

JCHR Call for Evidence - Protecting Human Rights in Care Settings Joint Response (Mencap and CBF)

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 1.4 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.

This response is informed by the lived experience of families of children and adults with a learning disability who campaign with our organisations and who we support through our information and support services.

Summary:

Our response sets out the evidence demonstrating how the human rights of people with learning disabilities are not effectively protected in care settings. Existing inequalities, including health inequalities have been exacerbated by the pandemic further impacting the human rights of this group.

The evidence and data suggests children, young people and adults with learning disabilities are regularly at risk of human rights abuses in care settings including:

- in hospital and when receiving physical healthcare,
- in ATUs and inpatient mental health settings,
- in residential care services and
- in their own home.

We believe individuals are at particular risk of having their human rights under Articles 2, 3, 6, 8 and 10 breached.

- Article 2 – right to life

- o In healthcare settings including lack of access to treatment, delays to diagnosis and care, inappropriate DNACPRs on the grounds of learning disability all contribute to the yearly high numbers of avoidable deaths of people with a learning disability.

- o Neglect of physical health needs in Assessment and Treatment Units and inpatient mental health settings is a recurring issue and has resulted in premature deaths

- Article 3 – protection from inhuman and degrading treatment:

- o Individuals with learning disabilities experience misuse of restrictive practices e.g., use of physical and chemical restraint, long-term segregation and seclusion.

- Article 6 – right to a fair trial:

- o Urgent improvements are needed to provide effective routes for challenge. Current safeguards in the Mental Health Act are inadequate and in need of reform.

- Article 8 – right to family and private life:

- o The average length of stay in inpatient units for individuals with learning disabilities and/ or autism is 5.4 years. As individuals are often placed outside their local area, this can have a huge impact on the ability to maintain relationships with family and friends.

- Article 10 - Freedom for expression:

People with severe learning disabilities may have limited verbal communication and can be reliant on family, friends and advocates to ensure that what is important to them is central to the decisions made about their lives. When in care settings, individuals are often cut off from family and friends.

1. What human rights issues need to be addressed in care settings in England, beyond the immediate concerns arising from the Covid-19 pandemic?

People with a learning disability are at high risk of routinely having their human rights breached in our society. We see evidence of discrimination from public services, which often goes unchallenged, and particularly during the pandemic, of vital public services which are designed in a way which does not consider, nor meet the needs of people with a learning disability, for example, when accessing healthcare.

We hear from many people who struggle to get access to social care, who need legal aid to take their case forward yet have no access to it. ¹The drastic cuts to legal aid hampers the ability of individuals to enforce their rights. It means that laws made to improve the lives of disabled people can be almost willfully ignored, as there is little consequence for authorities not following the law. When people with a learning disability do not have their social care needs met, they easily become at risk of admission to dangerous institutional settings.

Our experience shows there is an urgent need to build legal capability to ensure that people with a learning disability and their families know about their rights when accessing health and social care services, and when and how to seek legal advice. Furthermore, we see an urgent need for increased capacity within the voluntary and legal sectors to support those whose rights have been breached.

Human Rights abuses:

The HRA is a promising legal framework for protecting the rights of individuals with learning disabilities. However, despite this framework, people with a learning disability are at high risk of having their rights breached in multiple care settings, including healthcare settings, specialist inpatient units and in social care settings. It's also important to understand that human rights breaches can, and do, occur while people are being assessed for, and/or denied access to these services.

We believe there are particularly high levels of risk of human rights breaches for those who may be unable to speak up about what is happening, either due to the complexity of their needs, for example those with profound and multiple learning disabilities; or those in high risk institutional settings (inpatient units) who may be without advocates or witnesses as to what is happening to them. We are also particularly concerned for those from BAME communities, who may face double discrimination and multiple barriers when accessing services or support.

We believe individuals are at particular risk of having their rights under Articles 2, 3, 6, 8 and 10 breached.

Article 2 – right to life:

Healthcare settings: We have campaigned for many years on the inequality of access in our healthcare system for people with a learning disability. Issues including

¹ See Access Social Care submission (legal aid section) to the JCHR protecting human rights in care settings call for evidence (2021)

lack of access to treatment, delays to diagnosis and care, inappropriate DNACPRs on the grounds of learning disability all contribute to the high numbers of avoidable deaths of people with a learning disability each year. The pandemic brought these issues into sharp focus, and at Mencap we heard concerns of inappropriate DNACPRs rising, and people being encouraged not to access care should they become unwell, due to their 'support needs'. We have also supported several families who believe their loved one was denied appropriate care and treatment before they died. Others have experienced difficulties ensuring their loved one had the support they needed to access care in hospital due to visiting restrictions.

