

## **Written evidence from Mencap and the Challenging Behaviour Foundation (COV0243)**

### **Introduction**

The COVID-19 pandemic and the Government's response have presented a number of new challenges to people with a learning disability and/ or autism as well as exacerbating existing threats to human rights. We therefore welcome the Committee's inquiry. Especially the recent session on the experience of those locked away in in-patients units and the impact this is having on them and their loved ones.

### **About the Challenging Behaviour Foundation**

The Challenging Behaviour Foundation (CBF) is a charity which exists to demonstrate that individuals with severe learning disabilities who are described as having challenging behaviour can enjoy ordinary life opportunities when their behaviour is properly understood and appropriately supported.

### **About Mencap**

We support the 1.5 million people with a learning disability in the UK and their families and carers. We fight to change laws and improve services and access to education, employment and leisure facilities, supporting thousands of people with a learning disability to live their lives the way they want. We are also one of the largest providers of services, information and advice for people with a learning disability.

### **Impact of Government measures on human rights**

#### **Clear, timely and accessible advice and guidance**

Clear and accessible information is difficult to access at the best of times, and the Government response to COVID-19 has made this even more challenging for people with a learning disability, families and providers. The speed at which Government guidance is changing, as well as sometimes conflicting messaging in the media, is making it difficult for families and providers to keep up and understand what the official guidance is. In addition, much of the guidance has not adequately addressed the needs of this group.

Our organisations have been highlighting gaps in information from the start and producing resources to try to help meet the information needs of people with a learning disability and their families. This has included FAQs ([1](#) & [2](#)) answered by lawyers, as in many cases, legal input has been necessary to help apply the guidance to real life situations.

Clear and accessible information is critical in protecting human rights especially given the 'easements' in the Coronavirus Act to the Care Act, the Children and Families Act and Mental Health Act. Any information must clearly detail escalation routes and how to access

legal support, should a reduction or removal of support/care lead to crisis, placing the individual at risk of admission to an in-patient unit

The Government has assumed that everyone has internet access, but we know that people with a learning disability tend to have less access to technology than the general population<sup>1</sup>. Very little / no attention has been paid to those who do not, and all guidance is simply uploaded to gov.uk. This seriously disadvantages many individuals and families.

Funding from the Department for Health and Social Care for charities, announced in May, recognising the important role charities had been playing and continue to play to provide information and advice around COVID-19 is welcome. We are seeing increased numbers of calls to our helplines. Information and advice will continue to be crucial during the recovery period as guidance shifts as we come out of lockdown and/ or local lockdowns become more prevalent.

Although charities can help to get the guidance out there through provision of information and advice, the underpinning government guidance and policy needs to actually address the needs of people with a learning disability. It is therefore vital that the Government works with relevant stakeholders on the guidance itself.

We welcome the Government's outreach to our organisations which has allowed us to comment on and influence some of the guidance. This has helped to ensure some guidance addresses the needs of this group to some degree and has provided us with the ability to raise issues and concerns to officials.

It is crucial that these communication channels stay open during the 'recovery' phase and any second 'spike' in infections. Nevertheless, where input from our organisations has been sought e.g. supported living guidance, this has either had extremely quick deadlines to respond or not been issued in a timely manner. These have left families and providers without essential information.

**The Government must work with relevant stakeholders to: audit the guidance it has published to ensure it is fit for purpose, and where it is developing new policy and guidance to ensure the needs of people with a learning disability and families are fully addressed; ensure this guidance is accessible; and ensure that there is a clear plan to get the guidance to the relevant audience.**

## **Meeting health needs**

Accessing healthcare can be challenging for children and adults with a learning disability and/ or autism under normal circumstances. It is well established that this group faces significant health inequalities. We are concerned that during Covid-19 people with a learning disability and/ or autism's right to life could be threatened or access to healthcare and treatment deprioritised.

People with a learning disability are more likely to be in the 'high-risk' category for Covid-19 as we know respiratory conditions are a common cause of death among people with

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<sup>1</sup>[https://www.ofcom.org.uk/\\_data/assets/pdf\\_file/0026/132965/Research-summary-learning-disability.pdf](https://www.ofcom.org.uk/_data/assets/pdf_file/0026/132965/Research-summary-learning-disability.pdf)

learning disabilities (*In 2018/19 at least 41% of people with a learning disability who died, died as a result of a respiratory condition* (NHSE/I speciality guidance, March 2020).

This increased risk highlights the need for robust guidance to ensure the right to life and right to health for people with learning disabilities. Data from CQC published during the pandemic shows a **134% increase in deaths of people with a learning disability in April and May** when compared to the same period last year. Data also shows that the risk is higher for younger people than in the general population<sup>2</sup>.

