

Learning disability nurses' experiences during the COVID-19 pandemic: survey findings

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 and was hosted on Survey Monkey. The survey was designed by the Campaigns, Research, Communications and Policy teams. If you wish to use the data or have any questions please contact the research team: research@mencap.org.uk.

What is your usual job role? (n=239)

- 60% of respondents work as community based learning disability nurses
- 26% of respondents work as acute learning disability nurses
- 4% of respondents work as learning disability matrons
- 9% of respondents selected other. Of these respondents, answers included: learning disability health care assistant, learning disability day care nurse, rapid respond nurse and clinical lead nurse

Have you or members of your team been redeployed during the COVID-19 pandemic? (For example, you might have been redeployed to a more general nursing role or to discharge teams in the community) (n=237)

- 71% of respondents remained in their usual role
- 29% of respondents said they or a team member had been redeployed
- Around 11% of acute learning disability nurses said they or a team member had been redeployed; for community based learning disability nurses it was 34%

Of the community-based learning disability nurses who have been redeployed, many said that they have been redeployed to hospital inpatient services or Assessment and Treatment Units (ATUs) for people with a learning disability. A few others have been redeployed to other roles or services, such as COVID-19 crisis mental health teams, helplines, or COVID-19 testing services.

Meanwhile, some acute learning disability nurses said they had been redeployed to other wards or units. One commented, "I was redeployed for four weeks to [another] ward. During this period there was no specialist learning disability service provided across the Trust."

Which region are you based in? (n=236)

- 14% of respondents were based in the East Midlands
- 14% of respondents were based in South East England
- 14% of respondents were based in the North East
- 12% of respondents were based in Yorkshire and the Humber
- 9% of respondents were based in the South West
- 8% of respondents were based in the East
- 8% of respondents were based in the West Midlands
- 7% of respondents were based in the North West
- 6% of respondents were based in Wales
- 4% of respondents were based in London
- 2% of respondents were based in Northern Ireland

Has the way you work significantly changed during the COVID-19 pandemic? (For example, more remote working, or social distancing measures at work) (n=238)

- 94% of respondents reported that the way they work has been significantly changed
- 6% of respondents reported that the way they work had not significantly changed

The main ways in which learning disability nurses said their job roles had changed were in terms of social distancing measures at work, wearing PPE, and more remote working from home. Many nurses said there had been a significant reduction in face-to-face contact with patients with a learning disability, family members and staff teams. Instead, they were using video consultations, phone calls and text messages unless there was an emergency.

Learning disability nurses also discussed wearing full PPE on shifts, including for home visits, and wearing masks in communal and office spaces. One nurse commented that they have “**had to do desensitisation with patients and social stories about how nurses look with full PPE on,**” when caring for patients with a learning disability.

For some learning disability nurses, there has been a lot more working from home during the pandemic. This has led to less face-to-face interaction with colleagues, and a switch to video conferencing and phone calls.

During the COVID-19 pandemic, to what extent do you think the number of people with a learning disability admitted to hospital for reasons unrelated to COVID-19 has changed? (n=236)

- 56% of respondents said that the number of people has **gone down**
(25% down a lot, 31% down by a small amount)
- 19% of respondents said that the number of people has stayed the same
- 25% of respondents said that the number of people has **gone up**
(8% up a lot, 17% up by a small amount)

Why do you think this is?

Learning disability nurses who think the number of people with a learning disability admitted to hospital for reason unrelated to COVID-19 has **gone down** suggested a few reasons for this:

- **Fear** – Many learning disability nurses think that families and people with a learning disability have been afraid of going to hospital due to COVID-19. One nurse said, “people are telling me they are scared to come to hospital, or to send their family member or person they care for. Sometimes this has had awful consequences. As a hospital we have put every possible safety measure in place, but the media have made it sound as though hospitals are awful!!”
- **Fewer planned admissions and elective surgeries** – Some people suggested that hospitals may not have wanted to admit people during the pandemic unless this was essential. They said this may have led to people being admitted at a later stage, when their health needs were more critical. Others noted this may have been caused by a shortage of staff able to carry out reasonable adjustments, due to learning disability nurses being redeployed.
- **Inequalities in accessing healthcare** – A small number of participants highlighted that people with a learning disability experience inequalities when accessing mainstream services, and some feel that they are not seen as a priority group to treat during this time.
- **Shielding** – Learning disability nurses said that some people with a learning disability and/or their family members may be shielding at home, and so not wish to go to hospital.
- **Confusion over governmental guidelines** – A few learning disability nurses said that people may have been confused by government guidelines, and unsure whether they should visit hospital during the pandemic, even if they had serious symptoms.

