

**Human Rights Act Reform: A Modern Bill Of Rights - Consultation**  
**Response from the Challenging Behaviour Foundation and Mencap**

**About the Challenging Behaviour Foundation**

The Challenging Behaviour Foundation is a charity which supports children, young people and adults with a severe learning disability and challenging behaviour and their families. The CBF 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.

For more information about the CBF go to our website: [Homepage for the Challenging Behaviour Foundation](#)

**About Mencap**

Mencap supports the 1.4 million people with a learning disability in the UK and their families and carers. We fight to change laws and improve services and access to education, employment and leisure facilities, supporting thousands of people with a learning disability to live their lives the way they want. We are also one of the largest providers of services, information and advice for people with a learning disability. [www.mencap.org.uk](http://www.mencap.org.uk)

Our joint response has been informed by the experience of children and adults with learning disabilities, family carers with relatives with learning disabilities, members of the Challenging Behaviour National Strategy Group, and members of the CBF Legal Panel<sup>1</sup>.

We facilitated a virtual family carer focus group on 24th February, attended by 12 family carers, all of whom have a relative with a learning disability and lived experience in using the existing Human Rights Act to promote the rights of their family. CBF Legal Panel members were also invited to attend the focus group.

Family carers who were unable to attend shared written comments for inclusion in our consultation response.

This response includes direct quotes from families who shared their experiences with us. All quotes have been anonymised.

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<sup>1</sup> For further information about the Challenging Behaviour National Strategy Group and the CBF Legal Panel see here: [National Strategy Group - Challenging Behaviour Foundation](#)

## **Introduction and key points**

The Human Rights Act is vital for protecting the rights of individuals with learning disabilities and their families. The focus must be on better implementation of the existing Act, rather than on introduction of the proposals in this consultation which disregard the findings from the Independent Review of the Human Rights Act.

We need a greater focus on skilling up professionals to understand and feel confident using the Human Rights Act in their everyday work, and increased awareness amongst individuals with a learning disability and their families about their rights under the Human Rights Act.

We are completely opposed to the Government's proposals which would see the ways to access, use and benefit from these rights reduced.

**If introduced, the proposals would result in weakened protections and restricted access to justice. This is very concerning for us all but particularly for individuals with a learning disability and their families who already too often see their human rights breached and experience barriers to accessing justice.**

The HRA is a promising legal framework for protecting the rights of individuals with learning disabilities. However, despite this framework, children and adults with a learning disability are at high risk of having their rights breached in multiple care settings, including healthcare settings, specialist inpatient units and in social care settings.

Issues faced by individuals with a learning disability, including health inequalities, avoidable deaths and inappropriate detention in inpatient units are at their core about the human rights of children and adults with a learning disability not being respected. On one hand the Government says it is committed to tackling these well-recognised human rights abuses and inequalities but on the other hand it is proposing reforms that would reduce protections against human rights breaches and access to justice.

We want to see the focus on maximizing the potential of the HRA through better implementation – certainly not weakening duties and protections as is proposed in this consultation. We welcome the work the British Institute of Human Rights (BIHR) has been doing to skill up professionals in use of the Human Rights Act. Implementation must be the focus, not weakening protections.

**We do not believe there is a need to change the Human Rights Act. Neither the Independent Review into the HRA or the JCHR inquiry into the HRA and how it is working found that the HRA needs to change.**

The JCHR said ‘evidence we heard has led us to conclude that there is no case for changing the Human Rights Act’<sup>2</sup>.

**Key points:**

- We are extremely concerned about the impact of the proposals in the consultation for children, young people, and adults with a learning disability and their families.
- We hold the view that the current Human Rights legislation is sound – and should be strengthened and better implemented rather than weakened.
- We do not believe there should be any change to the Human Rights Act.
- The consultation paper is complicated and technical and has not been accessible. Although an easy read version was published at a late stage, and 2 additional engagement sessions for organisations supporting disabled people were held, neither explained the proposals in a meaningful way and were inadequate.

**Full response to consultation questions**

**A permission stage for human rights claims**

**Question 8:** Do you consider that a condition that individuals must have suffered a ‘significant disadvantage’ to bring a claim under the Bill of Rights, as part of a permission stage for such claims, would be an effective way of making sure that courts focus on genuine human rights matters? Please provide reasons.

We strongly disagree with the proposal to introduce a permission stage for the following reasons:

- All human rights breaches are serious.

All human rights breaches are significant and should be taken seriously by the courts, whatever the disadvantage caused. Proving ‘significant disadvantage’ is an unnecessary permission stage which we do not think should be implemented.

- Adding additional administrative hurdles to the already tight timeframe will further limit access to justice for children and adults with learning disabilities and their families.

