**Some key areas/points re: people with a learning disability – to feed into UNCRPD monitoring**

**(For info we can turn this into a more formal response – but just sending these points/areas for now)**

**Introduction**

People with a learning disability are at high risk of routinely having their human rights breached in our society, whether that be their right to participate, right to family life or right to freedom from inhuman treatment. We see evidence of discrimination from public services, which often goes unchallenged. We have seen evidence, particularly during the pandemic, of vital public services which are designed in a way which do 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. [[1]](#footnote-1)The 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 wilfully ignored, as there is little consequence for authorities not following the law.

There is an urgent need to build legal capability to ensure that people with a learning disability and their families know about their rights, 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 people whose rights have been breached.

**Social care**

**Social care crisis /inadequate funding and impact – a longstanding issue and brought into sharp focus during the pandemic.**

Many people with a learning disability saw their support cut during the pandemic and this must be reinstated. Getting the right social care support is fundamental to having their human rights met.

**Social care funding reform is** urgently needed to meet the needs of working age disabled adults.[[2]](#footnote-2)

There must also be **reform of the social care workforce.** 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:

* ***Recruitment***:There are approximately 110,000 vacancies in adult social care[[1]](https://outlook.office.com/mail/inbox/id/AAQkAGRlOTc5OGI0LTBmNjctNDFmMS1iYjIxLWFhMDVjMjkzYmI2YwAQAHjDwD8ZnFhGlM0nsGH5wTk%3D#x_x__ftn1) and a 42% staff turnover per year. This is likely to increase as other sectors re-open after lockdown and mandatory vaccinations are rolled out, meaning that some care workers are deemed ‘undeployable’. Our own voluntary turnover has gone up in recent months from 17% to over 21%.
* ***Lack of career progression:*** There are no opportunities or incentives to develop within a practitioner pathway and available qualifications are limited to the general social care diploma.
* ***Low pay***: A report recently commissioned by Community Integrated Care shows that many frontline workers in social care are “significantly undervalued” by as much as 39% – nearly £7,000 a year – compared to equivalent publicly funded positions, according to the report. The average pay for support workers in England who assist people to live independently in the community is £17,695 or £9.05 per hour – 45p per hour below the Real Living Wage.

We want to see a national care workforce plan to:

* Give the social care workforce parity of esteem with their NHS colleagues. This should be a set national care wage which, as a minimum, is the Real Living Wage.
* Recognise, reward and retain the high-quality support that is offered by the workforce
* Act to professionalise the care workforce
* Focus commissioning on providing packages of care rather than on hourly pay for staff

**Transforming Care**

**Over 2000 people with a learning disability and/or autism are in inpatient units where they are at increased risk of abuse and neglect.** The Government has repeatedly promised to transform care for people with a learning disability and/or autism, but to date their targets to build the right community support and reduce inpatient beds have been missed. The human rights abuses people are experiencing in these settings are well-recognised and must be urgently addressed. The latest Government target is to close 50% of inpatient beds by March 2024.

After pressure from individuals, families and campaigners the Government has now committed to publishing a cross-government action plan for Transforming Care which covers education, social care, health and housing. It is crucial this Action plan is robust and ensures that children and adults with LD/autism and behaviour that challenges can get the right support in the community and do not end up inappropriately in inpatient units. Early intervention is key. NHS England’s Building the Right Support service model sets out the support that should be in place in the community, to help prevent inappropriate admission or readmission to inpatient units – this includes care providers with the right skills, suitable housing and health professionals who can help prevent and manage crisis situations in the community. The key reasons for delayed discharge from inpatient units, reported in monthly NHS digital Assuring Transformation data, are lack of social care and lack of suitable housing.

See our **joint letter with CBF, Rightful Lives, LDE and NAS on 6th January 2022** to The Independent calling for a robust Action plan for Transforming Care: [www.mencap.org.uk/press-release/letter-independent](http://www.mencap.org.uk/press-release/letter-independent) (this letter includes key concerns and statistics)

**Mental Health Act reform**

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.