Meanwhile, the nurses who think the number of people with a learning disability admitted to hospital for reason unrelated to COVID-19 has **gone up** believe it is mainly due to the following factors:

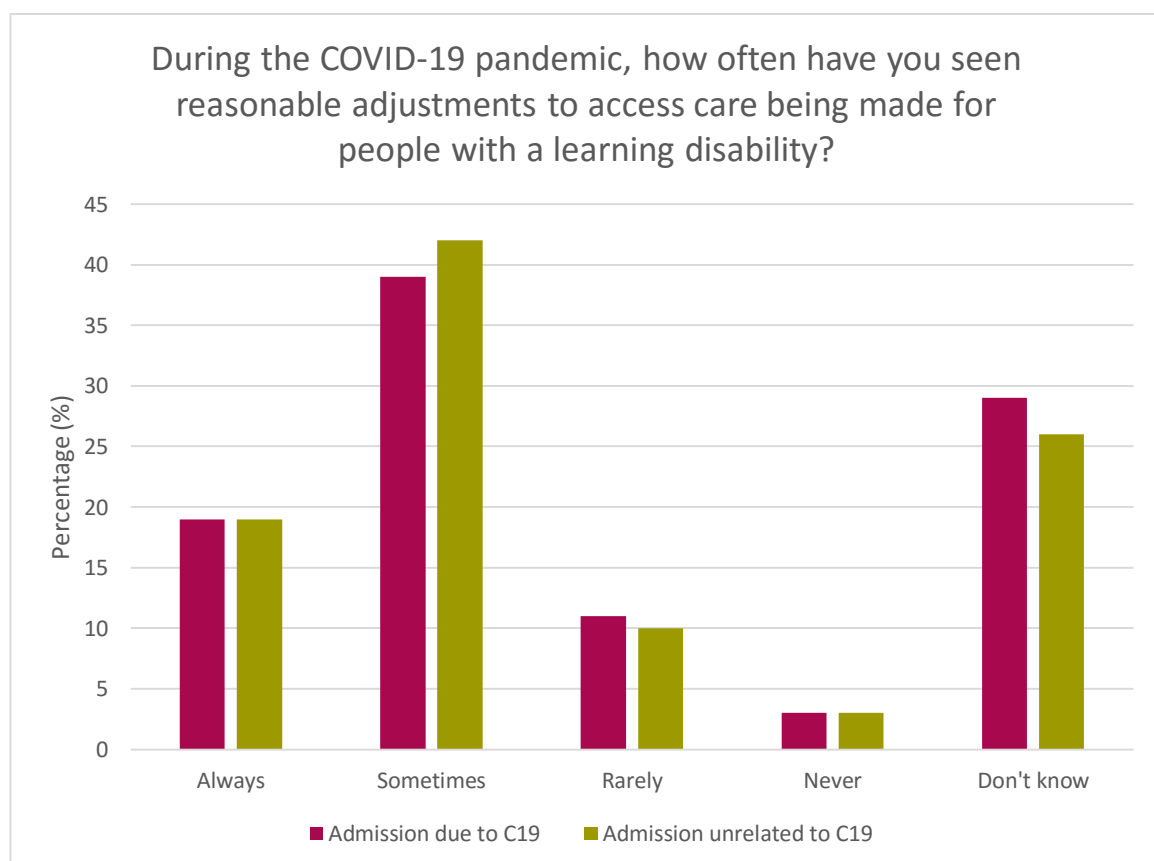
- **Mental health of people impacted by COVID-19** – Participants suggested that stress, anxiety, changes to routines and isolation caused by the COVID-19 pandemic have had a negative effect on the mental health of people with a learning disability. A few nurses suggested that this has led to self-injurious behaviours and/or people reaching crisis point in some cases.
- **Physical health of people impacted by COVID-19** – Participants also felt that changes to people’s routines have had a negative effect on their physical health, for example with people being less active.
- **A reduction in community-based support** – Numerous participants said that a reduction in respite and community-based services have 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.