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<sup>2</sup> [No case for reform of the Human Rights Act, says Joint Committee on Human Rights - Committees - UK Parliament](#)

It is already difficult for people with a learning disability and their families to understand and navigate the legal system. Timeframes are already often challenging, alongside day-to-day life, which may involve significant caring responsibilities for family carers of children and adults with a learning disability.

*“When there is a time limit, families are often too busy trying to sort out the issue rather than explore legal options (which they may not even be aware of)”* (Family carer)

*“By the time we have sorted out the issues around our children we are too late to take action.”* (Family carer)

Implementation of the proposed permission stage is not justified as the existing human rights act already includes provisions to ensure the court is not overwhelmed with claims. This already negatively impacts children and adults with learning disabilities and makes it harder for them to submit claims.

Family carers going through the justice system are often worn down and traumatized by the process. The last thing families need in addition to this is to have to fight to prove they are ‘significantly disadvantaged’.

*“[as a family] You get so worn down and traumatised that the very last thing you want to need to be doing is prove that you have been significantly disadvantaged”.* (Family carer)

*“Issue with this permission point, is that it is bringing in another hurdle in an already quite complex area of legal technicalities for people to access justice”* (Family carer)

One member of the CBF Legal Panel highlighted:

*“The burden in terms of evidence for people with learning disabilities is already higher, and this [proposal] is going to give us even less time to gather that evidence to get through the permission stage just so we can issue the claim in court.”*

*“It is another procedural and technical barrier that will have a real impact, particularly because we can’t just sit down with our client who may not have capacity to be interviewed.”* (CBF Legal Panel member)

Multiple families emphasised how additional hurdles to making human rights claims would particularly negatively impact families caring for relatives with learning disabilities:

Moreover, by adding an unnecessary hurdle for individuals whose human rights have been breached and their families, the permission stage would create additional unnecessary pressures for the system. The introduction of the proposed permission stage would introduce another tier to any claim and create further burdens for both public authorities and for the Courts, as they would be asked to verify two-part claims.

- ‘Significantly disadvantaged’ is subjective. It is unclear how individuals and families will be expected to prove ‘significant disadvantage’ and we are not reassured that whoever is making the decision will have sufficient knowledge and experience.

*“It is something that is individual to each person” (Family Carer)*

The family carers we consulted in order to respond to this consultation told us they were particularly concerned by the subjectivity of the term ‘significantly disadvantaged’. For human rights breaches involving individuals with learning disabilities and their families, determining ‘significant disadvantage’ will require understanding of learning disability, challenging behaviour and best practice guidance for service design and delivery. However, we are not reassured that this has been or will be considered.

One family expressed concern that whoever is determining ‘significant disadvantage’ may not think their son is ‘significantly disadvantaged’ because he is living in a hospital 20 minutes away from his family home. However, he does not live at home (where he could with appropriate support) and still has restricted access to family life.

This example demonstrates the additional barriers individuals with learning disabilities and their families are likely to face when proving ‘significant disadvantage’.

Proving significant disadvantage may be particularly hard for families of children and adults with severe or profound learning disabilities who may use limited formal communication.

**Question 9:** Should the permission stage include an ‘overriding public importance’ second limb for exceptional cases that fail to meet the ‘significant disadvantage’ threshold, but where there is a highly compelling reason for the case to be heard nonetheless? Please provide reasons.

**We strongly disagree with the proposal to introduce a permission stage.** The permission stage should not be implemented and therefore an exception will not be required.

However, if implemented, which would significantly weaken the human rights of the whole population, **an exception to the permission stage must be included for all individuals with learning disabilities and autistic people and their families.**

Individuals with learning disabilities already face additional barriers to accessing their human rights. We know that lack of appropriate support and services for children, young people, and adults with learning disabilities and autistic people mean they are at greater risk of having their human rights breached<sup>3</sup>.

One family told us:

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<sup>3</sup> [Detention of children and young people with learning disabilities and/or autism \(parliament.uk\)](https://www.parliament.uk)

*“As we are all aware, vulnerable individuals, particularly those who are unable to communicate their needs or distress other than by presenting behaviour described as challenging are greatly at risk of having their human rights ignored.”* (Family carer)

Families are often juggling multiple responsibilities relating to the care of their relatives. Family members are also often already traumatised by their experience fighting for the right support for their relative, and may not have the time or energy to prove the significant disadvantage of their relative.

Families shared their past experiences with us in response to this proposal, reflecting on how when they were fighting for the human rights of their relative, it would have been impossible to also prove ‘significant disadvantage’ as part of this process.