**Building new large-scale inpatient units for people with LD/autism**

Despite the commitment from government to reduce the number of beds in inpatient units, and the increased risk of closed cultures in large inpatient settings, Mersey Care has received planning permission for a new 40-bed low secure unit for people with a learning disability and/or autism on the Maghull site in the North West using £33m of government funding. This goes against NHSE’s own recommendation following the Calderstones re-provision consultation.

The Maghull site is a geographically isolated site. The new 40-bed low secure unit is to be built on this site, next to a recently opened 123 bed medium secure unit (which has 45 beds for people with a learning disability and/or autism) and a high secure unit.

**Healthcare for people with a learning disability**

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

People with a learning disability have been 3.7 times more likely than the general population to die of coronavirus during the pandemic (ONS data). In addition, during 2019/2020 people with a learning disability were 3 times more likely to die avoidably of a cause which was treatable with good quality healthcare. The pandemic has brought long standing issues with access to care and treatment into sharp focus, including long standing issues with compliance with the Equality and Mental Capacity Acts.

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.

The above issues have been picked up in various research and reports including the LeDeR annual report,[[3]](#footnote-3) CQC’s state of care report,[[4]](#footnote-4) CQC’s review of DNACPR during the pandemic,[[5]](#footnote-5) Mencap’s report on access to healthcare during the pandemic,[[6]](#footnote-6) and CBF’s New Normal report.[[7]](#footnote-7)

**Improving access to apprenticeships, training opportunities and employment for people with a learning disability.**

We would like to see the Government going further with supporting people with learning difficulties and/or a Disability (LDD) and to make the flexibilities around the maths and English requirements for apprenticeships currently available to those with Education, Health and Care Plans, also available to a wide group of people with a learning disability and/or difficulty who have through a clear process of assessing need been identified as requiring these flexibilities.

We would like to see adjustments to the entry criteria for apprenticeships made, for people with a learning disability who don’t have an EHCP. The systematic barriers to accessing apprenticeships must be addressed.

There is a significant disability employment gap in the UK, and this gap is widest among people with a learning disability. Only a very small number of people with a learning disability are currently in employment, with most recent figures standing at 5.6% of those local authorities provide services to. In 2019, around 21% of adults with a learning disability were in employment. Both sets of data are not very reliable. Nevertheless, they show the stark issue with employment for people with a learning disability.

Many national employment programmes like Kickstart and Restart are not accessible to people with a learning disability. As such, employment support for people with a learning disability is to a large extent at the discretion of local government. It is not currently a statutory requirement for local authorities to provide employment support, and hence Mencap understands that many have in recent years cut the amount they spend on this provision. As a result, employment support is patchy, as is the quality.

Disability Confident supports employers to hire disabled people. Within this scheme, employers can apply for three levels: Disability Confident Committed (level one), Disability Confident Employer (level two) and Disability Confident Leader (level three).

In the past, Disability Confident level one employers were required to provide disability equality training for all staff and conduct an annual self-assessment of how to improve. Since 2016, employers are simply required to assess themselves on their own performance within the first two levels, after which DWP will send them a badge and a certificate that they can use to promote their “disability confidence”.

It is only if they want to become a Disability Confident Leader that their self-assessment must be “validated” by another organisation. Requiring more of employers to secure membership to the Disability Confident scheme would make it more attractive to employers and boost its credibility among disabled people. We would like some detail as to how this initiative has increased the number of employers taking on disabled members of staff and has changed employers’ attitudes toward disabled people as workers.

**Welfare benefits**

**On Universal Credit uplift:**

In March 2020, in response to the Covid-19 pandemic, the Government announced a temporary emergency increase of £20p/w for both Universal Credit and Working Tax Credits. However, the same increase was not extended to other ‘legacy’ benefits, such as Employment and Support Allowance (ESA), excluding around two million disabled people. There is a strong argument that the exclusion of legacy benefits was discriminatory, given that they are disproportionately received by people who are disabled or have long-term health conditions. There is also good evidence of the hardship associated with this exclusion.