Specialist inpatient units: Neglect of physical health needs in Assessment and Treatment Units and inpatient mental health settings is a recurring issue and has resulted in premature deaths. Individuals with learning disabilities in inpatient settings must be able to get the right support, including management of long-term health conditions, treatment for new physical health issues e.g. injuries from restrictive interventions, and support for keeping healthy e.g. nutrition, oral healthcare, physical activities. Individuals who have been in inpatient settings can also be at risk of suicide from trauma and learned self-injury and suicidal behaviours from other patients. It is important to note that a failure to fully meet social care needs in the community increases the risk of admission to these kinds of settings. In the rest of this response, we will refer to these as 'inpatient units'.

Article 3 – protection from inhuman and degrading treatment:

People are experiencing inhuman and degrading treatment from misuse of restrictive practices e.g., use of physical and chemical restraint, long-term segregation and seclusion.

The inappropriate environment of inpatient settings can lead to escalations in an individual's challenging behaviour, including self-injurious behaviour. As a result, individuals can be placed in seclusion and/ or denied access to the basic facilities eg. washing facilities.

Article 6 – right to a fair trial:

Once an individual with learning disabilities and/or autism is admitted to inpatient settings, it is often very difficult to get them out. Current safeguards in the Mental Health Act are inadequate and in need of reform. Urgent improvements are needed provide effective routes for challenge.

The MHA white paper proposes care and treatment plans be put on a statutory footing and it made a requirement that recommendations made in Care (Education) and Treatment Reviews are considered. This is welcomed but CETRs must themselves be of sufficient quality and made mandatory so that they deliver good outcomes for people.

Routes for challenging detention, including CETRs and Tribunals, will only be effective if they involve people with the right expertise around good support for people with a learning disability and/or autism. Having professionals with the right expertise who are able to provide 'clinical challenge' can be crucial in getting people out of inpatient units. MHA reform must ensure this happens. We see many people with a learning disability and/or autism without an IMHA, even though they are entitled to one when detained under the MHA. Access to IMHAs should be 'opt-out' and must have the necessary skills to support individuals with learning disabilities.

Failure to commission the right support in the community can result in individuals remaining as inpatients for far longer than is necessary. Without appropriate community support available, Tribunals and the Court of Protection are limited in the discharge options that can be considered for an individual, potentially leading to longer than necessary stays in inpatient settings.

Tribunal and CoP judges and lawyers need to have an improved understanding of how individuals with learning disabilities and autism can be supported well in the community.

Families also often face gagging orders from the courts, preventing them from speaking out about their relative's experiences and publicly highlighting potential human rights abuses.

Article 8 – right to family and private life:

The average length of stay in inpatient units for individuals with learning disabilities and/ or autism is 5.4 years. As individuals are often placed outside their local area, this can have a huge impact on the ability to maintain relationships with family and friends. At the end of September 2021, 440 individuals in inpatient units were reported as over 50km from home. However, this is not representative of all inpatients - data on distance from home is missing for 955 patients.²

Article 8 includes the right to physical and psychological integrity. While in inpatient units individuals often do not have access to meaningful activities, or get the right support around nutrition and exercise.

Article 10 - Freedom for expression:

People with severe learning disabilities, who have difficulty communicating and may use limited formal communication can be particularly reliant on their family to ensure that what is important to them is central to the decisions made about their lives. When in inpatient units, individuals are cut off from family and friends who are often best placed to support them to express their wishes. This impacts on their right to freedom for expression.

² NHS, (2021), *Learning Disability Services Monthly Statistics - AT: September 2021*, MHSDS: July 2021 Final, Available at: [Learning Disability Services Monthly Statistics - AT: September 2021, MHSDS: July 2021 Final - NHS Digital](#)

Transforming Care

Following the abuse scandal at Winterbourne View hospital in 2011, **the Government promised to ‘Transform Care’** for people with a learning disability and/or autism. But progress has been slow and to date **all national targets to close inpatient beds and develop the right community support have been missed.** The bottom end of the 35-50% inpatient bed reduction target promised by March 2019 has still not been met. Latest figures show there has been a national reduction of 29%. **The target is now to reduce inpatient provision by 50% by 2024.**³

At the end of September 2021 there were **2,085 people with a learning disability and/ or autism in inpatient units**, including 210 children (an increase of 40 on the previous month).⁴

The CBF and Mencap have heard from many families whose relatives have experienced poor treatment in care settings.