One family noted, reflecting on a period where their son was placed out of area, 250 miles from home:

*“My world was a minefield at the time. I was at a significant disadvantage to prove we had experienced significant disadvantage!... To prove it [a significant disadvantage], and to be given deadlines, it’s a nightmare.”* (Family carer)

Another family highlighted the following:

*“[as a family] You get so worn down and traumatised that the very last thing you want to need to be doing is prove that you have been significantly disadvantaged”.* (Family carer)

If the proposed permission stage is applied, it is likely to heighten an existing inequality in access to justice for individuals with learning disabilities. **We do not agree that a permission stage should be introduced.** If it is, then it is essential that **an exception to the permission stage is included for cases involving individuals with learning disabilities and autistic people.**

<p><b>Question 10:</b> How else could the government best ensure that the courts can focus on genuine human rights abuses?</p>
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The Government is suggesting a problem and stating their preferred solution, with little evidence to back this up. The Independent Human Rights Act Review did not look at this issue, so it is unclear what evidence the Government is using for these proposals. The UK courts can already draw on a range of laws when making decisions, as identified by the IHRAR. Therefore, the draft clause is unnecessary.

**Question 11:** How can the Bill of Rights address the imposition and expansion of positive obligations to prevent public service priorities from being impacted by costly human rights litigation? Please provide reasons.

Positive obligations under the Human Rights Act (HRA) are very important for protecting the human rights of individuals with a learning disability and their families. It is essential that there is a duty on public authorities to take proactive steps to make sure human rights are protected.

The HRA empowers public bodies to deliver care that protects individuals' human rights. Any reduction in these positive obligations is extremely worrying for individuals with a learning disability and autistic people.

Therefore, we are very concerned that the Government seems to be suggesting positive obligations put too much pressure on public authorities and can result in courts interfering with the ability of public services to set their own decision-making agenda.

*“They are asking how they can reduce access to human rights - obviously they mustn't do that”.* (Family carer)

We do not agree that any change is needed around positive obligations. We are concerned the changes proposed will mean public authorities are less proactive in protecting rights. Instead, we think more should be done to ensure public bodies understand their duties under the HRA and are following their duty to take proactive steps to protect human rights. We want professionals to better understand the HRA and for it to be properly embedded in the practices of public authorities.

*“All services... have already got so many excuses anyway. There is a lot of work to be done to ensure professionals on the ground understand the Human Rights Act.”* (Family carer)

For example, we know that too many individuals with a learning disability and autistic people are stuck in inpatient settings, where they are at increased risk of abuse and neglect and where there is significant evidence that human rights are being breached.<sup>4</sup> The average length of stay for individuals with a learning disability and autistic people currently in these settings is 5.5 years.<sup>5</sup>

We know poor commissioning of health and social care support leads to inappropriate admission to inpatient settings. Individuals with learning disabilities may need bespoke

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<sup>4</sup> For more information see the following:

[Government Response to the Joint Committee on Human Rights reports on the Detention of Young People with Learning Disabilities \(publishing.service.gov.uk\)](#)  
[Restraint, segregation and seclusion review: Progress report \(March 2022\) | Care Quality Commission \(cqc.org.uk\)](#)

[Independent Care \(Education\) and Treatment Reviews - GOV.UK \(www.gov.uk\)](#)  
[Cawston Park Serious Case Review - Challenging Behaviour Foundation](#)

<sup>5</sup> [NHS Digital Assuring Transformation data, February 2022](#)

packages of care in the community. Under the HRA every professional involved in an individual's care has a clear duty to take steps to protect human rights. Without existing positive obligations, it will be too easy for public bodies not to do the right thing to protect human rights. Front line professionals need to be trained up in human rights and there must be a focus on working in line with the HRA.

*“There is a complete lack of awareness and incompetence [around the Human Rights Act].”* (Family carer)

One family member shared her experience of public authorities/bodies such as Dentists, Council, the NHS etc. who already make excuses and have not done a lot of work to understand the HRA – let alone implement it.

The proposed change could further push accountability away from these institutions and fail the person who needs their rights listened to the most

The consultation states that an aim of this proposal is to prevent public service priorities from being impacted by costly human rights litigation. However, existing positive obligations on public bodies are a useful tool for individuals with learning disabilities and their families to use to ensure professionals providing their care and support are adhering to the HRA on a day-to-day basis. By weakening these duties, the Government would reduce the HRA's effectiveness as an everyday tool which can be lifesaving for children and adults with a learning disability.

**Question 14:** Should a new database be created to record all judgments that rely on section 3 in interpreting legislation?

We agree with the IHRAR that gathering more information on how the HRA is used would be useful, including a database on the use of Section 3.

**Question 15:** Should the courts be able to make a declaration of incompatibility for all secondary legislation, as they can currently do for Acts of Parliament?

We understand from BIHR that this proposal would reduce people's protections and access to justice by removing the power to disapply secondary legislation that breaches human rights (as is currently the case). We therefore do not support this proposal.