On 17th and 19th November 2021, the High Court heard a case from two people challenging the Government’s decision to not provide the £20p/w uplift provided to people on Universal Credit to those on legacy benefits. We are awaiting a decision on this case.

**On inadequacy of benefit rates:**

DBC surveyed disabled people who claim legacy benefits (the majority claim ESA), [*Millions Missing Out, 2020*](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fdisabilitybenefitsconsortium.files.wordpress.com%2F2021%2F08%2Fthe-millions-missing-out.pdf&data=04%7C01%7CBella.Travis%40mencap.org.uk%7C5fd1b669d5c249bb371308d9d101b89f%7Ced4dd050e39e4e0ea9994097f9afb165%7C0%7C0%7C637770627580782854%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000&sdata=uBKO2XMsAC0qdGhDA3u%2B%2FpA4SeBu9bHLdilxQMcuTa4%3D&reserved=0)

“The pandemic was preceded by a 10-year long cut of £30 billion in expenditure on benefits and tax credits. The burden of these cuts fell most heavily on disabled people, creating an environment that is difficult and unforgiving. Previous DBC research found that disabled people had lost benefit payments of around £1,200 on average for each of those years while nondisabled people saw a reduction of around £300 each year.”

* 78% of disabled claimants have found their financial situation worsen since the start of the pandemic.
* Two thirds (67%) are unable or struggling to eat a balanced diet
* Just under half (46%) reported that they were now falling behind on rent or mortgage payments
* Discriminatory was the most common view (43%) of how the government had treated people in disability benefits during the pandemic

Also, according to [Understanding Society](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.understandingsociety.ac.uk%2F&data=04%7C01%7CBella.Travis%40mencap.org.uk%7C5fd1b669d5c249bb371308d9d101b89f%7Ced4dd050e39e4e0ea9994097f9afb165%7C0%7C0%7C637770627580782854%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000&sdata=6vNA2f5b2C0o45bu0S94iXXNFIXf%2FCjIzBH50iSiO8w%3D&reserved=0) data from 2021 (which is a representative survey of about 15k people):

* Over half a million (502,000) disabled people on ESA are currently in debt with a total of 35% behind on bills and/or housing payments
* the average amount of debt for people on ESA was £2580

**Participation in political and public life**

People with a learning disability have has much right to vote as anyone else. However, multiple barriers prevent people with a learning disability from being able to engage in politics, register to vote and vote itself. As a result, many people with a learning disability do not feel engaged in the democratic process.

The barriers many people with learning disabilities face when engaging with the voting system include:

* A lack of understanding among some people with a learning disability of their right to vote, and belief among some that there is a ‘mental capacity test’ to be able to vote.
* The way some politicians and political parties communicate can be inaccessible.
* Voter registration forms are often complicated and not accompanied by an easy read guide. However, the online form does have an easy read guide which Mencap produced.
* Many people with a learning disability don’t get the support they need to learn about the policies of the different parties and candidates.
* Polling stations can be inaccessible and confusing which may lead to a bad experience and therefore put people off voting.

*Voter ID*

We are concerned that the introduction of voter ID could result in another barrier to people with a learning disability participating in elections. This is due to the lower levels of ownership of photo ID, such as a passport or driving licence, among people with a learning disability as few drive and/ or can afford to or are able to travel overseas.

However, the Government have taken some steps to mitigate the impact of the policy by widening the list of eligible ID, especially with regards to travel passes, which we know many people with a learning disability have. But the reduced ownership of other forms of ID could lead to a situation where people with a learning disability are heavily reliant on either their travel pass or applying for an Elector Card.

We are also concerned at the provisions in the Bill to allow the Government to alter the list of acceptable ID through secondary legislation. We acknowledge that changes must be done in “accordance with a recommendation of the Electoral Commission”, we are concerned that travel passes might be seen in the future as not ‘secure’ enough compared to other ID and therefore removed from the acceptable list of ID.