“My son was horrifically abused. [He] was extremely vulnerable with no speech, he was regularly thrown down into the prone position with several staff on top of him, he was kicked and spat at by members of staff with psychological torture thrown in. Predictably, this broke him, his innocence and childhood was stolen along with his trust in humankind.” Lynne (whose son, Christopher, was in units 2007-2016) Tea, smiles and empty promises WV⁵

“The environment was torture for her. She was kept in a bright ward with strip lights that hurt her eyes. It was a ward full of distressed youngsters. She couldn’t cope with this. It triggered the behaviours that put her in the unit in the first place – an unbreakable circle of restrictive interventions followed – restraint, seclusion, segregation, secure clothing, PRN to sedate her and a straight-jacket of antipsychotic medication that reduced her from a person to a diagnosis” Jeremy (whose daughter, Beth, was in a unit 2012-2015, and 2016-2019) Tea, smiles and empty promises WV⁶

““My daughter was handcuffed by the police and put face down on the floor in [her] own home. Then being taken away in an ambulance without anyone to act as [an] interpreter or advocate. Having a blood sample taken from them whilst in ambulance whilst in handcuffs behind her back. At hospital when I arrived to find her, I was denied access until I demanded to see the papers which specified that I could not see her. The care home that she was taken to didn’t want us to see her for three weeks, and when we were allowed to see her she had multiple bruises and was so

³ NHS (2019), *The NHS Long Term Plan*, Available at: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf> (Accessed 04/11/21)

⁴ NHS, (2021), *NHS Digital Assuring Transformation and MHSDS data*, Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/at-september-2021-mhsds-july-2021-final>

⁵ See Appendix 1

⁶ See Appendix 1

drugged that she didn't recognise me for about half an hour." (family carer quote, Broken CBF final report (challengingbehaviour.org.uk)⁷)

The most recent data from NHS Digital shows **4,070 reported incidents of restrictive interventions** (within July 2021), **with 930 of these against children**. For July 2021, only data for **4 out of 16 independent providers** and **32 out of 55 NHS providers** on use of restrictive interventions was reported, therefore the actual figure is likely to be much higher.⁸

The continued detention of autistic people and people with learning disabilities in hospital settings may be in breach of their right to be treated in a dignified, humane manner, where they can freely express their personalities and live fulfilling lives, in accordance with Articles 3 and 8 ECHR. This is particularly the case when there is no acute medical reason for the individual to be in hospital, and when they remain an inpatient because a suitable community placement has not been arranged, or transition is delayed.

We need a robust cross-government action plan for transforming care which covers education, social care, health and housing. It is vital that children and young people with a learning disability who display behaviour that challenges, and their families, get the support they need early on in their local communities. There must be a real focus on prevention and early intervention to stop unnecessary admissions and avoid the subsequent risk of abuse and neglect.

Early intervention is crucial to prevent a pathway of exclusion that can lead to children with a learning disability and/or autism who display behaviour that challenges, ending up in inpatient units. Children with a learning disability must have access to the right support across education, social care, and health.

Lack of community support

Lack of social care funding is resulting in people with a learning disability and/or autism ending up in inpatient units. Urgent funding reform is needed to meet the needs of working age disabled adults.⁹ There must also be reform of the social care workforce. Staff changes and higher use of agency staff, where people are no longer supported by people they know well and who understand their needs, puts people at risk of not having their needs met, and challenging behaviour escalating. Low pay and lack of career progression for social care staff must be addressed as a matter of urgency and the social care workforce valued for the very important work they do.

⁷ See Appendix 2

⁸ NHS, (2021), *NHS Digital Assuring Transformation and MHSDS data*, Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/at-september-2021-mhsds-july-2021-final>

⁹ See Access Social Care submission to JCHR call for evidence (protecting human rights in care settings)

Changes to LA charging policies result in individuals being charged more with less money to spend on meaningful activities, again putting them at risk of their behaviour escalating.

Some cash-strapped LAs only see social care as personal care – ‘making sure people are fed and washed’. Everything else is being seen as a luxury. This is not in line with the Care Act. When people don’t get all their needs met, including access to the community and meaningful activity, this can have a huge impact on the person’s behaviour. Behaviour can escalate as a result of needs not being met and people can end up in increasingly restrictive settings as a result.

It is well recognised that there is a perverse financial incentive around admission to inpatient services. If the local authority fails to meet the person’s social care needs it can lead to the bill being picked up by the NHS.

We also see people ending up being fully health funded in the community due to very challenging behaviour as a result of unmet health and care needs. This can lead to people being placed in care provision funded by health that is more restrictive e.g. large care/nursing homes or large-scale supported living, and receiving care which is not in line with the principles and vision set out in the Building The Right Support service model,¹⁰ and in NICE guidance.¹¹ These more restrictive care settings can be further away from people’s family, friends and local community and ultimately, they can lead to admission to an inpatient unit if the person’s behaviour continues to escalate.

Care Act not followed

It is crucial people are getting proper needs assessments in line with the Care Act. This should be carried out by professionals with the right expertise, including a functional assessment of someone’s behaviour where needed and very importantly, involving the person, their family and others who know them well.

LAs are not always meeting their duties under the Care Act, including not identifying all the person’s needs and/or not properly meeting all eligible needs. We also see families not told about the individual’s and their rights under the Care Act. For example, we may see families struggling and trying to get respite, who don’t know that the individual themselves is entitled to care and support to meet eligible needs that the carer is not ‘willing or able’ to provide.

Lack of appropriate care in the community leads to individuals spending longer than necessary in inpatient settings, and being readmitted after discharge. For the families we support, it often takes legal support to help get the person discharged with the right support in place. This should not be the case.