**Question 16:** Should the proposals for suspended and prospective quashing orders put forward in the Judicial Review and Courts Bill be extended to all proceedings under the Bill of Rights where secondary legislation is found to be incompatible with the Convention rights? Please provide reasons.

We understand from BIHR that this proposal would reduce people's protections and access to justice, by restricting the remedies that are currently available to people whose rights have been breached. We therefore do not support this proposal.



**Question 19:** How can the Bill of Rights best reflect the different interests, histories and legal traditions of all parts of the UK, while retaining the key principles that underlie a Bill of Rights for the whole UK?

The joint statement from the Scottish and Welsh governments is clear that there is no support for the proposed changes to the Bill of Rights from Scotland and Wales. “We have grave and deep-seated concerns in relation to both the current proposals and the UK Government’s longer-term direction of travel.”<sup>6</sup>

*“The Scottish Government’s principled objection to the proposition that the Human Rights Act requires to be “reformed” or replaced by a “modern Bill of Rights”...“Reform”, as you characterise it, is not just unnecessary, but undesirable. [It is] difficult to view the proposals...other than as a pre-planned and politically motivated attack on human rights, constitutional certainties and the rule of law.”* Deputy First Minister of Scotland, John Swinney<sup>7</sup>.

*“We are disappointed by the pejorative and leading nature of the report and the consultation questions. It remains our firm view that human rights are, and should continue to be, irreducible and apply equally to all persons. The consultation, in places, seems to veer off course from this important and fundamental principle... The UK Government’s proposals raise significant concerns.”* Welsh Government Minister for Social Justice, Jan Hutt MS<sup>8</sup>.

**Question 20:** Should the existing definition of public authorities be maintained, or can more certainty be provided as to which bodies or functions are covered? Please provide reasons.

We think the existing definition of public authorities should be maintained.

We are aware that when parliament first debated the definition of public authorities in 1998, it was recognized that a deliberately flexible definition was needed, to cover the different ways that public power works in the UK. The HRA therefore includes both core public authorities and organisations carrying out a public function.

The consultation suggests that the approach to defining public authorities is ‘broadly right’ and provides little evidence of why this should change.

We would be very concerned about the potential consequences of a change to the definition of public bodies. Families have shared their concerns with us that ‘changing it’

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<sup>6</sup> [Devolved nations criticise “unwelcome and unnecessary” UK Government plans to drop Human Rights Act | GOV.WALES](#)

<sup>7</sup> [Human Rights Act: letter to the Lord Chancellor - gov.scot \(www.gov.scot\)](#)

<sup>8</sup> [Written Statement: UK Government Proposal to Reform the Human Rights Act 1998 \(12 January 2022\) | GOV.WALES](#)

is likely to mean 'narrowing it' because of the direction the proposals in the consultation paper seem to be going (weakening duties and protections).

It is vital that the settings/ circumstances where individuals with learning disabilities have their human rights protected are not narrowed.

*“Any weakening of the existing Act will make it even more difficult to establish accountability when the authorities have behaved in a way that allows an individual's human rights to be ignored.” (Family Carer)*

A particularly relevant example is private inpatient units for individuals with a learning disability. Issues have been raised since the start of Transforming Care programme (which recognises that too many individuals with a learning disability are in inpatient units when they should be receiving the right support in the community) about private inpatient providers. There are perverse incentives for private providers to keep individuals with learning disabilities in units where their treatment is providing no therapeutic benefit as the provider continues to benefit financially from public funds. Additionally, there continues to be low reporting of restrictive interventions by inpatient providers, particularly in private/independent inpatient units. It is really important the rights of individuals with a learning disability are protected in all care settings including private inpatient settings, and therefore that the definition of public authority remains as it is.

**Question 21:** The government would like to give public authorities greater confidence to perform their functions within the bounds of human rights law. Which of the following replacement options for section 6(2) would you prefer? Please explain your reasons.

Option 1: provide that wherever public authorities are clearly giving effect to primary legislation, then they are not acting unlawfully; or

Option 2: retain the current exception, but in a way which mirrors the changes to how legislation can be interpreted discussed above for section 3.

This proposal assumes there is a problem with how things are currently and asks respondents to pick a replacement option. We don't think a change is needed.

*“The HRA is the closest the UK has to a codified constitution. This means that currently the HRA will be supreme against any modern laws passed by Parliament. If the options proposed in Q21 are implemented, it might change this and mean that Parliament are allowed to pass laws even if it is incompatible with an individual's human rights.” (CBF legal panel member)*

Section 6 is an integral way of making sure individuals can access their rights. It is the legal duty which makes it clear that those who have public power to make decisions about our lives must do so in a way that respects our rights.

