

# Access Social Care – Evidence relating to the United Convention on the Rights of Disabled People (CRDP) (Shadow Report)

*November 2021*

## Background

Access Social Care (ASC) is a new charity working to provide access to justice for people with social care needs. We act as a central hub for social care advice, providing advice and casework to beneficiaries in social care provision. We operate in the early legal help space, providing casework support up to and including pre action letters, advising hundreds of people since our launch in April 2020.

We have extensive experience advising on care and support in various types of care settings. Our operating model allows us to obtain in-depth insight into current trends and challenges within care settings, regularly liaising with frontline care managers and senior executive teams. We collaborate with the wider sector, chairing a national helplines data sharing project which collates insight from tens of thousands of callers. Our State of the Nation report was published in May 2021<sup>1</sup>

## Response

Our response to this call for evidence addresses adults aged 18 or over and their unpaid adult carers in England only.

We address some of our key concerns with reference to the Committee on the Rights of Persons with Disabilities Concluding Observations document (2017) (“concluding observations”)<sup>2</sup>.

### **(A) General principles and obligations (Articles 1 – 4)**

As the annual Care Quality Commission State of Care report highlighted in October 2021, the pandemic has further exposed and exacerbated existing inequalities<sup>3</sup> for disabled people in England, many of which raise significant and, in many cases, worsening human rights issues. Many of these inequalities were already worsening against the backdrop of ten years of austerity, including crippling local authority budget cuts and welfare benefits reform. We set out below a summary of key concerns on specific convention rights below, although many of our cases involve multiple potential breaches.

Access Social Care commissioned health economists at Oxford University this year to report on the structure of funding for social care and how this differentially affects

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<sup>1</sup> [State of the Nation Report \(accesscharity.org.uk\)](https://www.accesscharity.org.uk/state-of-the-nation-report)

<sup>2</sup> [Treaty bodies Download \(ohchr.org\)](https://www.ohchr.org/Treaty_bodies/Download)

<sup>3</sup> [State of Care | Care Quality Commission \(cqc.org.uk\)](https://www.cqc.org.uk/state-of-care)

local authority areas<sup>4</sup>. The authors conclusions reflect the findings of the Association of Directors of Adult Social Services (ADASS). For several years, ADASS has carried out an annual survey of its members. In the survey published in July 2021, 79% of the ASC directors who responded have either partial or no confidence that their 2021/22 budgets would be sufficient to meet their statutory duties. This is a shocking statistic. Statutory duties include:

- Assessments
- Information and advice
- Prevention and wellbeing
- Personal budgets/ services to meet statutory needs
- Safeguarding
- Deprivation of Liberty

All these statutory duties will have an impact on at least one Convention right. The researchers noted that there is a dearth of studies that specifically look at unmet need, especially for people from BAME backgrounds and LGBT groups. They did not find any empirical studies pertaining to unmet needs specific to people from Black, Asian or Minority Ethnic (BAME) backgrounds living in England. Willis et al., (2016) measured satisfaction of social care services with 82 service users and family carers from white British and South Asian backgrounds in Hampshire, Portsmouth and Southampton. They found that the majority of their sample reported a positive satisfaction rating when using a questionnaire, but at interview, their narratives at interview gave a more negative perspective. However, this study did not directly measure unmet needs. The majority of participants in most studies mapping unmet needs [e.g. Brimblecombe et al., (2017) and Forrester-Jones et al., (2020)] were White British, Irish or Other White). This indicates a major gap in evidence of the particular barriers people with disabilities from BAME background face in meeting their need for social care. Likewise, the unmet needs of LGBT older adults and adults with disabilities in England have not been mapped sufficiently. If their experiences equate to those of their counterparts in America (see for example, Brennan-Ing et al., 2014 whose study sample included a third from BAME backgrounds), they will face additional difficulties getting their needs met, including discrimination from service providers. There is therefore a need for more studies exploring unmet need in relation to intersectionality. More detail is available in the report on our website.

Other recent data, from our Helplines Data Collaboration project, incorporating Access Social Care data with that of other social care advice organisations across the sector and analysing over 62,000 enquiries over two years, indicates an increase of over 120% in calls to helplines about problems with existing care and support in just one year (August 2020 to August 2021). Increases were seen primarily in callers contacting helplines about poor quality support, or requests for help to challenge care planning decisions. Many of these people are struggling to secure the appropriate support required to meet their needs, often raising concern over at least one (and usually multiple) Convention rights. Our findings also set out additional areas of concern in relation to social care in our most recent report, available on our website<sup>5</sup>.