During the COVID-19 pandemic, how often have you seen reasonable adjustments to access care being made for people with a learning disability who have been admitted to hospital due to COVID-19? (n=238)

- 19% of respondents reported that they had always seen reasonable adjustments
- 39% of respondents reported that they had sometimes seen reasonable adjustments
- 11% of respondents reported that they had rarely seen reasonable adjustments
- 3% of respondents reported that they had never seen reasonable adjustments
- 29% of respondents reported that they don't know if they had seen reasonable adjustments

During the COVID-19 pandemic, how often have you seen reasonable adjustments to access care being made for people with a learning disability who have been admitted to hospital for reasons unrelated to COVID-19? (n=237)

- 19% of respondents reported that they had always seen reasonable adjustments
- 42% of respondents reported that they had sometimes seen reasonable adjustments
- 10% of respondents reported that they had rarely seen reasonable adjustments
- 3% of respondents reported that they had never seen reasonable adjustments
- 26% of respondents reported that they don't know if they had seen reasonable adjustments



On 8th April 2020, NHS England released guidance that adjustments should be made to the hospital visitor policy to allow one family member/ supporter to accompany people with a learning disability wherever possible. Since then, have you seen any examples where people with a learning disability have not been allowed to be accompanied by a family member, carer or supporter in hospital? (n=238)

- 53% of respondents have **not seen any examples** where people with a learning disability have not been allowed to be accompanied by a family member, carer or supporter in hospital
- 25% of respondents **have seen examples** where people with a learning disability have not been allowed to be accompanied by a family member, carer or supporter in hospital
- 23% don't know if they have seen any examples

On 7th April 2020, NHS England published a letter including guidance on DNACPR orders. Since then, based on your own experiences, how would you perceive the level of risk for people with a learning disability receiving inappropriate DNACPRs? (n=238)

- 19% of respondents reported that there is a high level of risk
- 35% of respondents reported that there is a moderate level of risk
- 14% of respondents said there is a low level of risk
- 5% of respondents said there is no risk
- 27% of respondents reported that they don't know the level of risk

During the COVID-19 pandemic, to what extent do you feel that hospital passports have helped healthcare professionals to treat people with a learning disability? (n=237)

- 35% of respondents said that hospital passports had helped greatly
- 42% of respondents said that hospital passports have helped to some extent
- 8% of respondents said that hospital passports have not helped at all
- 14% of respondents said they don't know whether hospital passports have helped

During the covid-19 pandemic, how often have hospital patients with a learning disability been tested for COVID-19 before being discharged? (n=236)

- 25% of respondents reported that hospital patients with a learning disability were always tested for COVID-19
- 26% of respondents reported that hospital patients with a learning disability were sometimes tested for COVID-19
- 4% of respondents reported that hospital patients with a learning disability were rarely tested for COVID-19
- 3% of respondents reported that hospital patients with a learning disability were never tested for COVID-19
- 41% of respondents don't know whether hospital patients with a learning disability had been tested for COVID-19
- 1% of respondents selected 'other', either because testing had changed over the course of the pandemic, or because there had been no discharges where they work

To what extent do you agree with the following statements? Please base your answers on your experiences during the COVID-19 pandemic.

Statement	Percentage selecting each option				
	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Wearing PPE has made it easier for healthcare professionals to communicate with patients with a learning disability. (n=236)	1%	3%	14%	36%	46%
	4% agree			82% disagree	
Healthcare professionals wearing PPE has caused distress for patients with a learning disability. (n=236)	18%	50%	24%	6%	3%
	68% agree			9% disagree	
Healthcare professionals have always had enough time to properly plan for the discharge of patients with a learning disability. (n=235)	3%	13%	26%	43%	14%
	16% agree			57% disagree	
Healthcare professionals have not always had enough time to ensure the right support is in place for patients with a learning disability upon discharge. (n=235)	13%	44%	25%	15%	3%
	57% agree			18% disagree	

Do you have any examples of good practice in caring for patients with a learning disability during the COVID-19 pandemic? This could be something you have witnessed or been involved in. Please tell us about it.

