

## **Written evidence from the Royal Mencap Society and learning disability (HRA0073)**

We support the over 1.5 million people with a learning disability in the UK and their families to change laws and improve health and care services as well as access to education and employment.

We also directly support over 5,000 people with a learning disability to live their lives the way they want. This support goes to the heart of what we do to support people with a learning disability. A learning disability is caused by the way the brain develops before, during or shortly after birth. It is always lifelong and affects intellectual and social development.

### **Summary**

This is a response from Royal Mencap Society to the call for evidence issued by the Independent Human Rights Act Review. Our comments are not framed in response to the IHRAR's specific questions, but to evidence the impact of the Human Rights Act (HRA) as a tool for developing and accessing legislation, policies and practices.

The HRA guarantees the rights of people with a learning disability. It enshrines benchmarks for fundamental rights and a legal basis to guarantee minimum rights. This is very important for people with a learning disability. Those who have the most complex needs and may not be able to speak up for themselves, for example people with profound and multiple learning disabilities, can be at particular risk of having their human rights breached.

People with a learning disability are among the most disadvantaged people in society, and despite legal protection, too many continue to suffer abuse, neglect and discrimination.

While significant progress has been made, both in terms of the level of public understanding and acceptance of people with a learning disability, as well as in terms of the laws and policies which govern the way they are treated and the services they receive, there is more to be done to strengthen the Human Rights Act and fulfil the rights of people with a learning disability.

We believe that IHRAR should engage more broadly with the HRA and its practical implications.

### **Summary of key calls:**

Mencap calls for the inappropriate detention of people with a learning disability and/or autism in inpatient units to stop and people to get the right support in the community, increased judicial training on the needs of persons with learning disabilities, and a move to implement human rights-based cultures across all health, care and education settings.

## **Main response**

Key areas where we are seeing human rights of people with a learning disability being breached:

- inappropriate and long-term detention of people with a learning disability in inpatient units,
- unequal access to healthcare, and
- experiences of discrimination during the Covid-19 pandemic.

### **Inappropriate and long-term detention of people with a learning disability in inpatient units**

Human rights abuses are particularly visible in inpatient units. Thousands of vulnerable people with learning disabilities continue to be detained in institutions, often far away from their families, unable to return home, subject to physical restraint, overmedication, and being kept in isolation. Parliament's JCHR inquiry into detention of people with LD/autism has found breaches of human rights and made recommendations, which need to be followed as a matter of urgency. We also need all commissioners of care and treatment for people with a learning disability to be making decisions from a human rights starting point. It is very troubling that inappropriate placements continue to be commissioned that put the person at known risk of human rights abuses.

### **Unequal access to healthcare:**

Discrimination against people with a learning disability in relation to the provision of health services, and the numbers of avoidable deaths of people with a learning disability, has been well documented (Mencap 2007, 2012, 2018, 2020): Inappropriate DNACPRs or decisions to withhold care and treatment, stating learning disability or Down's syndrome as the reason have long been a concern.

However, at the start of the pandemic, in Spring 2020, the NICE emergency guidance on acute care, played a role in creating huge concern about potentially inappropriate use of DNACPR (Do not attempt cardio-pulmonary resuscitation) orders in relation to people with a learning disability. Numerous reports emerged of families being asked to agree that their loved ones with a learning disability would not go to hospital for treatment if they contracted Covid-19, and if they did, would not opt for resuscitation. GP surgeries wrote to care settings about this and contacted family members and people with a learning disability directly. The concerns about this practice were so significant that the Secretary of State for Health requested the Care Quality Commission carry out a review into this<sup>1</sup>, and the CQCs interim report was published in December 2020<sup>2</sup>.

Despite multiple letters of clarification to healthcare professionals from the NHS England, we continue to see examples of inappropriate DNACPRs and families concerned about loved ones missing out on life saving treatment. This shows just how

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<sup>1</sup> <https://www.cqc.org.uk/news/stories/cqc-review-use-dnacpr-during-pandemic>

<sup>2</sup> <https://www.cqc.org.uk/publications/themed-work/review-do-not-attempt-cardiopulmonary-resuscitation-decisions-during-covid>

open to abuse the rights of people with a learning disability remain, and how vital it is that we have strong legislation, which impacts on both policy and practice.