The Elections Bill also introduces an ‘Elector Card’ which is designed to provide a form of ID for those who do not own one of the acceptable IDs outlined in the Bill. While the inclusion of a free elector card is a welcome, there are several issues which need to be addressed.

We expect a significant number of people with a learning disability will require an elector card. The process to obtain an elector card must be accessible and well-advertised if the Government is to meet its intention to not place additional barriers to people with a learning disability voting.

Currently, the Elections Bill simply states that while forms and provision of documents will be required, the details of these are left to further regulations. To ensure that the forms and processes for obtaining an elector card are accessible, they should be co-produced and co-developed with people with a learning disability. We welcome our engagement to-date with officials on the design of the application process and hope this continues.

In addition to the application process, local electoral services teams will have a crucial role to play in running the Electoral Card process. This is especially the case for people with a learning disability as we know that these teams often support people with a learning disability to engage in the democratic process more widely. The Government must provide the additional support required to ensure that these teams are able to undertake more outreach services and support in the lead up to any introduction of voter ID.

**Children and young people with a learning disability**

**Ensuring disabled children, including those with a learning disability, and their families get the right support.** Mencap is one of the founding members of the Disabled Children’s Partnership, a coalition of 100 organisations that campaigns for better health and social care support for disabled children and their families. In 2020, in conjunction with Scope – another of its founder members – DCP published an economic analysis showing a pre-pandemic annual funding gap of £2.1 billion for health and social care for disabled children and their families.

On top of this pre-existing funding gap, the pandemic has had a devastating impact on disabled children and their families. This is set out in detail in the recent report by the Disabled Children’s Partnership, Then There Was Silence. It showed how families with disabled children had been left isolated and abandoned during the pandemic as vital support was reduced or stopped altogether. All members of the family have endured isolation and deteriorating mental health and well-being, and disabled children have seen their development regress. What is more, support has been slow to return even as lockdown restrictions have eased and families remain isolated. It is vital, therefore, that central and local government and the NHS prioritise the needs of disabled children and their families in their covid recovery plans.

**Avoiding the pathway into inpatient units for children and young people with a learning disability** (See also the ‘Transforming Care’ agenda section)

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. It is crucial that children with a learning disability can access the right support across education, social care and health, when they need it.

**Addressing the broken EHCP system.** Tribunal panels upheld local authority decisions in only 193 of 3,770 hearings in 2020 – an LA success rate of 5%, the worst on record (<https://www.specialneedsjungle.com/95-decisions-favour-parents-nobody-wins-send-tribunal/>).

Families are having to go through expensive, time-consuming and stressful tribunals to get legal rights enforced. This is unacceptable.

The issue of Local Authorities not upholding the rights to support and provision of children with a learning disability and their families must be addressed.

1. See Access Social Care submission (legal aid section) to the JCHR protecting human rights in cares settings call for evidence (2021) [↑](#footnote-ref-1)
2. See Access Social Care submission to JCHR call for evidence (protecting human rights in care settings) [↑](#footnote-ref-2)
3. University of Bristol, (2020), *LeDeR annual report*, Available at: [NHS England » University of Bristol LeDeR annual report 2020](https://www.england.nhs.uk/publication/university-of-bristol-leder-annual-report/) [↑](#footnote-ref-3)
4. 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/major-reports/soc202021_01c_challenges-ld) [↑](#footnote-ref-4)
5. 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/themed-work/protect-respect-connect-decisions-about-living-dying-well-during-covid-19) [↑](#footnote-ref-5)
6. 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)](https://www.mencap.org.uk/sites/default/files/2020-12/MyHealthMyLife_COVID%20report.pdf) [↑](#footnote-ref-6)
7. CBF New Normal report://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/changing-poor-practice/new-normal/ [↑](#footnote-ref-7)