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<sup>4</sup> [Access Social Care briefing report](#)

<sup>5</sup> [Helplines Data Collaboration Group – Interim Report indicates sharp rises in community care advice provision \(accesscharity.org.uk\)](#)

## **(B) Article 5 – Equality and non-discrimination**

We note in the concluding observations that the Committee observed with concern:

*“The insufficient incorporation and uneven implementation of the Convention across all policy areas and levels within all regions, devolved governments and territories under its jurisdiction and/or control”<sup>6</sup>*

A key concern at the outset of the COVID-19 pandemic in relation to Article 5 (often combined with Article 23) related to visiting family members or receiving visits in supported living accommodation, a type of accommodation distinct from both private family homes and care homes.

We quickly became concerned that central government were failing to afford adults in supported living accommodation with sufficient protection through either Regulations or guidance in the same way that care home residents had been. The Health Protection Regulations 2020 and subsequent guidance afforded residents in care homes certain legal rights and protections to ensure that their needs under the Care Act 2014, Human Rights Act 1998 and other UNCRDP rights, were specifically protected (although we note in practice sometimes misunderstood or not implemented appropriately in relation to care homes).

Access Social Care spent several months across 2020 collecting evidence and providing casework support for people in supported living who, in many cases, were experiencing serious breaches of their convention rights (examples attached). In October 2020, we referred a client affected by these issues to Bindmans Solicitors. We supported the client’s application for judicial review. Our letter to the then Secretary of State for Health can be found on our website<sup>7</sup>.

The case demonstrated integral failings by government across the pandemic for people who had care and support needs and were not living in residential care homes. This is an example of uneven implementation of the Convention across all policy areas and all levels, a recommendation the government should have addressed from 2017. Over 600,000 people in supported accommodation throughout periods of restrictions were left without any legal protection to ensure that their human rights were respected. These clients, as demonstrated in the attached annex of evidence<sup>8</sup>, were often unable to see family members with devastating consequences. Government must learn from these cases to ensure that disabled people in every type of accommodation, receiving varying types of care and support, never experience such harrowing breaches of their human rights again.

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<sup>6</sup> [State of the Nation Report \(accesscharity.org.uk\)](https://www.accesscharity.org.uk/state-of-the-nation-report)

<sup>6</sup> [Treaty bodies Download \(ohchr.org\)](https://www.ohchr.org/treaty-bodies) paragraph (6) (a)

<sup>7</sup> [Access+Social+Care+-+Supported+Living+Letter+\[REDACTED\].pdf \(squarespace.com\)](#)

<sup>8</sup> [\\*Supported living\\* \(accesscharity.org.uk\)](https://www.accesscharity.org.uk/supported-living)

### **(C) Convention Article 10 - Right to life**

RB is a young adult who attended a specialist school until the age of 16. They had a series of subsequent placements in supported living accommodation, all of which broke down due to ongoing behavioural and addiction issues which were not adequately addressed by their funded level of care. We raised safeguarding concerns with the local authority. Their response was that RB had capacity to make unwise decisions. RB eventually became homeless, despite desperate attempts by their mother to secure further support to safeguard them. Living on the streets, RB became target for local drug gangs. We supported RB to secure urgent council accommodation pending further needs assessments under the Care Act 2014. We raised multiple safeguarding concerns with the local authority about the urgent nature of risk to RB. The local authority did not put in place adequate interim support pending assessment, and RB again fell victim to local drug gangs and "mate crime". RB became suicidal, making attempts on their life. RB was eventually admitted to hospital.

Concerns around potential breaches of Article 10 arise in a variety of cases. An increasing amount of community care cases involve ongoing failures by a local authority to safeguard the life of an adult who is disabled. This can be due to multiple complex issues, including self-neglect, potential abuse, or a lack of appropriately funded hours to meet eligible need, putting a person's health, wellbeing, and life at risk.

The case of RB above further raises significant **Article 16** concerns relating to freedom from exploitation, violence, and abuse. We support many other individuals either at serious risk of exploitation, violence, or abuse or who are in fact currently experiencing such treatment.