### **Procedural/ use of the HRA:**

The HRA is a fundamental piece of legislation as it enables people to bring cases of human rights violations to the domestic courts and seek remedies. However, within the justice system, it seldom has the impact we believe it should. Prosecutors rarely bring forth legal challenges on the sole grounds of HRA violations. Human rights violations typically form a secondary argument, using another piece of domestic legislation as the primary basis for litigation. In cases involving people with a learning disability, the claims are often retrospective, and if the claimant is awarded damages, these are often minimal.

Perhaps more concerning, the outcome of HRA cases does not seem to have the wider impact on policy or delivery it merits. It is concerning that procedural changes to prevent violations rarely take place, even if cases have received national media and political attention. One area where this has been continually experienced is in the detention of people with a learning disability and/or autism under the Mental Health Act, combined with the use of restrictive interventions, including restraint and being kept in isolation.

Within the justice system, Mencap calls for increased judicial training on the needs of persons with learning disabilities and a move to implement human rights-based cultures and frameworks across institutions.

Critically, HRA embedded human rights in domestic regulations, extending its impact beyond the judiciary. S.6 obligates public authorities to act in a way that is compatible with the rights set out in the HRA. In this way, the HRA is a proactive piece of legislation: instead of necessitating litigation when rights are breached, the HRA is intended to assert and enforce people's rights at the point when regulatory decisions are made.

The Public Sector Equality Duty and implementation of Equality Impact Assessments (EIAs) took clear steps toward this end by requiring public authorities to have due regard to several equality considerations when exercising their functions. However, when the Justice concluded in *R (Brown) v Secretary of State for Work and Pensions* [2008] that there is no duty to carry out an Equality Impact Assessment, 'equality considerations' were reduced to little more than a box-ticking exercise. Giving due regard for the rights of all persons through EIAs is a practical extension of the HRA. All public sector organisations should be required to conduct EIAs on new policy or programmes using a rights-based framework.

Additionally, S.19 requires that all new legislation be assessed for compatibility with the HRA. The government Minister responsible for introducing new legislation to Parliament is required to make a statement that the Bill is compatible with the Convention. Yet there is no requirement to evidence that claim or demonstrate that the impact on human rights (particularly those of equality groups) has been meaningfully considered. Legislation like the Coronavirus Act demonstrates that government is not required to substantially assess new legislation against the HRA. We want to see a

mandatory human rights-based assessment framework – to be used when new legislation and policy is being developed - to demonstrate compliance with the HRA.

Another concern is the lack of accessible information available to individuals, organisations and public authorities about the rights contained in the HRA. It is challenging for people to understand proportionality when it comes to their human rights and which rights are absolute. This confusion has led to people failing to assert their rights when it would be appropriate to do so. There needs to be clear information for people with a learning disability and their families about their human rights, and how to challenge breaches to those rights. The time for this could not be more pertinent.

As previously referenced in the Health section above, the Coronavirus pandemic has exacerbated existing inequalities and precipitated considerable breaches of the HRA against people with a learning disability, including the inappropriate use of DNACPRs, the temporary mis-application of the Clinical Frailty Scale to disabled adults of working age, and blanket bans on hospital visits. As we move into a period of economic recovery, there is likely to be huge pressure on local government finances. We are deeply concerned that the increased budget cuts in local authorities will result in increased HRA violations against vulnerable persons.

Decisions about funding for care and treatment services must formally and thoroughly acknowledge HRA duties, and the likely impact on affected persons. It is vital that people with learning disabilities continue to receive the care and support they need in line with the HRA and Care Act. Many people with a learning disability have already experienced cuts or changes to their support during the pandemic. For example, thousands of people are having to cope with less face-to-face support, and we are concerned that there may be an unwillingness to reinstate necessary support, when local authorities have less resources. It is imperative that the obligations set out in the HRA are fulfilled. It is particularly important that people with a learning disability and families receive support to understand their human rights, including how to access legal support when required.

The rights set out in the Human Rights Act must be enshrined in domestic law, policy and practice. We welcome the IHRAR review of the HRA, and hope this will translate into substantial mechanisms for rights protection in practice. The routes to challenge human rights breaches are inaccessible in the current system. There needs to be more information for people with learning disabilities and their loved ones, about what constitutes an HRA violation, how to challenge it when it occurs, and how proactive measures are being put in place to prevent future HRA violations from occurring.

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