Key examples of good practice:

- Joined up working between different health and social care professionals
- Use of communications technology in caring for patients
- Providing care at home
- Making reasonable adjustments
- Health and social care professionals going the extra mile

Learning disability nurses identified a variety of examples of good practice in caring for patients with a learning disability during the COVID-19 pandemic. The first good practice identified was that of **joined up working between health and social care professionals**. One participant said the “links between hospital liaison matron and community nursing team have been very good. Support provided by our team to services has been good – regular phone contact and offer of support.” Such instances of joined-up working can have positive impacts on people’s health outcomes – for example, one nurse told the story of a “gentleman with chest problems – we all thought that if he contracted [COVID-19] then he would be admitted to hospital and ventilated; however with good care coordination and the support of a physio to organise chest care he pulled through.” In other instances, there has been sharing of resources and information between GPs, consultants, community learning disability nurses, acute hospital staff, social care professionals, family members

and others - and at times technology such as video conferencing has facilitated discussions, care plans, and hospital discharges.

Such **use of communications technology** was flagged by many as another example of good practice during the COVID-19 pandemic – not only for discussions around care, but also for ensuring that hospital patients are able to stay in touch with their family members. As one nurse explained, “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.” A number of participants also noted the “creative use of technology to communicate with people who may not have had access to specialist support due to lockdown and restrictions,” with one reflecting that some young people seem to like this alternative style of appointment using phone or video calls.

In adapting service delivery, there have been times when **care has been provided at home** for people with a learning disability, either by hospital or community-based staff. As an example, one nurse said, “people who administered COVID tests visited people’s homes rather than the big test sites so that people felt more at ease having the tests and they spent longer with people to ease their anxieties regarding the tests.” Some professionals have come up with creative means of providing care, such as doing tests and check-ins with people in their gardens, where possible.

The nurses who took part in Mencap’s survey also gave good examples of **reasonable adjustments for people with a learning disability**, such as allowing key possessions onto wards. For example, “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.” In other settings, nurses noted that staff have made photo cards to show what they look like without PPE, or allowed people with a learning disability to try on the PPE, so that they do not feel so scared or alienated by it. Other good examples of reasonable adjustments taking place in hospitals and services have included Easy Read information about topics such as social distancing and hand washing, exceptions to rules around hospital visitors, increased use of hospital passports and specific COVID-19 hospital passports, ‘social stories’ to talk to people about PPE, and the use of transparent face masks to support people with communication. Alternative approaches to swabbing and testing have also been put in place for some people with a learning disability – for example, one nurse recounted a time when “the health professional organised a general anaesthetic for the patient due to them [being] unable to cope with the tests when awake.”

Linked to this, a number of nurses gave examples of **health and social care professionals going the extra mile** and taking a caring approach. One participant explained, “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.” Other examples of staff going the extra mile have included taking extra time to sit and talk with people with a learning disability and their families, providing reassurance, delivering care packages to people with a learning disability living alone in the community, and welfare calls and check-ins with patients living in the community. Other people gave examples of creative means of supporting people with a learning disability during this time, such as a nursing home which “opened a tuck shop as our residents missed the local corner shop.”

Do you have any areas of concern around caring for patients with a learning disability during the COVID-19 pandemic and into the future? Please tell us about it.

Key areas of concern:

- Inappropriate uses of Do Not Attempt Cardio-pulmonary Resuscitation (DNACPRs)
- Lack of reasonable adjustments at times
- Communicating with people whilst using PPE
- The impact of reduced face-to-face contact between healthcare professionals and patients
- Social distancing rules being confusing, particularly as they start to change and relax
- The impact of the COVID-19 pandemic on physical and mental health
- Reduction in community-based care and support services

Learning disability nurses identified a number of areas of concern around caring for patients with a learning disability during the COVID-19 pandemic and into the future. The first concern was around the **inappropriate uses of Do Not Attempt Cardio-pulmonary Resuscitation (DNACPRs)**. One nurse commented, “DNACPRs are constantly being put in place for people with LD and often inappropriately... [We] challenge them daily but still these are happening.” Similarly, another said, “GPs [are] writing DNACPRs without consultation with family and due to the person’s learning disability not physical health.” At times, participants suggested the DNACPRs have been put in place by GPs without the correct processes being followed, such as multidisciplinary team meetings being carried out with all involved. One nurse said, “this is not reasonable and is not putting the person at the heart of care.” Others suggested this was happening because GPs and/or clinicians need more training on the Mental Capacity Act (MCA), and believe this issue needs to be addressed as a priority. For example, one nurse commented that, on some medical forms, clinicians “are saying ‘no’ for [the] person having capacity yet [there is] no MCA assessment or reference to capacity/ lack of in [their] clinical notes. I am able to assess of course but if clinicians are saying people lack capacity then the same clinicians need to back up their clinical decisions with an assessment.”