We work closely in partnership with Royal Mencap Society, providing casework support to individuals inappropriately admitted to Assessment and Treatment Units. These people are often autistic or have a learning disability. Sadly, some die in these Units because of poor-quality care or abuse. Assessment and Treatment Units can cause significant long-term trauma to those who are inappropriately admitted into them, with an average stay of five years. In some cases, this trauma leads to additional self-harm and suicide attempts. Poor quality care can also occur in health cases receiving NHS treatment. We understand that Royal Mencap Society are submitting additional evidence on this issue and echo their additional concerns raised.

### **(D) Article 12 – Equal recognition before the law and Article 13 – Access to Justice**

In assessing whether persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life (Article 12 (2)), we have concerns about individual ability to effectively take part in the care and support processes through the use of advocacy support as well as wider concerns around access to legal aid (Article 13). These Articles are regularly connected in practice in relation to social care.

Independent advocacy is a crucial aspect of assessments and care planning for many who have 'substantial difficulty' taking part in Care Act processes. In one case, our client was told that the local authority 'no longer commissions advocacy support'. Following casework intervention, we were able to secure an advocate. Without our support the client is unlikely to have secured advocacy support and therefore would not have had equal recognition. In another case, a client was told that it will 'be quicker and easier' if they did not have to wait for an advocate.

We recently surveyed members of our advisory panel comprised of senior leaders and executive members of our member organisations, with responding members representing over 28,000 people with care and support needs. 80% reported that it can be problematic finding advocacy support, and sometimes it is not possible to secure it. This raises serious questions as to how the state party is taking 'appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity' (Article 12 (3)).

Local authority complaints processes are not only lengthy in terms of response time but lack the required transparency, including substantive information on outcomes. Some complaint responses provide information about Local Government and Social Care Ombudsman (LGSCO) procedures as a next step, but not consistently. The ability to secure urgent interim relief through a complaints process is also hugely problematic.

Many individuals who do not have the correct care and support provision simply cannot afford to wait the requisite period for a complaint's response (sometimes up to 40 days), as their health and safety is compromised, and an interim package of care is required pending full discussion of the challenges.

The complaints process can vary between local authority area, as recently outlined by the LGSCO annual review into adult social care complaints. The report notes that 72% of complaints are upheld, and that a lack of standardised complaints procedures and no mandatory signposting to the LGSCO is leaving many without appropriate redress:

*"...Viewed through the lens of complaints from the public, this is a system that is increasingly failing to deliver for some of those who need it most. To this end, we set out in more detail later in this report where legislative changes could achieve this. These include eliminating some gaps in our jurisdiction and powers to investigate some sections of the care sector, which currently leaves some people without a means of redress"*

Access to community care solicitors is problematic for some of our clients, with a national shortage of specialist community care solicitors and the availability of legal aid seriously restricted. Further detail on these concerns is found on our website<sup>9</sup> and provides further detail on key Article 13 concerns.

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<sup>9</sup> [Blog & News, legal advice and support, customer success \(accesscharity.org.uk\)](#)

**(E) Article 14 Liberty and security of person**

L is a young adult with Downs Syndrome and learning disability who used to attend a day opportunity for 3 full days per week. He lives in residential care. L has recently been told that the day opportunity cannot meet his continence needs without 1:1 support to assist him. Requests from L's family to the local authority for appropriate support to continue to meet L's needs during the day have not been responded to.

L's four friends, whom he lives with, continue to travel to the day opportunity but L has to stay at his care home. He does not have additional 1:1 support to leave the care home to explore any other community-based activity. He is unable to leave his care home Monday to Friday. We are currently advising L on a range of rights, including his right to liberty.

Deprivation of Liberty Safeguard concerns are also a commonly occurring theme in our casework. This may involve a failure by a local authority to follow correct procedures around standard authorisations, or in some cases not following them at all. The CQC's annual 2021 State of Care report<sup>10</sup> noted:

*'We continue to have concerns about delays in authorisations, which mean that individuals are deprived of their liberty longer than necessary, or without the appropriate legal authority and safeguards in place'*

We are particularly concerned that due to severe budget constraints, some local authorities are suggesting that individuals be deprived of their liberty, rather than appropriate support be put in place. In one case, this involved a local authority suggesting that individuals could be locked in their bedrooms rather than have waking night support.

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<sup>10</sup> [State of Care | Care Quality Commission \(cqc.org.uk\)](https://www.cqc.org.uk/publications/state-of-care)

**(F) Article 15 - Freedom of torture or cruel, inhuman or degrading treatment or punishment**

T, a 36-year-old man, lived in a London Borough receiving care and support in his supported living accommodation. Towards the end of 2019, his needs for care and support increased when his mother died. The funding panel turned down his social worker's application for additional hours to meet his increased need. The situation spiralled and T was admitted to hospital following self-harming. He lost his accommodation.