Any changes to this duty will mean that it is harder for people to hold public authorities to account, this includes Government departments, as well as more local bodies that people interact with every day, e.g., the council, NHS, police forces, state schools etc.

This duty helps ensure staff within public bodies are thinking about human rights in their work and treating people with equal dignity and respect. This is very important in helping to ensure the human rights of children and adults with a learning disability are met.

The IHRAR did not identify any problems with Section 6 of the HRA. The references to this section in the IHRAR report highlight this duty on public bodies is an important part of the framework for protecting rights under the HRA.

**Question 23:** To what extent has the application of the principle of 'proportionality' given rise to problems, in practice, under the Human Rights Act?

We wish to provide more guidance to the courts on how to balance qualified and limited rights. Which of the below options do you believe is the best way to achieve this? Please provide reasons.

Option 1: Clarify that when the courts are deciding whether an interference with a qualified right is 'necessary' in a 'democratic society', legislation enacted by Parliament should be given great weight, in determining what is deemed to be 'necessary'.

Option 2: Require the courts to give great weight to the expressed view of Parliament, when assessing the public interest, for the purposes of determining the compatibility of legislation, or actions by public authorities in discharging their statutory or other duties, with Any right.

We would welcome your views on the above options, and the draft clauses after paragraph 10 of Appendix 2.

Proportionality is a very important part of the way human rights are protected. It means that when looking at whether a restriction to someone's non-absolute right is allowed eg. Article 8 Right to Family Life, it must be the least restrictive option possible. This is an important balance, enabling public bodies to make restrictions that may be needed, but ensuring they do not go too far and that some element of the person's right remains. Without the careful consideration that proportionality currently allows, which looks at the facts of each situation rather than trying to apply an unfair blanket approach, there is a real risk that people's human rights will be restricted far more than necessary.

We are really concerned that the Government's proposals are seeking to restrict the ability of courts to make this important balancing exercise, by setting rules to direct how courts make that decision.

We do not think change is necessary. We think the courts are balancing this well.

Already individuals with learning disabilities can experience too many restrictions. The Human Rights Act is a vital tool to help individuals with a learning disability and their families challenge these restrictions.

It is of real concern if power shifts even further away from the individual and their rights. Many families say how hard it is to challenge the 'system' and how powerless they are against the system. This was a key theme in the JCHR inquiry into detention of young people with a learning disability and/autism<sup>9</sup>. It was also raised in the 'No voice unheard, no right ignored' green paper<sup>10</sup>, which recognized the need for strengthened challenge mechanisms for children and adults with a learning disability and/or autism.

Individuals with a learning disability need personalized care – a lack of attention to their needs and the right support is leading to avoidable deaths and trauma and harm. Any changes which enable less careful consideration of rights and which enable more blanket approaches are likely to have a negative impact on the rights and lives of individuals with a learning disability and their families.

As highlighted above, improved training and focus for professionals following the Human Rights Act is needed. It will always be easier for public authorities to take a blanket approach and spend less time considering individuals' needs and rights – it is vital that the law does not enable or allow this.

**Question 24:** How can we make sure deportations that are in the public interest are not frustrated by human rights claims? Which of the options, below, do you believe would be the best way to achieve this objective? Please provide reasons.

Option 1: Provide that certain rights in the Bill of Rights cannot prevent the deportation of a certain category of individual, for example, based on a certain threshold such as length of imprisonment.

Option 2: Provide that certain rights can only prevent deportation where provided for in a legislative scheme expressly designed to balance the strong public interest in deportation against such rights.

Option 3: Provide that a deportation decision cannot be overturned, unless it is obviously flawed, preventing the courts from substituting their view for that of the Secretary of State.

Limiting the scope of any of our human rights goes against the very point of human rights; that they are universal and for all people. We strongly disagree with these proposals.

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<sup>9</sup> [Detention of children and young people with learning disabilities and/or autism \(parliament.uk\)](https://www.parliament.uk/publications/2017/10/10)

<sup>10</sup> [Government response to No voice unheard, no right ignored - a consultation for people with learning disabilities, autism and mental health conditions \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/614442/green-paper-no-voice-unheard-no-right-ignored-a-consultation-for-people-with-learning-disabilities-autism-and-mental-health-conditions.pdf)

**Question 25:** While respecting our international obligations, how could we more effectively address, at both the domestic and international levels, the impediments arising from the Convention and the Human Rights Act to tackling the challenges posed by illegal and irregular migration?

We disagree with this proposal. We are concerned that in making changes to the Human Rights Act in this way, the proposals may have wider consequences regarding the implementation of Article 2: Right to Life.