¹⁰ NHS, (2015), *Building The Right Support*, Available at: [ld-nat-imp-plan-oct15.pdf \(england.nhs.uk\)](#)

¹¹ NICE, (2018), *Learning disabilities and behaviour that challenges: service design and delivery*, Available at: [Overview | Learning disabilities and behaviour that challenges: service design and delivery | Guidance | NICE](#)

A comprehensive needs assessment, fully involving the individual and their family, is crucial to making sure an individual's needs are met. However, we know this is not always incorporated in discharge planning – It is important the processes under the Care Act are followed to avoid traumatic readmission to inpatient settings. An essential part of this process is listening to the individual, their family and those who know the person well.

As has been highlighted in numerous reports, poor commissioning and a lack of person-centered support services remains an issue. Too often commissioners do not listen to families or value their knowledge and expertise. The power in the system is weighted against individuals and their families. We have heard numerous examples where the Mental Capacity Act has been used inappropriately to exclude families from decisions and not share information with them. Even with legal support these issues can take time to challenge and be detrimental for the individual and their pathway to getting the right care in the community, causing a lot of distress for families.

Children and young people:

“They don’t see my child as a human being” (Family Carer)

One family explained the “shock of separation” when their child was detained in an ATU. Data provided to the Children’s Commissioner’s Office by NHS Digital shows that for children in hospital at the end of February 2019 on average, children with autism, a learning disability or both had spent 6 months (184 days) in their current hospital stay, and 8 months (240 days) in inpatient care in total. Around 2 in 5 (95) children had spent at least 6 months in their current hospital spell with their current provider. Around 1 in 7 (35) had been there for at least a year. Nearly 1 in 4 children (60) had a total length of stay of at least 6 months and were in a ward at least 50 km (31 miles) from home. Around 1 in 10 children (25) had a total length of stay of at least a year and were in a ward at least 100km (62 miles) from home.¹²

Our joint report Keeping in Touch with Home found many families are discouraged from visiting their children, LAs often fail to fund travel and telephone/ digital contact is rarely used as it might be in schools, e.g., through video diaries / photos. In our view this breaches Articles 7,9, 20 and 23 of the UNCRC, Articles 9,19 and 23 of the UNCRPD and Article 8 of the ECHR (right to family life). Our Keeping in Touch with Home report sets out best practice in maintaining links with families and the community when children are away from home, including action for LAs. Children in

¹² Children’s Commissioner, (2019), Far Less Than They Deserve, Available at: [CCO-far-less-than-they-deserve-2019.pdf \(childrenscommissioner.gov.uk\)](https://www.childrenscommissioner.gov.uk/wp-content/uploads/2019/04/CCO-far-less-than-they-deserve-2019.pdf)

ATUs are most at risk of restrictive intervention, including seclusion, restraint and inappropriate use of medication.¹³

Children in ATUs are often unable to access meaningful education, breaching Articles 28 and 29 of the UNCRC.

“He remained in ATUs for five and a half years, where he lost the ability to speak clearly, his right to education and his right to family life.” ‘Juliette’ (whose son was in units 2012-2017 - Tea, Smiles and Empty Promises WV¹⁴

2. How effective are providers at respecting the human rights of people under their care?

Numerous reports including the JCHR inquiry into the detention of children and young people with a learning disability and/or autism,¹⁵ Baroness Sheila Hollins’ independent review into long-term seclusion and segregation,¹⁶ the Commons Health and Social Care Select Committee report,¹⁷ the CQC’s review into restraint, seclusion and segregation,¹⁸ and the Three C’s report, ‘Less than the sum of the parts’¹⁹ - all clearly show the human rights abuses happening to individuals with learning disabilities.

Families have shared examples of providers across a range of care settings failing to respect the human rights of people under their care and using unnecessary

¹³The Challenging Behaviour Foundation and Mencap (2016), Keeping in Touch with Home: How to help young people with learning disabilities and their families keep in touch when they are living away from home, Available at: [Keeping-in-touch-with-home-web-version.pdf \(challengingbehaviour.org.uk\)](https://www.challengingbehaviour.org.uk/keeping-in-touch-with-home-web-version.pdf)

¹⁴ See Appendix 1

¹⁵ JCHR, (2020), *JCHR reports on the detention of young people with learning disabilities or autism: government response*, Available at: <https://www.gov.uk/government/publications/jchr-reports-on-the-detention-of-young-people-with-learning-disabilities-or-autism-government-response>

¹⁶ Baroness Hollins & Oversight Panel, (2021), *Independent Care (Education) and Treatment Reviews*, Available at: [Independent Care \(Education\) and Treatment Reviews - GOV.UK \(www.gov.uk\)](https://www.gov.uk/independent-care-education-and-treatment-reviews)