Our fears were founded in the first version of the NICE guidance on Critical Care which would have seen working-aged disabled adults subjected to the ‘frailty scale’ designed for those aged 65 and over, risking decisions being made on an inappropriate basis.

Following a public outcry, this guidance was quickly revised by NICE but the impacts are still being felt. This has manifested itself in the letters sent out by GPs to care settings asking people to sign a ‘do not resuscitate’ form with some letters even directly stating that the individual in question was likely to not receive treatment should they have to be hospitalised. While those responsible have apologised for this action, and the Government has made it clear that these letters are inappropriate, this remains an area of great concern and highlights the need for vigilance during this period.

### **Meeting health needs – children and young people**

We know from the families we support that the Government’s response to Covid 19 is having a significant impact on access to healthcare for children and young people with learning disabilities and/ or autism.

The Disabled Children’s Partnership [#LeftInLockdown report](#) found that many families were seeing declines in both mental and physical health during lockdown.

We have heard examples of children’s healthcare staff being redeployed to support adults and we know that families are not seeking healthcare support for children during this period and treatments are being delayed.

Many children who normally receive health care support, including therapies such as Speech and Language Therapy or Occupational Therapy, through their special school have been left with nothing during school closures. Although some have managed to use direct payments flexibly, other requests have been refused and those who do not usually receive direct payments are left with little support. Some children have been denied treatment for conditions such as kidney stones.

### **Visiting rights**

Since the start of the pandemic we have heard from families who are very concerned about what will happen to their relative should they need to be hospitalised, either with coronavirus or any other health need.

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<sup>2</sup> <https://chrishatton.blogspot.com/2020/06/>, data source: [CQC](#), [LeDeR](#)

Many people with a learning disability and/ or autism need someone to support them when they are admitted to hospital for treatment. The person may need support with communication, particularly where they do not use formal communication like words or signs. Someone who knows the person well will be able to provide information on the person's health, conditions and request reasonable adjustments which can play a crucial role in ensuring the person's health needs are met.

One family told us: *“the thought of my daughter becoming infected and needing intensive and invasive treatment is absolutely horrifying – she would have no idea whatsoever about what was happening, why people were wearing masks, etc. and would be terrified.”*

*“She needs at least 2 carers with her at all times when out of her home, and it would be imperative that carers and/or family members were permitted to help with her care if a hospital admission was necessary”.*

Due to measures in place in hospitals in response to Covid-19, another family, whose loved one with severe learning disabilities has been in ICU on life support in recent weeks, has had to fight especially hard for access to the ward to be with their daughter. In this case, the individual has a severe learning disability, does not communicate verbally and is blind. Therefore, her close family are best placed to recognise any signals which indicate changes in her condition or needs that might well not otherwise be picked up by hospital staff. Family members have spent time and energy challenging the access restrictions at a time when they have many additional worries about their daughter's health. They were eventually allowed only one member to be able to be with their daughter.

On 5<sup>th</sup> June the NHSE visiting guidance was updated<sup>3</sup> which indicates that one close family member may now be present at a patient's bedside. We believe that those who are there supporting the needs of a patient i.e. a family carer/support worker/personal assistant should not be counted as an additional visitor.

While we welcome these recent changes to the national guidance, we remain concerned that services/ hospitals are implementing their own policies. More must be done to ensure that guidance is being followed correctly.

Family carers not only have significant knowledge and expertise regarding their relative and their care and support needs, they also act as powerful advocates. The combination of the issues above relating to illegal DNARs for example, and restrictions on family carer access to their relative raise justified concern about how people's human rights are being protected.

### **Meeting health needs in inpatient settings**

As the Committee knows, many people with a learning disability and/ or autism are at risk of not getting the right support and treatment for physical health needs in in-patient settings. This is a concern we raised in our joint submission to the Independent Review of the Mental Health Act. During the COVID-19 pandemic this issue is very central and of concern (see Annex case study).

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<sup>3</sup> <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0524-visiting-healthcare-inpatient-settings-5-June-2020.pdf>

Clear guidance and support must be provided to staff in in-patient units on how to meet an individual's physical health needs. As the evidence of Andrea Attree and Adele Green showed, physical health needs are not being addressed adequately for people with a learning disability and/or autism in inpatient settings.

We have deep concerns about what this could mean if someone with a learning disability and or/ autism in an in-patient unit were to become infected with COVID-19. People with learning disabilities may not be able to communicate if they are feeling unwell or having difficulty breathing, or are in pain, so it will be important staff understand the person's existing health needs, ways of communicating and what their usual/ baseline presentation is and the person is able to access timely effective treatment.

In light of our concerns around inpatient units, we are particularly concerned about the recent announcement of a brand new 40 bedded unit, on a remote site, next to a secure hospital, to be built to send people with learning disabilities to<sup>4</sup>. This does not fit with *Building the Right Support* which commits to moving away from inpatient institutions to community based, individualised support and services.