**Question 26:** We think the Bill of Rights could set out a number of factors in considering when damages are awarded and how much. These include:

- a. the impact on the provision of public services;
- b. the extent to which the statutory obligation had been discharged;
- c. the extent of the breach; and
- d. where the public authority was trying to give effect to the express provisions, or clear purpose, of legislation.

Which of the above considerations do you think should be included? Please provide reasons.

We don't think a change is needed. The current system encourages public bodies to respect human rights, which is important.

**Question 27:** We believe that the Bill of Rights should include some mention of responsibilities and/or the conduct of claimants, and that the remedies system could be used in this respect. Which of the following options could best achieve this? Please provide reasons.

Option 1: Provide that damages may be reduced or removed on account of the applicant's conduct specifically confined to the circumstances of the claim;

or Option 2: Provide that damages may be reduced in part or in full on account of the applicant's wider conduct, and whether there should be any limits, temporal or otherwise, as to the conduct to be considered.

We **strongly disagree** with the implementation of either option 1 or 2. The Human Rights Act is based on the idea that every person has the same human rights which are universal and inherent in all people. Implementation of any of the proposals in question 27 would create a system where some individuals would be deemed less deserving of their human rights. The proposed options are particularly concerning for individuals with learning disabilities whose behaviour challenges and their families. There is a general lack of understanding around behaviour that challenges, and we fear this proposal could lead to disabled people being discriminated against because of ignorant and prejudiced views around their behaviour and the reasons for it.

One family in response to question 27 said:

*“I could actually sit and sob when I look at that” (family carer)*

Both options aim to limit, reduce, or remove the damages that an individual may receive based on the individual's past conduct/behaviour. If implemented this would mean that an individual's rights are deemed less important because of their past actions and sets an extremely dangerous precedent. Human rights are meant to be a universal right for all human beings regardless of other factors, therefore, suggesting that some individuals are worthy of less compensation or damages suggests that they are less entitled to human rights than others and ultimately less human, creating a hierarchy of rights where people's entitlement to rights is ranked based off perceived good or bad behaviours.

Additionally, the consultation makes no indication in regard to what might be considered behaviour or conduct which might be cause to limit the compensation/damages an individual would receive. If implemented, we are very concerned this proposal would have significant negative consequences for individuals with learning disabilities whose behaviour challenges.

### **Lack of understanding around challenging behaviour**

We are very concerned that if an individual has displayed challenging behaviour in the past, this will limit the compensation they receive if their human rights are breached. In previous legal cases, such as the Atlas trial at Bristol Crown Court, challenging behaviour associated with an individual's learning disability has been misunderstood by the judiciary.<sup>11</sup> Therefore, we are concerned that if this proposal is implemented and a human rights abuse occurred against an individual their past episodes of challenging behaviour may be used to reduce the compensation and damages they would receive. This is a great concern especially as individuals with learning disabilities are frequently subject to human rights abuses.

We know that challenging behaviour displayed by individuals with learning disabilities is communication of an unmet need.<sup>12</sup> However, the individuals who are making decisions about past behaviour and appropriate compensation are unlikely to have this level of understanding of challenging behaviour and the particular experiences of the individual who is making the claim.

*“We are seen as difficult and our loved ones as in the wrong when it's the services that do not meet the needs of our children.” (Family carer)*

### **Defining 'past behaviour'**

Families have expressed serious concern around who will determine the threshold of 'past behaviour'. If they do not have the relevant expertise and specialist knowledge

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<sup>11</sup> ([Safeguarding Adult Reviews - Devon Safeguarding Adults Partnership](#))

<sup>12</sup> ([What is challenging behaviour? - Challenging Behaviour Foundation](#) )

around learning disabilities and autism, then this proposal could have a serious negative impact for individuals with learning disabilities and autistic people making human rights claims. One family carer said:

*“That’s the irony, we would be judging him on past behaviours that are caused by past trauma, linked to breaches of his human rights”*

Another family shared that their daughter has a criminal record. The family highlighted that their daughter’s actions are related to the trauma she has experienced as a result of abusive services, but under the new proposals if she makes a human rights claim she could be penalised for this behaviour.

*“We need to remember that when people display challenging behaviour, it is because they have a need that is not being met...and this is going to make them [the individual] at fault, when actually we should take responsibility”* (Family carer)

### **Negative impact on access to support for individuals and their families**

If implemented, the proposals in question 27 could discourage families from asking for help when they really need it, leaving individuals with learning disabilities and their families at risk of harm.

Families at the focus group noted they would be more cautious about asking for help to support their relatives, including calling the police, if they knew any record of their relative’s behaviour might impact their access to justice for human rights breaches in the future. Families highlighted this would add to existing concerns around the consequences of requesting help when needed.