¹⁷ Commons Health and Social Care Committee, (2021), *Fifth Report - The treatment of autistic people and people with learning disabilities*, Available at: [Treatment of autistic people and individuals with learning disabilities - Committees - UK Parliament](https://www.parliament.uk/business/committees/committees-a-z/commons-select/health-and-social-care-committee/fifth-report-the-treatment-of-autistic-people-and-people-with-learning-disabilities/)

¹⁸ CQC, (2020), *Out of sight – who cares?: Restraint, segregation and seclusion review*, Available at: [Out of sight – who cares? \(cqc.org.uk\)](https://www.cqc.org.uk/out-of-sight-who-cares/)

¹⁹ Jo Clare, Alison Love, Miren Cerezo, (2020), ‘Less than the sum of the parts’ *Lived experience of ATUs and mental health in-patient settings in the SELTCP region*, Available at: [AW_ATU Report MM.indd \(threecs.co.uk\)](https://www.threecs.co.uk/aw_atu_report_mm.indd)

restrictive intervention. It is important that any focus on protecting human rights covers all care settings.

Inpatient units

The serious HR abuses happening in inpatient units are well-recognised and there must be urgent action. In May this year, a group of families of people who were at Winterbourne View, wrote a report 10 years on since Winterbourne View: 'Tea, smiles and empty promises: Winterbourne View, and a decade of failures'.²⁰ In it, they reflect on their own experiences and that of other families since Winterbourne View, showing the lack of progress.

Abuse scandals in care services, including inpatient settings, have been widely publicised in the wake of the abuse uncovered at Winterbourne View Hospital,²¹ and recently in Whorlton Hall,²² Mendip House,²³ Yew Trees,²⁴ and Cawston Park.²⁵ Recently the Safeguarding Adults Review (SAR) 'Joanna, Jon and Ben' has been published – a deeply shocking review into the deaths of 3 young adults with learning disabilities at Cawston Park in Norfolk.²⁶

These and many more cases highlight that many providers are not effective at respecting the human rights of people in their care. Closed cultures and a lack of staff training have made these inpatient settings a breeding ground for human rights abuses.

Staff training and experience

We have heard concerns from families and members of the CBF legal strategy group that care staff do not have adequate training in the human rights of the individuals they are supporting.²⁷ Anecdotally we have heard that when a service is rated inadequate or put into special measures, organisations providing human rights training have found staff are less likely to take up human rights training, even though it is likely that it is in these services that human rights are most likely to be breached.

²⁰ See Appendix 1

²¹ BBC News, (2012), Timeline: Winterbourne View abuse scandal, Available from: [Timeline: Winterbourne View abuse scandal - BBC News](#)

²² BBC News, (2019 - 2020), *Whorlton Hall abuse scandal*, Available at: [Whorlton Hall abuse scandal - BBC News](#)

²³ Steven Morris & David Brindle, (2019), *CQC rebuked for failure to prosecute charity over care home abuse*, The Guardian, Available at: [CQC rebuked for failure to prosecute charity over care home abuse | Care Quality Commission \(CQC\) | The Guardian](#)

²⁴ BBC News, (2020), *Yew Trees hospital: Ten staff suspended at mental health unit*, Available at: [Yew Trees hospital: Ten staff suspended at mental health unit - BBC News](#)

²⁵ The Challenging Behaviour Foundation, (2021), *Joanna, Jon and Ben: a Serious Case Review*, Available at: [Cawston Park Serious Case Review - Challenging Behaviour Foundation](#)

²⁶

Norfolk Safeguarding Adults Board, (2021), *Safeguarding Adults Review: Joanna, Jon & Ben*, Available at: [SAR-Rpt-Joanna-JonBen_FINAL-PUBLICATION02-June2021.pdf \(norfolksafeguardingadultsboard.info\)](#)

²⁷ See Appendix 3

This strongly suggests human rights are not seen as a priority by many care services.

Human rights of family carers

In addition to the impact on individuals with learning disabilities, family carers are also vulnerable to human rights abuses when their relatives are being cared for.

Families have told us how care providers working in an individual's own home have failed to respect the human rights of the individual receiving the care, and their family members.

"We are not seen as people who should have the same rights as others. We are people who have less value and the funding and those that administer the funds are allowed carte blanche to dictate the quality of our life." (Family carer)

"I haven't experienced care regimes that really respect the human rights of people in care even though my son is living at home with me for four years." (Family carer)

Individuals with learning disabilities and their families are not always informed about their rights, and as such are unable to effectively act on them. Many families who contact our charities are not aware at the time that a human rights violation has occurred. Families are not empowered to employ the HRA in day-to-day interactions (such as those with service providers or LA), and furthermore, lack the capacity or energy to use it to launch a legal challenge. Where families do employ the HRA, they often do so using resources (template letters, toolkits etc) provided by voluntary organisations, however, those who are not in touch with such organisations may miss out on the protections of the HRA. The HRA cannot be an effective framework for these families until they are empowered to use it. In addition to not understanding their rights and specifically, their human rights, families are often unaware of the role of various regulators, including the CQC, but also the GMC and NMC for healthcare professionals.