### **Challenging behaviour**

We are concerned that the combination of social distancing, requirement to shield, restrictions on visiting, and the use of Care Act easements may lead to an increase in frequency or intensity of challenging behaviour (e.g. self-injurious behaviour or pica behaviour) for people with learning disabilities.

Increase in challenging behaviour could have a serious impact on the health and wellbeing of children and adults with learning disabilities and their families. An increase in behaviour that is challenging is an indication of an unmet need. We know that typical responses to challenging behaviour are containment - addressing the symptom rather than the underlying cause. Challenging behaviour may have increased due to pain caused by a physical health need (e.g. toothache, or ear infection). At this time, when health checks are even more difficult to access, there is a risk that the response to the behaviour is a traditional one which there has been great efforts to move away from, i.e. prescription of inappropriate medication.

Failure to address this issue with the appropriate allocation of funding and support in line with NICE guidance will add strain on the health and social care systems as increases in challenging behaviour may lead to increased admission to inpatient units.

*Note: the rule around only being able to go out once a day for exercise was eased for people with a learning disability and/or autism following families and the sector raising concerns about the impact and consequence of this for people with a learning disability who display behaviour that challenges and others who have a health or social care need which means they need to be able to move around etc., and following legal action<sup>5</sup>.*

### **Education**

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<sup>4</sup> <https://www.bbc.co.uk/news/uk-england-merseyside-53277803>

<sup>5</sup> <https://www.bindmans.com/news/government-guidance-changed-to-permit-people-with-specific-health-needs-to-exercise-outside-more-than-once-a-day-and-to-travel-to-do-so-where-necessary>

Despite the commitment to educate children with EHCPs within school, some special schools were closed during lockdown. Children with learning disabilities are extremely disadvantaged by home schooling. The DfE online SEND resources are not appropriate for those with a severe learning disability.

Many families have not had any contact from school and have struggled to get access to vital equipment. There have been significant increases in challenging behaviour as routines have changed and life has become more restricted with usual activities not available.

The return to school is likely to result in anxiety/increased levels of challenging behaviour with routines and activities looking so different. The guidance is very vague on what “extra support” will be available to support children with learning disabilities or autistic children through this. The guidance needs to spell out much more concrete expectations, working with families and the sector, to ensure effective support to make this transition.

### **Mental Health Act**

We have serious concerns about the easements to the Mental Health Act (MHA) in the Coronavirus Act which if activated have the potential to lead to further breaches of human rights.

The weakening of the safeguards to the MHA make it easier for people with a learning disability and/ or autism to end up sectioned in inpatient units where we know they are at increased risk of abuse and neglect.

The in-patient environment is likely to be even riskier during this time due to reduced staff numbers and a potential reduction in scrutiny around appropriate ‘isolation’. People with a learning disability and/ or autism must have an independent Care and Treatment Review as soon as possible and within 2 weeks of admission. There must be a continued drive to get the person out as quickly as possible into the right community provision.

One important protection to prevent people inappropriately ending up in these settings is to require professionals involved in admission to have had to explore – and rule out - a community-based placement, and to understand the *Transforming Care* agenda. Any decision to section someone with a learning disability and/or autism must have a written rationale for why a bespoke option did not happen and why the person requires a period of inpatient care at that time.

Before Covid-19 people with a learning disability and/ or autism were already overmedicated. The Government’s response to the COVID-19 pandemic must not result in a reduction of the safeguards around administering of medication. This goes against the *Transforming Care* policy direction and *Stopping over medication of people with learning disability, autism or both* (STOMP). The Independent Care and Treatment Review must also scrutinise medication.

NHS Digital Assuring Transformation data published in May 2020 showed 5 people with a learning disability and/or autism died in inpatient units in April. This is the first time deaths have been reported in this monthly dataset since it began (the number of deaths during a particular month is only reported if the number is 5 or more). As the JCHR has said in its recent report ‘It is essential that we have comprehensive and accessible data about the number of those who are autistic and/or learning disabled who have contracted and died of Covid-19. This must include a focus on those in detention, for whom the state has heightened responsibility for their right to life’ . MHSDS data published in July showed 3,330 recorded instances of restrictive interventions being used in April 2020, of which 805 were against children. However, there was only data on use of restrictive interventions for 2 out of 15 private/independent providers and 23 out of 56 NHS providers. All settings must report the use of these interventions. This must be addressed by NHSE as a matter of urgency as the little data we are already getting is likely to be the tip of the iceberg.

The independent review of those in long-term segregation was a welcome step. However, it has since been indicated by CQC that they do not intend to publish this report until the autumn. Steps must be taken to ensure that the individuals who have been identified as being in long term segregation or seclusion have been and continue to be supported to move out of seclusion and return to the community.