*“When you’re in a dangerous situation, the only thing you’re allowed to do is call the police”* (Family carer)

Families also expressed concern over the impact this would have on families who do not know about the changes to the HRA and the potential impact for their relatives. For example, if you call the police, the future impact of this might be that your child’s ‘past behaviour’ is considered in court.

### **Question 29**

#### **Part 1. What do you consider to be the likely costs and benefits of the proposed Bill of Rights?**

We are very concerned about the impact of the proposals in the consultation for children and adults with a learning disability and their families. We hold the view that the current Human Rights legislation is sound – and should be strengthened and better implemented rather than weakened through introduction of the proposals in this consultation.

*“Given the current situation where examples of the most horrendous neglect and abuse come to light ... anything that is likely to make matters worse is totally unacceptable.”*

*“None of the options being proposed are at all satisfactory”*

*“I think my biggest concern is the underlying assumption that many human rights cases are unfair and that claimants are seeking unreasonable privileges.”*

*“Given the difficulties around ensuring the implementation of the current law, such a change would be hugely detrimental and allow for injustice to prevail. Any weakening of the existing Act will make it even more difficult to establish accountability when the authorities have behaved in a way that allows an individual's human rights to be ignored.”*

The human rights act as it currently stands is an essential framework for individuals with learning disabilities and their families to ensure human rights are upheld. This was highlighted by the experiences of families we consulted in order to respond to this consultation.

Reflecting on a complaint in relation to her relative's care, made to and upheld by the Ombudsman, one family noted:

*“It's [the Human Rights Act] an absolute requirement. If I wanted to take this further... I would be taking legal action under the human rights legislation and **that is such an important protection.***

*If it doesn't happen in the way it should happen, you need that recourse.”*

Another family highlighted how the human rights act in its current form has been essential for their family:

*“The only time we've been successful in getting something done for our son is when we did use human rights legislation when we couldn't see him during covid. We went without seeing him for 15 weeks and 1 day...We took it to Welsh government and finally did actually get a change.”*

*“We used human rights legislation in a really good positive way. What would that mean now [with the proposed changes in the consultation]?”*

The Human Rights Act as it currently stands must remain and implementation strengthened. We cannot foresee any benefits to the proposed Bill of Rights for individuals with learning disabilities and their families.

**Part 2. What do you consider to be the equalities impacts on individuals with particular protected characteristics of each of the proposed options for reform?**

The proposals will have significant impacts on those with protected characteristics, in particular individuals with learning disabilities who already experience breaches of their human rights and inequality in access to justice. We do not want to see any change to



the Human Rights Act, but we have highlighted the most concerning proposals (these are covered in more detail in the rest of the response):

### **Access to Human Rights law/ the Permission stage**

A requirement to prove 'significant disadvantage' as part of human rights claims will particularly disadvantage children and adults with learning disabilities and their families.

- All human rights breaches are serious.

All human rights breaches are significant and should be taken seriously by the courts, whatever the disadvantage caused. Proving 'Significant disadvantage' is an unnecessary permission stage which we do not think should be implemented.

- Adding additional administrative hurdles to the already tight timeframe, will further limit access to justice for individuals with learning disabilities and their families. The proposed additional permission stage will also create additional administrative burden for the legal system.

Some children and adults with learning disabilities e.g. individuals with severe learning disabilities who do not communicate verbally, will be reliant on family carers to make human rights claims on their behalf. Families are already often dealing with multiple significant issues in securing care and support for their relative, and a requirement to prove 'significant disadvantage' is an unnecessary additional barrier which may prevent family carers from making claims on behalf of their relative or themselves.

- 'Significantly disadvantaged' is subjective. It is unclear how individuals and families will be expected to prove 'significant disadvantage' and we are not reassured that whoever is making the decision will have sufficient knowledge and experience to make this decision.

Lack of specific knowledge of learning disabilities, challenging behaviour, and best practice in service provision by whoever is determining 'significant disadvantage' will negatively impact access to justice for children and adults with learning disabilities.

### **Accountability/ weakened duties for public authorities and proportionality**

Children and adults with a learning disability are already facing human rights breaches e.g. avoidable deaths, inappropriate and lengthy stays in inpatient mental health units. We need a focus on better implementation of the Human Rights Act not weakening duties. Positive obligations are very important as they require professionals to take proactive steps in protecting human rights. We need these duties to be at the forefront of the minds of professionals when making care decisions and we need there to be accountability when the needs and rights of children and adults with a learning disability are neglected.

Proportionality is vital in ensuring the rights of individuals with a learning disability are properly considered and there is not an over-the-top restriction of rights e.g. blanket

policies and decisions implemented. Children and adults with a learning disability already have their rights restricted in many different ways – it is vital that there is a focus on embedding human rights rather than making changes which risk further restricting the rights of children and adults with a learning disability.