On discharge from his local hospital ward, he was allocated council accommodation and offered a limited and inadequate number of 'outreach' hours to help him go shopping every week. His council accommodation was a basement flat within a larger block, and only had one very small window in the bathroom which did not open properly. T was not supported adequately, and regularly urinated over his home, was not able to clean effectively and lived in squalor by the time he was referred to us. He urgently required an uplift in care and support, which had it been implemented in 2019, would have avoided significant inhuman and degrading treatment.

T is one of many cases we have supported in which Article 15 rights are at risk due to a lack of appropriately funded care package support. As in T's case, an increasing amount of our cases involve the use of funding panels turning down either high cost or specialist care and support, without an adequate alternative available to a person with unmet care and support needs.

Article 15 breaches are also sadly seen commonly in Assessment and Treatment Units, for example with the use of excessive restraint, lack of access to exercise or daylight and no access to bathrooms. Some individuals engage in significant self-harm, for example by breaking and swallowing mirrors, without effective intervention and understanding by the Unit as to what is triggering these behaviours. We share the significant concerns raised by Mencap and the Challenging Behaviour Foundation on these issues and have contributed examples included in their submission.

**(G) Article 21 – Freedom of expression and opinion, and access to information**

We include concerns over potential breaches of freedom of expression under Article 12 evidence above. We recently surveyed our members on access to information for disabled people in their care, with 60% reporting that the local authority rarely provides information on a person's right to social care. The remaining 40% reported that the local authority 'sometimes' provided information.

**(H) Article 23 – Respect for home and the family**

The majority of our legal casework team witness Article 23 breaches in every

aspect of our work. Such breaches span a broad range of our casework, from community-based day packages to intensive hospital treatment. We include an Article 23 example on supported living under our Article 5 evidence above and within the attached supported living evidence.

Many of our cases involve local authority failure to meet eligible needs. These needs are basic rights, such as maintaining personal hygiene or using the home safely<sup>11</sup>, and regularly fall within the ambit of Article 23.

Our recent data analysing key social care trends<sup>12</sup> also highlights significant increases in advice provision for unpaid carers – 266% increase in one year. Ongoing failures by local authorities to meet both the needs of the person with disabilities as well as the needs of their unpaid carers is leading to exhaustion and burnout.

### **(I) Article 31 – Statistics and Data Collection**

70% of our Access Social Care advisory panel members this year reported that local authorities rarely have effective systems in place to ensure accountability and monitor quality and consistency of decisions about individual rights. Regulators are reliant on robust data to ensure they can effectively regulate but this data is lacking. Without these systems in place, we have serious concerns as to how regulators can effectively protect Convention rights.

The LGSCO 2021 annual review of adult social care complaints<sup>13</sup> proposed that the LGSCO take on a statutory role in setting and overseeing complaints standards, due to the inconsistent nature of data on both volume of complaints, type of complaints and outcomes per local authority area. This highlights the ongoing challenge around lack of published data on decision making.

To formulate and implement policies to give effect to the present Convention, state parties must undertake to collect appropriate information, including statistical and research data (Article 31 (1)). We believe that this requires the need for fundamental data capture on the core foundations of the Care Act 2014 in every local authority area, collected to the same standard and in a transparent manner. Data capture should look closely at the quality of assessments, eligibility determinations, care planning and financial charging. Government could more confidently satisfy itself that Convention rights are being protected if they collected this data. We would welcome independent oversight of this process.

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<sup>11</sup> Full list of eligible need outcomes [Definition of eligibility and outcomes listed for the Care Act 2014 | SCIE](#)

<sup>12</sup> [Helplines Data Collaboration Group – Interim Report indicates sharp rises in community care advice provision \(accesscharity.org.uk\)](#)

<sup>13</sup> [Adult social care complaint reviews - Local Government and Social Care Ombudsman](#)

## **Conclusion**

The government are failing to fulfil CRDP obligations in several areas as set out above. We urge the government to implement as a matter of urgency the key recommendations from the Committee's Concluding Observations, 2017, to ensure that convention rights of persons with disabilities are protected across all areas of life. To do this will require significant reform by way of financial investment in our increasingly frail social care system.