### **What needs to happen?**

#### **Social care funding**

This pandemic has shone a light on the importance of social care in supporting people in their daily lives and keeping people safe and healthy. While we welcome the additional money made available to the social care sector, this has been insufficient to address higher levels of spending required to meet support needs. The Government must make additional funding available to stabilise social care during this period for current and future users.

This pandemic has resulted in families being required to provide significantly increased levels of care and support, and highlighted the lack of investment in valuing and supporting them in this role (training, support, short breaks etc).

The social care system must be adequately funded to ensure providers and families can provide good quality care and respond to developments such as staff absence, suspension of services, renewed lockdown measures or additional demand.

#### **Contingency planning**

Contingency planning must start immediately for anyone at risk of admission to an in-patient unit if their current placement breaks down. These individuals will likely be known to their local authority so are easily identifiable. Contingency planning will allow providers and families the flexibility to come up with creative solutions if a person’s support package is impacted by COVID-19, for example staff shortages due to illness.

#### **Monitoring/ scrutiny of health and social care**

We are concerned about the lack of oversight of inpatient units particularly given the CQC's ceasing of regular inspections at the beginning of the pandemic. This combined with reduced face-to-face contact and visiting from people external to the unit, including families and independent advocates, means what has been happening in units has been much more 'out of sight'. It is important CQC return to regular inspections as a priority.

### **Key recommendations**

- Targeted accessible information must be produced for children and adults with learning disabilities and their families in a timely fashion, especially with regards to any local lockdowns.
- There needs to be comprehensive and robust data collection on the care and treatment of people with learning disabilities and/ or autism in in-patient settings, and this needs to be properly analysed and released regularly. This must include use of restrictive interventions and this information must be provided by all inpatient providers.
- The Government must take all possible action to ensure that no one is at risk of missing out on the healthcare they need due to disability. This includes enhanced and continued efforts to spread the message across the NHS that decisions must be made on an individual basis, that disability must not factor in decisions to withhold care or treatment, and the Clinical Frailty Scale must not be applied to disabled people. Clinical decisions must be made according to the law, including the appropriate involvement of families and those who know the patient well.
- The CQC must return to routine inspections at the earliest opportunity and set-up a new system of monitoring where physical inspections are not possible.

### **Opportunities**

While COVID-19 and the Government's response have tested and strained the health and social care systems, it has also presented opportunities for new ways of working. It is vital that where creative commissioning has happened that has benefitted people with learning disabilities, that this is able to continue and this good practice is shared. The Government and local authorities must seize the opportunity to strengthen people with a learning disability and/ or autism's right to independent living. This could be done through the fast-track development of community support packages for those at high-risk of ending up in in-patient units.

This pandemic has shone a light on what we already knew, that the social care system is at breaking point, but that it is also staffed by highly skilled people. The Government must provide immediate funding to stabilise the system in the short-term while pursuing reforms. Without this funding we heighten the risk of more individuals in inappropriate in-patient units where they are at risk of having their human rights breached.

**22/07/2020**

## **Annex – Case study**

Anonymous case study of family of someone with LD and/or autism in an inpatient unit, during the pandemic:

“Our daughter has been locked away in inpatient units for nearly 15 years now. We were finally looking forward to her being discharged into a community placement with 24-hour care in March, when the coronavirus crisis struck, and everything was put on hold. This came as a devastating blow to our family. We had been planning for her next stage of life, for her to finally achieve a level of independence, and her freedom was almost in grasp.

“This has had a massive impact on my daughter. Not knowing when she will be coming home has led to her anxiety levels increasing. Lockdown has also meant that we haven’t been able to visit her, and we haven’t been told when we can next see her. Throughout lockdown, she has been confined within the inpatient unit with only walks in the small courtyard; although she will be able to go out for limited walks with one of the support staff soon.

“We were worried sick that our daughter might contract COVID-19 while she is still locked away. Being trapped in an inpatient unit can make people physically vulnerable; I know from our daughter’s experience that it is difficult for patients to get regular physical exercise, eat healthily and people are often overmedicated. That kind of lifestyle takes a serious toll on the body. I was also worried about whether she would get the medical treatment she needs at the right time if she fell seriously ill.

“Our worst fears were realised when our daughter started displaying COVID-19 symptoms. We felt completely helpless because we couldn’t do anything to care for her while she was unwell. Although she was never tested, she was treated by the inpatient unit as being positive and was isolated for eight days. Thankfully, she is over the worst of it now but other people in her hospital are also suspected to have had it.

“What is the hardest thing for my daughter and our family during the coronavirus crisis is not having a discharge date that we can look forward to. We hope that she will be out before her next birthday so that we can celebrate together, that’s all we can do to help keep us going.”