Children and adults with a learning disability need personalized care – a lack of attention to their needs and the right support is leading to avoidable deaths and trauma and harm. Any changes which enable less careful consideration of rights and which enable more blanket approaches are likely to have a negative impact on the rights and lives of people with a learning disability and their families.

### **Responsibilities**

The proposals in Question 27 to limit, reduce or remove the damages that an individual may receive based on the individual's past conduct/behaviour will particularly disadvantage individuals with learning disabilities whose behaviour challenges.

Families have expressed serious concern around who will determine the threshold of 'past behaviour'. If they do not have the relevant expertise and specialist knowledge around learning disabilities and autism, then this proposal could have a serious negative impact for individuals with learning disabilities and autistic people making human rights claims.

We know that challenging behaviour displayed by individuals with learning disabilities is communication of an unmet need<sup>13</sup>. However, the individuals who are making decisions about past behaviour and appropriate compensation are unlikely to have this level of understanding of challenging behaviour and the particular experiences of the individual who is making the claim.

*“We need to remember that when people display challenging behaviour, it is because they have a need that is not being met...and this is going to make them [the individual] at fault, when actually we should take responsibility” (Family carer)*

For some individuals, it has been poor treatment in services, including human rights abuses, which has led to individuals displaying behaviour described as challenging. Under the proposals in the consultation, this could limit their access to justice.

*“That’s the irony, we would be judging him on past behaviours that are caused by past trauma, linked to breaches of his human rights”(Family carer)*

### **Lack of accessibility of the consultation for individuals with a learning disability and their families**

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<sup>13</sup> [What is challenging behaviour? - Challenging Behaviour Foundation](#)

The consultation paper is very technical and complicated and fairly impenetrable for non-lawyers. There have been limited attempts to include the views of groups with protected characteristics, such as individuals with a learning disability or autistic people. The consultation was launched with no easy-read version making it inaccessible for many, and the full easy-read version was only published one day before the original consultation deadline. An extension was made but required individuals and organisations to request this extension.

The government should not have launched this consultation until an easy-read version was available.

The published easy read version has not included tangible examples about what the reforms would mean for individuals with a learning disability. The language used has also been confusing e.g. around public authorities it asked if the law should be made clearer, which many people are likely to say yes to. Whereas in fact the proposal is about making the definition more specific, which is different. Again, the implications for individuals with a learning disability are not explained.

*'It is really long and quite complicated... I don't think it's really accessible – there are 29 questions in a 40 page long document.'* (A Mencap local group)

We have attended the two MoJ sessions aimed at organisations supporting disabled people. These have not been accessible and have not made the proposals in the consultation paper easier to understand or provided tangible examples about what the proposals would mean for children and adults with a learning disability and their families.

### **The interests and needs of individuals with learning disabilities are not considered within the proposals.**

The inequalities and human rights breaches experienced by children and adults with a learning disability are well recognized, and there have been repeated commitments from Government to address these.

However, the Government is proposing reforms which would weaken HRA duties and protections for individuals with a learning disability. We are very concerned by the proposals and that there is insufficient transparency about the impact the proposals would be likely to have on the rights and lives of individuals with a learning disability.

The potential impacts section of the consultation paper does not make any attempt to use what the government already knows about the experience of individuals with a learning disability and the known human rights breaches occurring.

It is important to remember that the HRA is not just about court cases, it is also about having a strong legal framework for the protection of human rights – which then underpins policy & practice. The Government appears to be making proposals with the

aim of reducing human rights legal cases, but the consequences will impact day to day use of the human rights act as well. We are concerned about the impact on both these areas: day to day use and access to justice.

Both the Human Rights Act and the Equality Act are key pieces of legislation that are there to protect the rights of children and adults with a learning disability. The focus should be on embedding these laws in everyday practice, not weakening them.

The positive obligations on public bodies to protect human rights under the HRA, like the Public Sector Equality Duty under the Equality Act, require public bodies to be proactive in thinking about individuals' needs and protecting rights.

We are very concerned to read about the proposals for weakening these duties under the HRA.

### **Part 3. How might any negative impacts be mitigated?**

Negative impacts will be mitigated if the current Human Rights Act remains in place, and significant investment is put into implementation across society (including by Public Bodies) and none of the proposed changes in this consultation are made.

The Human Rights Act is a promising legal framework for protecting the rights of individuals with learning disabilities when interacting with public bodies or organisations which take on a function of a 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.

In order to strengthen and protect the human rights of all individuals, including children and adults with learning disabilities, autistic people and their families, we believe that rather than implementing the proposals in the consultation, the government should urgently focus on:

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 realise and 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

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assumptions which all too often prevent disabled individuals from securing their rights.