3. How effective are regulators in protecting residents from human rights breaches and in supporting patients and residents who make complaints about their care provider?

The current CQC regulatory framework is insufficient to ensure that residents' human rights are protected, and that accountability and systemic change occurs when their rights are breached. The regulator does not act quickly enough to prevent abusive cultures towards learning disabled and/or autistic residents becoming embedded in care settings.

"I have no idea who 'regulators' are.? There is no effective regulation I have ever experienced that I am able to report. It has been chaos and a regime designed to make my son's disability more profound by being put in poor and inefficient care environments for the profit of a care company?" - Family Carer

"It is too dangerous to make a complaint about a care home because it's impossible to be anonymous and so no-one risks the care home staff taking it out on the

vulnerable person in their care. Social services hound parents and lie about them in court so the whole experience of having a disabled relative is scary and makes one traumatised all the time. I am so worn out by all of this and fed up that I can't protect my daughter adequately." (Family Carer, Broken report)²⁸

"One of [the units Kayleigh was in] was run by an organisation that has had various different names, and each time they receive a bad CQC report, a simple name change ensures all past reports are lost forever in the system. Same staff team, same responsible individual, same poor care with a different name." Wendy, mum of Kayleigh, (Tea, Smiles and Empty Promises WV)²⁹

We hear from families that early indicators of failing services are not recognised by the relevant authorities and when relatives voice these concerns, they are often ignored. There is a clear lack of communication with family carers and a lack of signposting and advocacy support when their relative is in an inadequate inpatient unit.

Unsatisfactory investigations

When investigations are instigated, often the outcomes are not satisfactory. Regulatory processes, including hearings and related court processes, can lack the awareness and sensitivity of learning disabilities, autism, and challenging behaviour which are necessary to ensure that rights can be upheld effectively. We believe mandatory training in learning disability should be apply to regulatory bodies.

The CBF report *'Broken: The psychological trauma suffered by family carers of children and adults with a learning disability and/ or autism and the support required'* outlines the regular experience of trauma suffered by families, not least of all during court proceedings and tribunal hearings.³⁰ Family carers have told us that their children with learning disabilities are treated as though they are *"unreliable witnesses"* when interacting with the legal system, and that their children always seem to be *"on trial"* when in court.

Regulation of inpatient settings

Repeated abuse scandals continue to reoccur in services and institutions that the CQC has previously rated "good", leaving residents exposed to egregious breaches of their human rights. CQC inspections often fail to uncover abuse and mistreatment of residents, which may not be exposed until undercover footage is obtained privately or by media investigations.

"If you don't get the abuse on film it really doesn't seem to count... The sad truth is poor providers are allowed to flourish when they are not monitored and held

²⁸ See Appendix 2

²⁹ See Appendix 1

³⁰ See Appendix 2

accountable by those who commission the care.” ‘Vicky’, whose son was in units (Tea, Smiles and Empty promises WV) ³¹

For example, the CQC rated Whorlton Hall hospital “good” after an inspection in 2017; whereas the BBC’s undercover panorama programme in 2019 revealed widespread abuse and assaults against patients with a learning disability at the service.

Safeguarding

Families also often raise safeguarding alerts with their local safeguarding team. For the immediate issue for their family member, too often the response from safeguarding is inadequate. Often safeguarding concerns raised about care and treatment in a unit are not properly investigated and/or acted upon by the local safeguarding team – as the unit is seen as a ‘specialist’ unit – so there is insufficient scrutiny. This is despite the Winterbourne SCR saying that these places are ‘high risk’ and safeguarding investigations should be more rigorous.

Healthcare settings

We have welcomed intervention at a national level from the CQC to issues affecting people with a learning disability that have been raised during the pandemic, including reviewing inappropriate DNACPRs, ³² and the State of Care report 20/21 which found that systems were not always able to take account of the needs of people with a learning disability.³³ However, we have yet to see whether the CQC’s national recommendations on solving these issues will be implemented and actioned.

At an individual case level, it has historically been very difficult and often frustrating to work with regulators. Often, when individuals with a learning disability have difficulties accessing care, it is due to a combination of individuals and system failures. Due to the fragmented approach of regulators, families can find themselves dealing with 1, 2 or even 3 different organisations in the aftermath. The findings of individual regulators may often decide that ultimately, the accountability lies elsewhere, or that an incident was due to a number of factors, not all within the individual practitioners control, and decide not to take any action. For families, this can lead to an outcome where there is no accountability.

Learning disability training for regulators is very important, and we welcomed the opportunity recently to work with the NMC to take steps to improve their approach, which we hope will go some way to improve how they are able to address concerns about care for people with a learning disability and support families.