The second concern raised by learning disability nurses was that, at times, there has been a **lack of reasonable adjustments for people with a learning disability during the COVID-19 pandemic**. For example, one nurse said, “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.” This mirrors the concerns of a number of nurses who took part in the survey, who have witnessed instances where family members and support staff were not allowed to accompany a patient with a learning disability onto a hospital ward. Another 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 chats.” Due to this lack of reasonable adjustments, some nurses 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.” Some nurses suggested that this is because healthcare services have been stretched 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.”

A number of nurses raised the concern that **PPE is not always suitable when communicating with some people with a learning disability**, with one person remarking, “PPE that doesn’t show our mouths [is] making it harder for us to be understood and our facial expressions to be seen.” Another nurse highlighted that some people with a learning disability rely on non-verbal communication, and

said that this has is “severely restricted with masks.” Meanwhile, other nurses flagged that some people with a learning disability may be fearful of PPE, and that these individuals “may be reluctant to even enter a hospital – even when it is paramount to their health.” There was a sense among some nurses that PPE makes it more difficult to build relationships with patients, with one noting, “I am concerned about the barrier that PPE masks have on building a therapeutic relationship between patient and professional.” On the other hand, the importance of PPE was still stressed by many, and concerns were raised that care homes and supported living settings had not always had adequate supplies of PPE or access to testing for COVID-19.

The next concern raised by learning disability nurses who took part in the survey was the **impact of reduced face-to-face contact with patients with a learning disability**. A number of nurses are 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, and increased risks of abuse. 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. 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. Many participants said they are worried about people with a learning disability accessing routine medical care if the pandemic continues.

Many learning disability nurses are also concerned about **social distancing rules being confusing, particularly as they start to change and relax**. One person said they are worried people with a learning disability “may not be able to follow social distancing rules and concerns that they may then become vulnerable to abuse when out independently.” Somebody else said this could also risk their own safety and “risk spreading the virus to people with poor health including carers.”

Another clear concern of learning disability nurses coming out of this survey is the **impact of the COVID-19 pandemic on the physical and mental health of people with a learning disability**. Shockingly, one nurse explained, “people [are] not coming into hospital for fear of what may happen to them re catching COVID. It has been heart-breaking to see as people have died/ come to significant harm as a result.” Others emphasised that people with a learning disability already experienced health inequalities before the pandemic, and suggested that such inequalities are now likely to be worsened, particularly if people with a learning disability are not seen as a priority group. For example, one participant said, “people with a learning disability have always been seen as second class citizens, and due to this they haven’t received the right and appropriate support. The worries with the current pandemic is that people with a learning disability won’t get the support they need, won’t have full recognition due to diagnostic overshadowing, and are at high risk of DNACPR due to lack of awareness by medical staff and these people are not always seen as their life is as worthy as others.”

In terms of the **negative impacts of the COVID-19 pandemic on people’s mental health**, many participants feel that the virus, lockdown, social distancing measures, loss of familiarity and changes to everyday routines have led to increased distress, anxiety and stress for people with a learning disability and their families. Some participants feel this has been compounded by a lack of face-to-face support including day services, respite, schools and mental health services during this time. One person comment that “some of our patients have been in such distress they have exhibited behaviours that have led to assaults, self-injury, damage to the environment which would be

unusual for them, now they have been labelled as risky or dangerous and will likely have limitations on the services they can access in the future because of this.” Other participants expressed worries that such mental health crises would continue into the future, as people with a learning disability struggle to adjust to a ‘new normal’.

The last area of concern for the learning disability nurses who took part in Mencap’s survey was the **reduction of community-based care and support services** during the COVID-19 pandemic. One participant commented, “social care is under a lot of pressure and constantly reducing hours for the client group and we have a constant fight to obtain appropriate and suitable care.” Similarly, somebody else said, “I am concerned that a lot of children we work with have had little/ no support during this pandemic so a lot of families may be in crisis.” A few nurses also suggested that there were times during the COVID-19 pandemic when people with a learning disability were discharged from hospital too early, as one nurse explained, “inappropriate discharges at [the] start of [the] pandemic result[ed] in hospital readmission and crisis.”