

Dimensions response to the Government's call for evidence on the Human Rights Act

Introduction

This response has been informed by participants in two focus groups on the Human Rights Act, made up of people who have a learning disability and/or autism, as well as family members of people who have a learning disability and/or autism. In addition, the response is informed by the views of colleagues working for Dimensions and involved in the day to day delivery of support to adults who have a learning disability and autism.

Dimensions is a not-for-profit support provider for adults who have a learning disability and autism. Currently, we support around 4,000 people across England and Wales.

In this response, we have sought to outline the day to day impact of the Human Rights Act and its value to people who have a learning disability and autism, and their families.

Key themes from the focus group respondents

The participants who informed this response believe the current protections and legal duties enshrined in the Human Rights Act are important.

The protections in the Act are important for a number of reasons. Participants in the group underlined that:

- The Act enables people and their families to raise concerns with public bodies and services when they feel their rights are not being upheld. For example:
 - o The pandemic has underlined the importance of rights protections for people who have a learning disability, where they have been subjected to the inappropriate application of DNAR orders on their medical records during admission to hospital or in anticipation of admission to hospital.
 - o The pandemic also saw the publication of inappropriate guidance on access to critical care from the National Institute for Care Excellence. This introduced a frailty score tool as a method for making decisions about access to acute and critical care, which would have inappropriately excluded people who have a learning disability and autism, who receive significant levels of social care support, from access to care if they contracted COVID-19.
 - o The pandemic saw significant restrictions on visiting rights in care settings, leaving many people in care homes without access to loved ones, which could have a serious impact on mental health and wellbeing. The HRA has helped to ensure a proportionate approach to restricting contact and has ensured that public bodies and services have taken steps to facilitate contact with loved ones as far as possible and in innovative ways – for example by facilitating digital communication.

Focus group participants highlighted that they believe the HRA has enabled positive change for them and for their loved ones. For example:

- Family members of people who have Downs Syndrome outlined how the HRA had been used to ensure access to live saving surgery for infants born with associated congenital heart defects. Before the introduction of the HRA, children born with heart problems associated with Downs Syndrome were regularly refused this surgery, which significantly shortened people's life expectancy and limited quality of life.
- People underlined the importance of the right to liberty for people who have a learning disability and autism, who can be at risk of detention where they display distressed and risky behaviour associated with their disability. The safeguards that have been introduced within the system of mental health detention and deprivation of liberty under the Mental Capacity Act 2005 result from the rights enshrined in the HRA. The groups highlighted that the current government White Paper on Mental Health Act reform is directly linked to the rights protections afforded by the HRA and maintaining the protections of the HRA will be essential to ensuring better, rights based outcomes for people who are at risk of detention.
- Family members underlined that the HRA had helped the secure the right support for their loved one, including having their SEND needs met and their communication needs met. They highlighted that this was an essential aspect of people's right to self-expression and their right to a family and private life.
- People who have a learning disability and autism in the focus group emphasised that the protections in the HRA were a key part of making sure they were given the support they need to lead good lives, with access to their community, opportunities to participate and contribute to society. They felt that many of their other rights, including those found in the Care Act 2014, were underpinned by the HRA.
- Finally, colleagues working for Dimensions outlined that the HRA was an essential basis for our approach to providing person centred care and support to people who have a learning disability and autism, including our duty to keep people safe, to support people to maintain their health and wellbeing, to protect people from abuse and mistreatment; and to enable people to engage with the things that create a meaningful life, such as contact with loved ones, employment and community engagement.

Participants in both focus groups expressed concern over the government making changes to the Human Rights Act following the review process. The groups felt the questions posed were largely outside their competence, but wanted to convey the importance of the Act to their day to day lives and express that the Act works well in its current operation. The participants outlined that the review of the Act should not lead to substantive change to the protections afforded to people.

A theme throughout the focus group discussion was the complexity of rights protections within social care. It was agreed that having an underpinning Act to protect fundamental rights was

particularly valuable and that a shift to create equivalent rights for people across other pieces of legislation would be problematic, not least because it would make the system of rights protections more complex and harder for people to understand and access. It was noted, for example, that the HRA had been used to provide a minimum threshold for social care provision during the pandemic, i.e. the Care Act easements introduced under the Coronavirus Act 2020. This underlines the utility of the HRA as it stands, as an essential and foundational source of rights protections.

We recommend that the review process seeks the views and input of people who have regular recourse to use the HRA as a way of securing service provision and support. We stress that whilst the review process may be limited in scope at present, there is significant concern that it is a starting point for wider reform that may alter and weaken the protections offered by the HRA.

We also underline that any change to the HRA will create a need to engage with communities who are regularly impacted by the HRA and who draw on it in their day to day lives. It is crucial that people are able to understand their rights and how they operate within the judicial system and how they bind public bodies that they engage with. Any change to the operation to the Act must be balanced against the impact it will have on people's understanding of their rights and their ability to access their rights.