mencap's concerns with the potential additional impact of COVID on people with learning disability and their family carers. However, whilst this is welcome, there was a significant lapse between Improving Lives being suspended and restarted, leaving many people with a learning disability and their families without support at key times over the summer.

Many day services are still set to remain closed until the spring, and we continue to challenge government & local authorities to mitigate for the impact on these closures on the mental health and wellbeing of people with a learning disability and their family carers.

At time of print, we await data on the impact of the second wave on infection and deaths of people with a learning disability in Wales.

Northern Ireland

Legislative responsibilities are devolved in most areas of government to the Northern Ireland Executive, including healthcare, and the health and social care system in Northern Ireland is integrated. There are an estimated 42,000 people with a learning disability living in Northern Ireland, many of whom experience persistent challenges accessing the services they need.

Policy development aimed at improving health outcomes for people with a learning disability is generally slow. Some progress has been made through introduction of the hospital passport, guidelines on care for people with a learning disability in hospital, and annual health checks. However, further work is needed to introduce more specific learning disability nursing roles and implement reasonable adjustments. Northern Ireland also lags behind other parts of the UK in key policy areas, notably the development of Learning Disability Improvement Standards and proposals for mandatory training on learning disability for all healthcare staff.

The COVID-19 pandemic has exacerbated many of the social, economic and health inequalities people with a learning disability in Northern Ireland already face. Together with the impact of shielding, some have experienced limited access to vital respite, day opportunities, allied health and other services which has further increased their isolation.

Support organisations are engaging with government and jointly influencing for clarity around the restoration of key services, the need to identify what additional provision is required, and information about the learning disability population. No figures are available on how many have died because of suspected or confirmed COVID-19; or the number of excess deaths amongst this population compared to the same period last year.

Key recommendations:

- Improved data collection about people with a learning disability in Northern Ireland, including a full and accurate assessment of COVID-19-related deaths amongst this population across all settings.
- A clear plan to restore essential health, social care and other key services for people with a learning disability.
- Mandatory training for health professionals in Northern Ireland on learning disability awareness, consent, mental capacity and reasonable adjustments, supported by a 'flagging system' in hospitals that lets staff know when a patient has a learning disability.
- The development of Learning Disability Improvement Standards for Northern Ireland, with Health and Social Care Trusts legally required to monitor and improve the way they identify and support the healthcare of people with a learning disability.