Regulation leading to system change

³¹ See Appendix 1

³² CQC, (2020), *Protect, respect, connect – decisions about living and dying well during COVID-19*, Available at: [Protect, respect, connect – decisions about living and dying well during COVID-19 | Care Quality Commission \(cqc.org.uk\)](https://www.cqc.org.uk/publications-reports/protect-respect-connect)

³³ CQC, (2020-2021), *State of Care*, Available at: [Increased challenges for people with a learning disability | Care Quality Commission \(cqc.org.uk\)](https://www.cqc.org.uk/publications-reports/state-of-care)

Despite the commitment from government to *reduce* the number of beds in these expensive and ineffective institutional settings, and the increased risk of closed cultures in large inpatient settings, last year Mersey Care received planning permission for a *new* 40-bed unit at Maghull using £33m of government funding. This goes against NHSE's own recommendation following the Calderstones re-provision consultation.³⁴

The proposed 40 bed unit is to be built on the same site as a recently opened 123 bed Medium Secure Unit, completed in 2020 at the cost of £60m, including 45 beds for people with a learning disability and/or autism.

4. What lessons need to be learned from the pandemic to prevent breaches of human rights legislation in future?

The pandemic has highlighted existing inequalities for children and adults with learning disabilities and their families.

The JCHR June 2020 report stated: *“Now that institutions are closed to the outside world as a result of the Covid-19 pandemic, the risk of human rights abuses are even greater. Unlawful blanket bans on visits, the suspension of routine inspections, the increased use of restraint and solitary confinement, and the vulnerability of those in detention to infection with Covid-19 (due to underlying health conditions and the infeasibility of social distancing) mean that the situation is now a severe crisis”*.³⁵

It is now even more important that lessons are learnt, and recommendations are followed (many of which were identified before the pandemic) to prevent further human rights breaches in the future.

- The repeated or inappropriate use of restraint and seclusion against individuals with learning disabilities should be treated as a safeguarding and human rights issue.
- Urgent action should be taken to implement the Transforming Care agenda.
- Urgent action should be taken to prevent the unlawful imposition of DNACPRs in relation to autistic people and people with learning disabilities.

At the start of the pandemic the CQC stopped in person inspections without alternatives in place and failed to maintain robust scrutiny of these services to ensure safety and quality, despite many of them being acknowledged as “high risk” environments. Regulators must learn from this and ensure robust scrutiny of services continues going forward and keep individuals and families informed of any concerns as soon as they arise.

³⁴ See Appendix 4

³⁵ JCHR, (2020), *Coronavirus has left young people in detention facilities highly vulnerable to Human Rights abuses*, Available at: [Coronavirus has left young people in detention facilities highly vulnerable to Human Rights abuses - Committees - UK Parliament](#)

- The CQC should contact all immediate relatives / next of kin after safeguarding issues are identified in a care setting, and particularly when a service is rated inadequate.
- Families should be provided with information about how to seek legal advice and assistance at an early stage.
- The CQC should make more use of its power to bring criminal prosecutions against health and social care providers for failing to provide care and treatment in a safe way.
- The CQC should ensure that residents who suffer abuse are enabled to provide their evidence to the investigation in a supportive manner, bearing in mind the individual's needs.

Healthcare

The pandemic has emphasised the inequalities suffered by people who have a learning disability and/or who are autistic. Before the pandemic, people with a learning disability were known to be at particular risk of missing out on the care they need, and it was understood that people were 4 times more likely to die from a cause that would be expected to be treatable³⁶. We know there can be a number of barriers within the healthcare system, including delays to care and treatment which can arise from issues including diagnostic overshadowing, a failure to identify and make reasonable adjustments, a lack of specialist support for those with the most complex needs (including those behaviour may challenge healthcare teams), and difficulties with decision making and compliance with the mental capacity act. Those risks were known to be pervasive throughout the healthcare system. Entering the pandemic we needed to see those risks addressed, and support for healthcare professionals to meet the needs of people with a learning disability in this new, dangerous environment. We needed the system to respond in a way which enabled people with a learning disability to access the support they needed, including that of family and familiar supporters, which can so often enable to effective advocacy which we believe saves lives.

Throughout the pandemic, the development of guidance has been rushed, and has either not met the needs of people with a learning disability, leaving them at risk of missing out on care, or at worst, actively caused harm – for example, the NICE Critical Care Guidance at the beginning of the pandemic which suggested that disabled people with support needs should not be given critical care treatment. This led to a number of GPs writing to disabled people advising them to consent to a DNACPR and not to attend hospital should they become unwell. We have also seen multiple examples of inappropriate DNACPRs based on disability, which led the Secretary of State to commission an investigation from CQC which found widespread issues.

During the pandemic we saw organisations not complying with the Public Sector Equality Duty (PSED), and the very serious consequences for people with a learning disability. We would welcome some specific work to improve compliance with the PSED, in relation to people with a learning disability, particularly reflecting on what happened during the pandemic.

