

Submission by the Challenging Behaviour Foundation to the government's Call for Evidence for its Independent Human Rights Act Review

Summary

For reasons that will be set out in this response, individuals with learning disabilities and their families are not able to effectively act on the human rights they are entitled to under the HRA.

If the HRA is to be an effective framework for the individuals we work with, then people with learning disabilities, autistic people, their families, and support workers need to be empowered to use Human Rights legislation to protect their rights in a way which many are not able to do presently, and human rights must be integrated into public organisations in a way which they are not currently. With that in mind, this response will cover the issues faced by individuals with learning disabilities and their families when attempting to act on their human rights, **with respect to the Review's self-stated purpose:**

We need to make sure that our human rights framework, as with the rest of our legal framework, develops and is refined to ensure it continues to meet the needs of the society it serves.

This response, however, will not cover the 'key themes' listed in the call for evidence, as from the information gleaned from families in our networks, neither the relationship between domestic and European courts nor the relationships between governmental branches are the main obstacles which families face when attempting to enact their human rights.

This response by the Challenging Behaviour Foundation will summarise and evidence our view that the Human Rights Act offers a promising framework to deliver on human rights for individuals with learning disabilities, but it **has fallen short of protecting these rights-in-practice** because:

1. Individuals with learning disabilities and their families are **not sufficiently informed on what their rights are** and are therefore not empowered to act on them.
2. Public authorities are often **let down by their assumptions, prejudices or lack of training/experience** which leads to a deficiency in human rights protections for individuals with learning disabilities.
3. The HRA will not be a truly effective legal framework while the legal system remains inaccessible and traumatising for individuals with severe learning disabilities and their families.

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.

Human Rights Act & Human Rights Issues

The Human Rights Act is a promising legal framework for protecting the rights of individuals with severe learning disabilities when interacting with public bodies or organisations which take on a function of public nature. In particular, the protection of rights to life (article 1), to not be treated in an inhuman or degrading way (article 2), to respect for private and family life (article 8) and the protection of all listed rights 'without discrimination' (Article 14) can

provide individuals with learning disabilities a useful framework for enforcing their rights in both day-to-day interactions with public bodies and in legal challenges.

However, even with the HRA, individuals with learning disabilities experience human rights violations regularly, with traumatic or even morbid consequences. The application of DNACPR notices to individuals with learning disabilities during the first wave of the pandemic, and [reports of the practice continuing through to January 2021](#), represents an egregious violation of their right to life (article 2), without discrimination (article 14). [Blanket bans on visitation imposed in care homes](#) denied individuals with learning disabilities and autistic people their right to a family and private life (article 8), while the JCHR has [reported an increase in the use of restrictive interventions and seclusion](#), violating the right to freedom from cruel or inhuman treatment (Article 2). The Human Rights Act can be useful by creating the framework for challenging these violations, but it is limited in preventing human rights violations against individuals with learning disabilities for the following reasons.

Awareness and Enforceability of Rights

Individuals with learning disabilities and their families are not always informed about their rights, and as such are unable to effectively act on them. In fact, many families who contact CBF Family Support regarding issues such as those listed above are not aware at the time that a human rights violation has occurred. Many families are not empowered to employ the human rights act in day-to-day interactions (such as those with service providers or Local Authorities), and furthermore lack the capacity, means, or energy to use it to launch a legal challenge. Where families do employ the Human Rights Act, 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 Human Rights Act. The Human Rights Act cannot be an effective framework for these families until they are empowered to use it.

Human Rights Cultures and Public Authorities

Secondly, many public bodies or organisations which take on a function of public nature are often let down by assumptions, prejudices, or a lack of experience/training regarding learning disabilities, autism, and challenging behaviour. Regarding the importance of visitation rights to residential services, one family carer told us that the root of the problem lies in the fact that “***They don’t see my child as a human being***”. Instituting human rights cultures in these organisations is necessary for ensuring that public bodies and organisations uphold human rights for individuals with learning disabilities, and many violations (highlighted for example by the application of DNACPR orders) occur when internal cultures do not value individuals with learning disabilities as **equal members of society**.

This is also true of many services commissioned specifically for individuals with learning disabilities. Abuse scandals in services, widely publicised in the wake of the abuse uncovered at [Winterbourne View Hospital](#) have continued to be exposed, recently in [Whorlton Hall](#) (2019), [Mendip House](#) (2019), and [Yew Trees](#) (2020). The account of a Family Carer, describing their son’s experience in a NHS specialist rehabilitation unit, summarises the lack of a human rights culture within services:

An independent report, undertaken by a clinical psychologist who had experience of managing specialist challenging behaviour services, concluded that the service did not meet our son’s needs. The report identified that our son was regularly subjected to restraint and was also vulnerable to assault by other residents. It also stated “It is not unreasonable to consider that he would have been stressed, anxious and may

*have been frightened". Because our son cannot speak and the report formed part of evidence that would be presented in court, any views expressed had to take into account the possibility of legal challenges. In our opinion and that of others currently involved in our son's care, he has been psychologically damaged by his experiences and is almost certainly suffering from complex PTSD. That an **NHS service** set up with the level of clinical expertise that was in place in our son's rehabilitation unit should fail so utterly offers irrefutable evidence that patients cannot thrive in fundamentally flawed environments. [...]. It is to be hoped that the current, often cruel, damaging mismanagement and traumatisation of people like our son will, in the future, also be regarded as unethical. They are not children of a lesser god without feelings and needs yet the system continues to fail to recognise their vulnerability and fundamental innocence. **Their human rights are all too often totally disregarded***

(case study reproduced with family's consent)

While the Human Rights Act creates the framework for legal recourse in cases of human rights violations, it has not necessarily instilled a human rights culture in public bodies which would be necessary to protect the human rights of individuals with learning disabilities who display challenging behaviour.

The Legal System

Finally, when it comes to holding these public bodies accountable, court proceedings lack the awareness and sensitivity of learning disabilities, autism, and challenging behaviour which are necessary to ensuring that rights can be upheld effectively. Our 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. We have been told by family carers 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.

If the Human Rights Act is to be effective for protecting the rights of these individuals, judicial cultures must be changed and training provided to prevent these individuals and their families from being dissuaded from entering legal challenges. We recommend that all members of the legal system (including judges, court officials) who are involved with people with learning disabilities and autistic people are given appropriate training (for instance, Oliver McGowan mandatory training) and have awareness of learning disability, autism, and the HRA, and that this is included in Judicial College and CPS training. This is necessary to ensure that individuals with learning disabilities and autistic people are given fair hearings in court. We furthermore recommend that judges be appropriately trained before they are permitted to judge a case for a person with learning disabilities or an autistic person (as is the case for completing appropriate training before being able to judge rape cases, for instance).

Conclusions

The Human Rights Act is essential to protect people, and we are pleased to see that the government has revised its 2015 manifesto position of replacing the HRA. However the HRA must be more thoroughly publicised and implemented if it is to effectively protect the rights of individuals with learning disabilities, autistic people, and their families. We recommend:

1. Proactively increasing awareness for individuals with learning disabilities, autistic people, and their families about what the Human Rights Act is, what rights it entitles them to, and how they can access support to employ it to enforce their rights.
2. Ensure that human rights issues are central in the institutional cultures of health and social care, and that training is provided which ensures that those working in these services recognise and can prevent human rights violations.
3. Provide training to judges and legal officials in learning disability, autism, and challenging behaviour so that they are not let down by unconscious biases and assumptions which all too often prevent these individuals from securing their rights.