³⁶ Bristol University (2020) LeDeR Annual Report 2019

People with a learning disability have been 8 times more likely than the general population to die of coronavirus during the pandemic³⁷. The pandemic has brought long standing issues with access to care and treatment into sharp focus, including a lack of compliance with the Equality and Mental Capacity Acts. Mencap have supported a number of families during the pandemic where families believe loved ones with a learning disability have died due to missing out on medical treatment. We have seen evidence of inappropriate DNACPRs, and people encouraged to consider these decisions, and to not seek admission to hospital should they become unwell, due to their support needs. We have supported several families who struggled to be with their loved one in hospital, despite a clear need for support.

These issues have been picked up in various research and reports including the LeDeR annual report,³⁸ CQC's state of care report,³⁹ CQC's review of DNACPR during the pandemic,⁴⁰ Mencap's report on access to healthcare during the pandemic,⁴¹ and CBF's New Normal report.⁴²

³⁷ British Medical Journal (2021) [Risks of covid-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform](#).

³⁸ University of Bristol, (2020), *LeDeR annual report*, Available at: [NHS England » University of Bristol LeDeR annual report 2020](#)

³⁹ CQC, (2020-2021), *State of Care*, Available at: [Increased challenges for people with a learning disability | Care Quality Commission \(cqc.org.uk\)](#)

⁴⁰ CQC, (2020), *Protect, respect, connect – decisions about living and dying well during COVID-19*, Available at: [Protect, respect, connect – decisions about living and dying well during COVID-19 | Care Quality Commission \(cqc.org.uk\)](#)

⁴¹ Mencap, (2020), *My Health, My Life: Barriers to healthcare for people with a learning disability during the pandemic*, Available at: [MyHealthMyLife_COVID report.pdf \(mencap.org.uk\)](#)

⁴² See Appendix 5

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Appendix

1. 'Tea, Smiles and Empty Promises' (May 2021)

In May 2021, a group of families with relatives who were at Winterbourne View published a collection of family stories 'Tea, smiles and empty promises', reflecting on the decade since BBC Panorama exposed abuse at Winterbourne View hospital and the lack of progress in Transforming Care.

Further details and the full report are available here: [Winterbourne View 10 years on - Challenging Behaviour Foundation](#)

2. 'Broken': The psychological trauma suffered by family carers of children and adults with autism and/ or a learning disability and the support required. (December 2020)

The CBF was a partner in a project with Respond, the Tizard Centre, and Three Cs funded by NHSE to look at the need for trauma support for the family carers of children and adults with learning disabilities and/or autism. In the first strand of the project CBF gathered the views of family carers. The findings are written up in this report.

Read the full report here: [Broken CBF final report \(challengingbehaviour.org.uk\)](#)

3. The CB-NSG Legal Panel

The Legal Panel is a subgroup of the Challenging Behaviour National Strategy Group, established in 2016, which aims to make better use of the legal framework for enabling families to get the right support for their relatives. It does this by:

- Providing information and initial guidance at an early stage
- Answering legal queries submitted by families in contact with the CBF, Mencap and NAS. The answers to these questions are returned to families directly, and [collated as FAQs on our site](#).
- Identifying strategic legal cases and issues of importance to families of individuals with learning disabilities and/or autistic people, and acting accordingly with support or legal challenges

- Coordinating and sharing legal work done by a range of groups relevant to learning disabilities and/or autism, with this work including involvement in legal cases, developing resources, and offering support and information

The legal panel meets regularly and is comprised of representatives of a number of leading law firms, academics and charities. Members work together to improve outcomes for individuals with learning disabilities and/or autistic people and their families when engaging with the legal system.

For further information about the legal panel, and the legal strategy group is available on the CBF website: [National Strategy Group - Challenging Behaviour Foundation](#)

4. 40 Bed Unit

NHSE recommendation in relation to low secure provision to replace Calderstones: **‘Commence the development of smaller units for low secure services across the North West**, which will provide approximately 70 low secure beds supported by community beds and specialist support teams. This new model of care has been developed in conjunction with the Transforming Care Partnerships (TCPs) across the North West and would be implemented to support the discharge of a number of service users as outlined in their Care and Treatment Review. **In addition, there would be a new community model for forensic support which would enable secure care to be provided in a different way, other than a hospital.’**

(See pg 6&7: <https://www.england.nhs.uk/wp-content/uploads/2017/03/nhs-consultation-proposals-redesign-ld-services-across-north-west.pdf>)

5. ‘New Normal’ reports

The CBF ‘New Normal’ survey ran throughout September and October 2020, asking open questions to family carers of individuals with severe learning disabilities and to those working in healthcare, education, disability or other relevant services. The survey aimed to collect their views on how well the practices and services instituted to meet the demands of the pandemic compared to what came before, and what new forms of ‘good practice’ they may have experienced.

The four short reports summarising the findings and key lessons to be learned from the pandemic are here: [New normal project - Challenging Behaviour Foundation](#)

